

**THE ROLE OF SELF-HELP GROUP IN
JORDAN FOLLOWING TREATMENT FOR
BREAST CANCER**

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ABSTRACT

Background/Rationale: Breast cancer is the most common cancer in women worldwide. Recent findings found that self-help group is helpful for maintaining treatment regimens and coping with breast cancer and associated fears. However, there is a paucity of evidence on how a self-help group shapes women's recovery, particularly in Jordan.

Purpose of the Study/Setting: To investigate a breast cancer self-help group in Jordan.

Study Design/Methods: Interpretative approach, with semi-structured interviews. A purposive sample of 34 participants was recruited from the King Hussein Cancer Centre comprising 15 women with breast cancer who participated in Sanad group; 13 non-participating women; and six health care professionals (two nurses and four social workers).

Data Analysis: All qualitative data were analysed thematically using NVivo 9 software.

Findings: The analysis revealed five categories and thirteen sub-categories. The first category was about decision-making: "finding other ways" involving two sub-categories focusing on the influences on making decisions and alternatives. The second category focused on the meaning of Sanad to women, involving three sub-categories, namely "getting out of the capsule", "being part of a new family" and "learning from each other". The third category focused on the perceived tensions in effective meetings involving two sub-categories: "it depends on who attends: behaviours and attributes in Sanad" and "from cohesion to disruption: dealing with loss in Sanad". The fourth category was about ideas of recovery for Sanad members and involved three sub-categories, namely "from isolation to 'recharging my battery'", "from reluctance to acceptance" and "from hopelessness to hopefulness". The fifth category addressed the ideas of recovery for non-attendees involving three sub-categories, from "being glued to my room to being attached to outside world", "from hopelessness to depression" and "from hesitation to rejection of the treatment plan".

It was found that dominating the meetings, being sarcastic and underestimating the feelings of others play a major negative role in shaping discussions and create communication difficulties in Sanad meetings. Indeed, the current analysis shows a lack of hope among non-attendees of Sanad, feelings of helplessness, and negative attitudes towards treatment itself. A conceptual model involving three spheres (family, Sanad and recovery) was designed to assist nurses in identifying factors affecting women's decisions about joining Sanad or not.

Conclusion: The recovery process following attending Sanad is multifaceted, thus it is important to examine women's values and needs, because the group is not homogeneous and commonality in terms of diagnosis is insufficient. Unless the components of the model proposed in this thesis and how they affect each other are understood by health professionals, addressing individual and social factors influencing women's recovery is highly complex.

Keywords: breast cancer, self-help group, recovery, semi-structured interviews, Jordan.

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CHAPTER 1: INTRODUCTION

The most common cancer among women globally is breast cancer (WHO, 2003, Coreil et al., 2012b, Lengacher et al., 2013, Amasha, 2013). It affects women aged 20 to 70 years and there are no age-related differences in rates of breast cancer (Rashid et al., 2006, Silva et al., 2013). Rates of breast cancer are increasing worldwide, and the number of global breast cancer deaths is expected to increase by 45% from 2007 to 2030 from 7.9 million to 11.5 million deaths (Nettleton et al., 2005, WHO, 2008). Published evidence supports the conclusion that in developing countries the costs of breast cancer are increasing, and breast cancer itself is associated with secondary costs relating to mortality and morbidity (Ngoma, 2006, Doumit et al., 2010b, Taha et al., 2012).

It is argued that changes in quality of life (QoL) as a result of being diagnosed with breast cancer affect women's social interactions, mood, overall physical health and occupation (Fox, 2013, Fang et al., 2013). Writers postulated that diagnosis with breast cancer requires extensive medical treatment (Allard, 2006, Berterö and Wilmoth, 2007) and the problems and life circumstances that women are dealing with are neither easily solved nor improved by therapies or direct interventions (Oka, 2013, Fang et al., 2013). Long-term physical and emotional symptoms are experienced by survivors of breast cancer, involving psychological (cognitive and behavioural) features of trying to control health and emotional condition (Arora et al., 2007, Fang et al., 2013).

Therefore to capture the personal, social context of patients, the lived experience needs to be examined in a deeper way (Ashing-Giwa et al., 2004, Banning et al., 2010, Fallbjork et al., 2012) and women's needs should be met in a friendly social environment that enhances their recovery (Griffiths et al., 2009).

An effective strategy to achieve this goal is through breast cancer support groups which are considered as a safe and supportive environment for women to share their cancer experience (Thorn and Kuhajda, 2006, Ussher et al., 2006, Pistrang et al., 2012, Chaudhary et al., 2013). Earlier research found that women with breast cancer were willing to attend the meetings of self-help groups wherein knowledge is shared and members are supported (Garssen et al., 2011, Goodwin, 2005). Likewise,

researchers have found that social support groups have a positive effect on women's mental health outcomes, QoL, symptom reduction, functional status (Coreil et al., 2012a, Goodwin, 2005, Sammarco, 2003). Others go beyond that to stress that a social support group is essential for maintaining treatment regimens and coping with breast cancer, associated fears, stigma and uncertainty (Zuidgeest et al., 2011, Taleghani et al., 2006, Wassersug and Oliffe, 2009, Seeborn et al., 2013). With this in mind, it is possible that over the coming years self-help groups will be growing in significance as a treatment for many psychological illnesses (Stang and Mittelmark, 2009).

However, only a small percentage of cancer patients join support groups (Lieberman and Goldstein, 2006) and factors associated with sustained participation have not yet been fully examined (Owen et al., 2007, Sandaunet, 2008). Although much has been achieved concerning screening, counselling and the prevalence of breast cancer (Aldrich and Hackley, 2010, Alkhasawneh, 2007, Vos et al., 2012), the potential impact of taking part in a self-help on women's recovery needs further illumination. Studies into women's experience of breast cancer and recovery are valued but are often small-scale, and tend to have a medical rather than a nursing focus (Kilgour et al., 2008, Bowen et al., 2002, Berger et al., 2010, Metcalfe et al., 2012). Others paid more attention to advanced stages of breast cancer (Reed et al., 2011, Reed et al., 2012), targeted mentally ill patients (Griffiths et al., 2009) or marginalized the perspectives of health professionals.

To date, women from all countries have to live with the effects of treatment for breast cancer but much of what is known about women's experiences and how attending a self-help group affects recovery has mainly come from English-speaking countries (Gurm et al., 2008b, Doumit et al., 2010a, Goodwin, 2005, Jones et al., 2012). Consequently women's experiences with breast cancer are under-represented in research studies, particularly in the developing countries (Ashing-Giwa et al., 2006), and given the differences in healthcare systems and cultures between developed and developing countries the applicability of the existing evidence to the latter is of doubtful efficacy (Wilmoth and Sanders, 2001, Goldblatt et al., 2012, Goldblatt et al., 2013).

A Jordanian self-help group, Sanad has been offering its services for women with breast cancer for more than a decade, but no study has yet explored its role in shaping the recovery process. This is an important issue to focus on given that breast cancer represents 20% of all cancer cases in Jordan, and 22% of cancer deaths in the country (Taha et al., 2012).

Understanding Jordanian women's experience of breast cancer and support processes within a self-help group may provide healthcare professionals, particularly nurses, with better insights into women's needs and concerns during the journey of diagnosis and treatment. Indeed, once the barriers preventing women from attending Sanad are identified, a future strategy to overcome them can be devised. The overall aim of this study was to investigate the role that self-help groups play in breast cancer recovery in Jordan. To achieve this aim, a number of objectives need to be investigated, namely to:

1. Explore the experiences of women who decided to take part or not take part in a self-help group.
2. Investigate women's reasons for and factors that affects their attendance or non-attendance in a self-help group.
3. Understand how being a member of a self-help group shapes women's ideas about recovery following the diagnosis and treatment for breast cancer.
4. Investigate healthcare professionals' perspectives on breast cancer self-help group and its contribution to recovery.

1.1 Study Context: Jordan

Jordan is a low-income country located in an important geographical and political position in the Middle East (see figure 1). Jordan has boundaries with Syria to the North, Saudi Arabia from the East and South, Iraq from the East, and the West Bank and Israel from the West (CIA, 2014). The population is an estimated six million people, but political instability over the past decade, particularly the situation in Iraq

since 2003 and the more recent Syrian conflict, means that the population is difficult to establish due to the large influx of refugees and migrants. It is reported that most of the population (75%) live in three main cities: 42% in the capital-Amman, 15% in Zarqa and 18% in Irbid (JDOS, 2007).



Figure 1: Map of Jordan

Source: CIA World Factbook (2014)

Although the extended family system has declined in recent years, it still predominates in Jordanian society. In this system, the elderly are often highly respected and considered as a source of wisdom, and they are largely involved in the decision-making process. Whilst there are some negligible ethnic minorities in Jordan (e.g. small African and Asian populations) Arabs are the overwhelming majority ethnicity. The main spoken language is Arabic, but English is widely used in education and is commonly understood among the upper and middle classes. The population comprises about 97.2% Muslims and 2.2% Christians (CIA, 2014).

The Jordanian healthcare system is modern in terms of funding and the training of healthcare staff, and its services are among the best in the Arab world, with the result that many people from neighbouring countries such as Egypt and Saudi Arabia rely on Jordan for medical treatment ((Rawabdeh, 2005)

Currently, the Jordanian healthcare services are delivered through three main sectors: public, private and military. Public healthcare insurance covers an estimated 8% to 12% of Jordanians. For many decades the public healthcare sector was delivered through the Ministry of Health (MOH), the Royal Medical Services (RMS) and two university affiliated hospitals (the Jordan University Hospital and the King Abdullah Hospital) (Al-Rimawi, 2012). Moreover, in the public sector health services are free for children below 5 years of age and elderly people above the age of 65 (MOH, 2008). Finally, the military sector covers Jordanian people who have at least one family member working in the military and it is almost free.

Particular for the PhD study

Having worked as a staff nurse in the surgical Intensive Care Unit (ICU) of Jordan Hospital, Amman, most of my early nursing practice was spent in caring for breast cancer patients in different clinical areas. My main duties were in the areas of drug administration and in coordinating clinical services for doctors' needs. My experience in the unit in general lacked many core attributes of defined support roles to care for breast cancer patients. The findings from previous works revealed that caring for both psychological and physiological needs is often neglected by nurses due to lack of information, training, adequate methodology, and understanding of how theoretical concepts can be applied within existing practical contexts. Thus, the primary challenge was to develop an understanding of the importance of the psychosocial support group intervention in enhancing QoL and improving the self-body image adaptation (e.g. after mastectomy or lumpectomy) amongst women with breast cancer. Furthermore, it was necessary to examine the best nursing intervention for this particular group of patients.

Following attending a workshop on how to support women with breast cancer in KHCC through organizing a self-help group (Sanad), I became more interested in exploring women's experiences, how they cope with this illness, and whether Sanad

really helps those patients to recover from the illness. I gathered different stories from some women about their lives following the diagnosis of breast cancer while chatting with them, but the picture was not clear. I felt that some properly constructed, coherent and scientific research was necessary to understand these issues. I felt that simply listening to those women with breast cancer was insufficient and could certainly not result in an evidence-based care plan to really help such patients unless women's experiences of breast cancer and how Sanad shaped their recovery was explored and understood. Despite the limitations of this work, I believe that the emergent findings are valuable in informing future plans for enhancing the QoL and recovery of women with breast cancer. In particular, enabling women with breast cancer to “get out of the capsule”, in the words of some participants in this study.

1.2 Literature Search

The materials pertinent to this study and its questions were located from different sources. Initially an online search was conducted to locate literature on the concepts of breast cancer, breast tumour, palliative care, self-help groups, mutual support, support group, peer group, recovery and Jordan. This was to become familiar with the main literature available and relevant to the study focus.

A subsequent, more detailed search of the available literature used a variety of health-related evidence databases such as Medline, CINAHL, PUBMED, PsychINFO, EMBASE, British Nursing Index and World Health Organisation database (please see table 1). Additionally, Google Scholar search engine was also used together with the British Library catalogue for PhD theses at Nottingham University. Moreover, a manual search in the reference lists of the gathered literature was also conducted. Recent books concerning breast cancer, support groups and recovery in general were located and reviewed. Finally, some references were located as a result of communication with my supervisors, other researchers and PhD students. All articles were written in English but a few relevant Arabic articles were also translated and included in the results. The search initially focused on the period between 2000 and 2010 and then was updated during the writing-up stage of the thesis to include literature from 2010 and 2014. Literature published prior to 2000 has been included where necessary, such as classic studies and texts about theoretical aspects (e.g. stress theory).

Hundreds of papers were initially located about breast cancer, but then the search was narrowed down to address the specific questions of this study. Some search questions were kept in mind, such as: what is known about women's experiences with breast cancer, self-help group and recovery? What is the most recent work in this area? Who are the key researchers? What topics have not been focused on? What is the Jordanian contribution to this area?

Initially, in the searching process, the concept of breast cancer was used in itself and then in combination, with the use of concepts including social groups, self-help, recovery, culture, spirituality, Jordan, Middle East/Mediterranean area.

Table 1: Keywords used in the search

Electronic databases used	Key Components	Keywords
* MEDLINE * CINAHL * PsycINFO * EMBASE * PUBMED * Web of Science * British Nursing Index * World Health Organisation * Google Scholar	Self-help group Psychosocial support	'psychosocial adjustment', 'psychosocial help', 'supportive care' 'mutual aid', 'patient counsel' 'self-help group' 'psychosocial care' 'peer support' 'family support' 'spouse support' 'healthcare professionals support' 'facilitators or inhibitors of joining support groups'
	Breast cancer women Muslim and Islam	'Breast metastasis', 'breast tumor', 'cancer, breast' 'breast adenocarcinoma' 'breast cancer women experiences' 'Muslim women' 'Islam and illness' 'Middle east countries' 'Mediterranean area'
	Recovery	'controlling my health situation' 'health related QoL' 'self-acceptance' 'a sense of purpose in life' 'empowerment' 'hope' 'self-confidence' 'back to normal life' 'spirituality'

1.3 The Structure of the Thesis

This thesis comprises seven main chapters, of which this chapter has presented the introduction, the background of the problem under investigation and the context of the study. The search of the literature, breast cancer meaning and consequences are also examined.

Chapter Two examines women's experiences with breast cancer, the role of healthcare professionals, spirituality and self-help groups. Factors affecting breast cancer women's decisions of whether to take part in a self-help group are explored in this chapter. The recovery concept, empowerment and hope concepts will be illuminated. Indeed this chapter focuses more on previous studies into women's

experiences and recovery. A detailed account of such studies is offered together with related gaps and the need for the current research.

Chapter Three addresses the study's methods and describes how a naturalistic design was employed with semi-structured interviews to achieve the study objectives. The sampling procedure, data collection process and related ethical issues are sketched in this chapter, along with the way in which qualitative data were thematically analysed using N-Vivo 9 software. The trustworthiness of data and relevant criteria are also explored.

Chapter Four outlines main respondents' characteristics. It reveals that of all participants (n=28), fifteen women took part in the Sanad group and thirteen did not. The majority of women from the sample were between 30 and 60 years of age. Nine women were diagnosed with Stage III of breast cancer, nine were diagnosed with Stage II, and seven with Stage I. Only three women were diagnosed with Stage IV.

Chapter Five elaborates upon findings pertinent to women's experiences with breast cancer and their decisions of whether to join Sanad. The chapter found that maintaining a sense of self to a large extent is a powerful drive for joining Sanad. The feeling of powerlessness and the belief that nothing can change bad luck or destiny were linked to the rejection of the Sanad concept, as explained in this chapter. The role of family (notably mother-in-laws) in informing women's decisions to taking part in Sanad will be examined.

Chapter Six sheds light on how being a member in Sanad affected the actual recovery of women with breast cancer. Perceived recovery is also examined from the perspective of those non-attendees. Related data of recovery among those two groups of women are compared and contrasted. The chapter revealed that, as a result of hope, Sanad members challenged the illness of breast cancer and related negative changes at personal and social levels. Data triangulation with health professionals confirmed that joining Sanad contributed positively to women's appearance and vitality. In this chapter responses from all women with breast cancer regardless of their attendance of Sanad contributed in different ways to the overall picture or "puzzle" of recovery following the diagnosis with breast cancer.

Chapter Seven compares this study's outcomes with relevant literature at the national and international levels to contextualize the main findings, and analyse the implications for nursing practice and recommendations for future research, along with highlighting the limitations of this study. The proposed conceptual model about recovery and how it might be affected by some factors at the family and social level is also explained.

1.4 Background of Breast Cancer

1.4.1 Meaning and consequences

As will be shown in this chapter, breast cancer and its treatment are both complex and worthy of international collaborative efforts, as more evidence is needed from different countries focusing on their short- and long-term effects. In recent years technological advancement, like mammography screening, has improved the detection rate of the disease at an early stage, thus facilitating effective treatment and avoiding complications. As a result of technological advances, more women are being diagnosed with breast cancer and therefore more women are becoming cancer survivors globally (Karbani et al., 2011, Alkhasawneh et al., 2009, Baron-Epel and Klin, 2009). In order to set up a context for the study and explore how self-help support groups might affect women's experience and recovery in subsequent chapters, there is a need to offer some theoretical background about breast cancer itself, its consequences, management and in particular within the Jordanian context. This section aims to highlights these areas of knowledge.

1.4.2 Definition and prevalence

Although there are various definitions in the literature, cancer is essentially a disease whereby a genetic mutation in patients' body cells results in uncontrolled cell proliferation and spreading through body tissues (Lezoche et al., 2007). Breast cancer is actually a group of tumour subtypes rather than a single illness, but collectively these tumours comprise the most common form of female cancer (Vincent-Salomon and Thiery, 2003). The development of breast cancer begins within breast tissue, consisting of milk glands, called lobules, connected to the nipple (Vincent-Salomon and Thiery, 2003). The rest of the breast is made up of fatty, connective and

lymphatic tissue (Vincent-Salomon and Thiery, 2003). Cancers are divided into benign and malignant. Breast cancer malignancy has five stages (0, I, II, III, IV); stage (0) is called *in situ*, during which the cancer is relatively easy to cure, but it becomes increasingly difficult to cure as it becomes more mature, moving through the stages from the early stage (I) to the most advanced (IV) (American Cancer Society 2007)..

The incidence of breast cancer diagnosis is high; for example, each year there are over 41,000 new breast cancer cases in the UK, and breast cancer accounts for almost one in three of all cancer cases in women; the lifetime risk is one in nine (UK, 2008). Younger women are likely to be diagnosed with breast cancer and suffer adverse physical and psychological consequences that affect the recovery process (Coyne and Borbasi, 2009). It was found that one in eight women are diagnosed with breast cancer before the age of 85 years, 25% of whom are under 50 (WHO, 2009).

Breast cancer is the most frequent cancer experienced by women in developed (Western) countries (Althuis et al., 2005), and is becoming ever more significant in many developing countries (Alkhasawneh, 2007, Obeidat et al., 2012a, Omran et al., 2012, Doumit et al., 2010b). In Jordan breast cancer development mirrors the situation globally, and cancer contributes tremendously to the morbidity and mortality. This is confirmed by some statistics revealing that breast cancer has become the second leading cause of death after heart disease (Alkhasawneh, 2007, Amasha, 2013) and the incidence of 817 cases among Jordanian women represented 35.8% of all recently diagnosed cancer cases (Tarawneh and Nimri, 2007). Furthermore, Jordan ranked breast cancer among the most frequent types of cancer in females, representing 34.8% of all female cancers (Tarawneh and Nimri, 2007). Despite the availability of advanced screening facilities, of all cases diagnosed in Jordan, about 74% of breast cancer cases are discovered at the advanced stages (III-IV), indicating low possibility of survival; only 30% of cases are diagnosed in the early stages (0-II) (Alkhasawneh, 2007). Breast cancer and its treatment comprise a significant health concern in society, and serious efforts are needed to address breast cancer among women in developing countries.

1.4.3 Management and consequences

Breast cancer can be diagnosed at the regular screenings, or after symptoms are reported (Yamakawa et al., 2003, Kavar, 2009). Treating breast cancer can be undertaken in numerous forms. For example, breast cancer can be treated surgically through a complete mastectomy, by which the entire breast is removed (Cheville and Tchou, 2007). This method is recommended either when the tumour occupies a large proportion of the breast or its borders are not well-defined, or when the local chest wall or regional lymph node are at high risk of becoming affected (Vinh-Hung and Verschraegen, 2004). Conversely, breast-conserving surgery attempts the local excision of the tumour while preserving the rest of the breast intact (Cheville and Tchou, 2007).

There are long-term complications of being diagnosed with breast cancer affecting women's physical, psychological and social lives (Kikuchi et al., 2004). These include infection and/or pain after surgery, body image, sexual attractiveness, satisfaction with sex life and emotional distress, depression, and negative impact on QoL (Ganz et al., 2002, Graves et al., 2012, Grimsbo et al., 2012).

Follow-on radiotherapy is given to prevent relapse, and to minimize the possibility of requiring further surgical interventions (Tepper et al., 2008, Wong and Malthaner, 2006). The duration of radiotherapy is usually five to six weeks, and may have short- and long-term effects, generally including pain, breathing problems (e.g. dyspnoea), coughs, skin reactions and possibly overall weakness and fatigue (Peeters et al., 2005).

Chemotherapy and radiotherapy are often used to treat breast cancer. It was found that these therapies in advanced breast cancer cases may lead to modest improvements in survival and women's QoL (Fang et al., 2011, Allard, 2006, Dell et al., 2008). However it is essential to remember that during treatments such as chemotherapy, patients may experience short-term negative effects such as diarrhoea, nausea, vomiting alopecia (hair loss) and neutropenia (low white blood cell count) (Marijnen et al., 2002). Moreover, patients who receive chemotherapy suffer from emotional distress, reflected in anxiety, difficulty sleeping and focusing etc., persisting both during and after treatment; however they generally resolve within months of

completion of therapy (Brezden et al., 2000, Jacobsen et al., 2002). Long-term side effects might include weight gain, infertility, cognitive impairments, cardiac dysfunction, and leukaemia, potentially causing longer-term functional and/or psychological consequences (Piccart-Gebhart et al., 2005, Carelle et al., 2002). In addition to the general impact of chemotherapy on cancer survivors, women who survive breast cancer may face numerous additional post-treatment factors (Bowlby, 2008, Ell et al., 2005, Cebeci et al., 2011, Fallbjork et al., 2012), including not only profound changes in their individual lives but also in their family and community spheres.

It has been noted that wider coverage of mammography facilities and the development of mammography generally has been associated with improved breast cancer screening and earlier detection (Elmir et al., 2010, Brahams, 2011, Petro-Nustas, 2001, Fang et al., 2011). However, despite this biomedical improvement, the vast majority of woman with breast cancer experience health trauma with psychological and emotional impacts, associated with social challenges resulting from diagnosis and treatment. This might add further economic pressure on their families and healthcare service providers, and ultimately national budgets. A more detailed account about women's experiences with breast cancer and the challenges involved is presented in the following chapter.

CHAPTER 2: WOMEN'S EXPERIENCES WITH BREAST CANCER, SELF-HELP GROUPS AND RECOVERY

2.1 Introduction

This chapter represents the main bulk of the literature. It explores the status of being diagnosed with breast cancer, related experiences and coping mechanisms that women used. It outlines the ways in which spirituality affects women's experiences with breast cancer and the role of healthcare professionals, then presents a synthesis of the literature related to the concepts of support group, as well as self-help interventions that have been examined with breast cancer survivors. The notion of support and, in particular, the benefits, difficulties involved, and contributing factors affecting the attendance and interactions among members are analysed.

This chapter uncovers and analyzes the concept of recovery and its components, such as rebuilding a sense of self, hope and empowerment. The main findings in relevant studies are reported, and gaps in the body of the literature justifying the current research are identified. Thus, this chapter constructs a coherent theoretical and empirical background against which the emerging findings from this work are discussed. The main studies relevant to women's experiences with breast cancer, self-support groups and recovery are summarised in Table 2.

2.2 Being Diagnosed with Breast Cancer

Researchers in different countries (e.g. the UK, Turkey, Japan, the USA, Jordan, Lebanon and Israel) have noted that the significance of the female breast extends beyond nurturing and motherhood; it is also closely related to women's self-perceptions about their appearance, femininity and sexuality, thus breast cancer is a major threat to psychological wellbeing and QoL as well as physical health (De Ver Dye et al., 2011), which is why this illness can cause emotional crises for patients and their families (Fang et al., 2013, Ohaeri et al., 2012).

At the point of diagnosis stage, many women fear the possibility of metastasis and death (Oka, 2013, Elmir et al., 2010). Such illness affects functioning of the family

because the patient becomes dependant and in need of contentious care and attention (Coreil et al., 2012b, Fox, 2012, Grimsbo et al., 2012). The need for more medical and psychological attention is mainly due to the long-term treatments and therapies and as a result impact a woman's daily life (Vargens and Berterö, 2007, Erci and Karabulut, 2007, Gartner et al., 2010, Binns-Turner et al., 2011).

When physical symptoms have been effectively completed, some women continue having psychological disturbances because of intrusive thoughts about the possibility of metastasis or recurrent illness (Lyons, 2006, Reynolds and Prior, 2006, Schmid-Buchi et al., 2008). In other words, breast cancer is a long-term condition with special issues and needs (Lyons, 2006), related to common experiences such as feelings of incompetence, disconnection and reduced QoL (Graves et al., 2012, Ganz et al., 2002). Many psychological aspects of having breast cancer are influenced by culture and perceived support, including sadness, mood disturbance, frustration, anger, anxiety, hostility, depression and reaction to the disease and its treatment (Nöres et al., Heidari Gorji et al., 2012, Lam et al., 2012b).

Other writers highlight that having breast cancer leads to a group of side-effects such as stress, body image disturbances, feeling helplessness, shame, dependency and a sense of loss of femininity and motherhood (Dunn and Steginga, 2000, Else-Quest et al., 2009, Lam et al., 2012b, Fobair et al., 2005). Others develop this argument further by proposing that worries and fears about death, alteration of femininity and changing body image are vital factors for converting psychological distress into depression following the diagnosis and treatment (Griffiths et al., 2009, Berger et al., 2010). In line with these arguments, it is reported that the incidence rates of depression women with breast cancer are twice as high as for the general female population (Ell et al., 2005, Metcalfe et al., 2012).

Well documented and growing evidence suggests that when depression occurs, this leads to poorer clinical outcomes, reduced compliance with prescribed treatment and increased length of hospital stays. On this basis, women with breast cancer often become emotionally vulnerable, first through loss of self-confidence, then growing feelings of powerlessness and even hopelessness, and finally exposure to recurrent bouts of depression and anxiety (Zorrilla et al., 2005, Stang and Mittelmark, 2009). Due to the seriousness of these psychological outcomes, the consequences of being

diagnosed with breast cancer, in addition to affecting women's general QoL, can lead to poor recovery and complications. Therefore, many researchers have been concerned with the implications of the psychological consequences and experiences of surviving breast cancer, with the result that it has been identified that women's adjustment to diagnosis is variable, depending on self-efficacy skills and the provision of support, among other factors (Taylor, 2012, Sherman et al., 2012).

In general, it is estimated that in the first year after diagnosis, up to 38% of women diagnosed with breast cancer have high levels of psychological distress (Baider et al., 2004). It has been found that among younger women breast cancer causes emotional distress and vulnerability, marked by a sharp decrease in morale (McKenzie and Crouch, 2004, Avis et al., 2004). Indeed, earlier research revealed that young breast cancer survivors were scared of the treatment they received, especially regarding the potential impacts of the cancer and its treatment on their future fertility (Coyne et al., 2006). The particular association of the breast with nurturing infants (i.e. breastfeeding) means that the loss of all or part of the breast is harder to accept, particularly for young women, thus it is often associated with identity crises among women (Avis et al., 2004, Kim et al., 2012, Omran et al., 2012).

In addition to the general impact of breast cancer on women's QoL, body image, self-perception and social roles, it can also influence their sexual and intimate relationships (Thewes et al., 2004, Hughes et al., 2011), particularly their ability to engage or maintain fulfilling sexual interactions, which might contribute to poorer QoL (Hughes et al., 2011, Bakht and Najafi, 2010). This is largely related to the psychological issues related previously; many women struggle to cope with the impact of the diagnosis of breast cancer and they hold distorted views of their own femininity and sexuality (Avis et al., 2004, Broeckel et al., 2002, Cebeci et al., 2010).

However, whilst the importance of sexual function is valued, other researchers found that some women with breast cancer were more concerned about how to survive for the sake of their children than maintaining an image of femininity and beauty for their husbands (Lam and Fielding, 2003). The reviewed literature would seem to imply that having breast cancer has negative effects that go beyond women's own lives, having knock-on 'ripple' effects throughout the community due to women's multiple responsibilities and commitments, particularly within the family (Sussner et al., 2009,

Sussner et al., 2011). It is argued that having breast cancer places an increasing burden on family members, and close associates are often equally distressed, in particular husbands and children (Kim et al., 2012). Whilst accessible treatments such as mastectomy and chemotherapy/radiation therapy minimize the effects of breast cancer and enhance prognoses (Allard, 2006, Dell et al., 2008), cancer might come back in a more aggressive form, which can be psychologically debilitating for women with breast cancer and their families (Binns-Turner et al., 2011, Fang et al., 2013).

2.3 Women's Experiences of Breast Cancer: Coping and spirituality

Scholars have argued that health professionals and researchers are unable to understand women's experiences with breast cancer, recovery and QoL unless these dimensions are explored from various perspectives (Adams and Glanville, 2005, Boesen et al., 2011, Fox, 2013). Given the complexity of being diagnosed with breast cancer, researchers suggest that to understand the contextual personal and social factors of patients, the lived experience needs to be examined (Ashing-Giwa et al., 2004, Banning et al., 2010, Fallbjork et al., 2012). Women from different cultures experience common and particular challenges in living with breast cancer, based on a review of different cultural experiences of women with the illness. Previous research has confirmed that women equate breast loss with loss of womanhood, thus it is seen as traumatic life experience that undermines their feelings of attraction and self-worth (Lam et al., 2012a, Ussher et al., 2012), which is common across cultural and ethnic groups (Howard et al., 2007, Doumit et al., 2010a).

Studies conducted among women diagnosed with breast cancer in Taiwan, China and Africa reported that a supportive and caring interventions were encouraged by uncertainty about the future (and thus seeking help) and improvements in social support (Liu et al., 2008, Wong-Kim et al., 2005, Heiney et al., 2011). In this context, using a qualitative interviewing approach with women with breast cancer (n=18), a study in Iceland revealed that the social and institutional support and care could mediate physical and emotional hardship (Palmadottir, 2009). Further findings showed that the women who generally responded to the cancer diagnosis positively and optimistically viewed their experiences more constructively than less positive patients (Palmadottir, 2009). Although the study cited the importance of social support to women's experiences, the evidence is undermined by the use of self-

selected convenience sampling carried out by managers, who were known to patients; “It is especially important to gather data from women who are not a part of a support system and explore how they deal with and adapt to the experience of breast cancer” (Palmadottir, 2009,P333). Recently this has been addressed by examining the experience of Arab-American women undergoing surgical treatment for early-stage breast cancer in the US (Obeidat et al., 2012b).

The analysis identified four major themes describing the participants’ lived experience emerged from the interviews, including living with losses; living with guilt feeling; living with fears and uncertainty; living with the need to know and to share that knowledge (Doumit et al., 2010b). These findings have been confirmed elsewhere in the literature (Cebeci et al., 2011, De Ver Dye et al., 2011, Fallbjork et al., 2012). Although the study findings offers valuable insights into married women’s experiences with breast cancer, such evidence might not be applicable to single patients.

Therefore, it would appear that more research needed taking into account the sample size and its characteristics to enhance of the credibility of the existing data. In addition to the need for the family support, it was found that women with breast cancer are in need of sharing information and knowledge about their condition (Cebeci et al., 2011). Specifically, women reported that loss of hair and being dependant on others (e.g. for household chores and self-care) during the acute phases of treatment as being the main problems of dealing with breast cancer. However, a Lebanese study focused only on married women and given the differences in the social and emotional context, these findings might not be generalizable to single women with breast cancer (Cebeci et al., 2011)

Semi-structured interviews (n=36) focused on factors that affected the lived experience of breast cancer among Pakistani Muslim women (Banning et al., 2010) revealed that the majority of women felt shock, horror, despair and fear of the unknown, and many of them rejected the possibility of breast cancer. However, the total sample (n=36) included 11 patients from London and 25 from Lahore, consequently the sample was dominated by women in Pakistan. In light of this, the reliability of the outcome of comparing and contrasting these two groups can be debated. Cultural studies in area of women’s experiences of breast cancer have shown

how their beliefs and immigration status affected the perception of being diagnosed with this illness. In line with the above study, a qualitative study examining the breast cancer experience among immigrant Chinese women in the UK (Karbani et al., 2011) conducted three focus groups with Chinese women (n=23) diagnosed with breast cancer. The study found that some Chinese women held the misconception that mammography was a preventive rather than a diagnostic measure. Other women in this study attributed their breast cancer to the effect of the stress of living in Australia due to language barriers and 'culture-shock' (Karbani et al., 2011).

Consistent with studies carried out in the Caucasian population and among women from minority cultures, Chinese-women experienced extremely negative reactions including unhappiness, uncertainty and hopelessness (Elmir et al., 2010, Grimsbo et al., 2012). Some participants hold an opinion that breast cancer is a white women's disease' resulted in feelings of shame which made it harder to cope with the diagnosis. However, whilst the study findings are valued, all participants were members of a Chinese cancer support group, and whilst this may have enhanced the openness with which they shared information in a group, the possibility for bias in the results cannot be ruled out. Indeed, only those women who were diagnosed with breast cancer for the last six months were included, thus the applicability of the above findings to other sufferers is questioned.

In addition to the above, a common theme to emerge from the literature on women's experiences with breast cancer is spirituality. The exploration of relevant literature showed that women with breast cancer in many cultures adopt a spirituality response such praying as a response to the suffering experience of having breast cancer (Budin et al., 2008, Cebeci et al., 2011). A meta-synthesis of fifteen qualitative studies of women with breast cancer from the Asian-American, Aboriginal and African-American populations published between 1994 and 2005 found that experiences of the illness were shaped by spirituality (Howard et al., 2007). Scholars suggest that a traumatic event such as having breast cancer may encourage patients to search for meaning in their predicament and find resources to cope with the situation (Thuné-Boyle et al., 2011).

Although spirituality and religious beliefs are interconnected and often affect individuals, these two concepts are not identical. It is argued that spirituality

comprises elements such as interconnectedness, transcendence of life and belief in sacredness of life (Reynolds, 2006, Chida et al., 2009). Whilst religion is presented as institutional and formal, spirituality seen as informal, existential and individual (Stefanek et al., 2005).

How spirituality affected women's experiences of breast cancer is examined in a number of studies pertinent to the current research and worth exploration. The experience of breast cancer among religious Canadian Punjabi women (n=20) was examined using a focus group methodology (n=4) (Gurm et al., 2008b). The findings showed that all women had strong spiritual feelings and beliefs, such as that their illness was due to fate or karma, and the will of God; the women were keen to verbalize their experience within a group of peers, suffering from the same condition (Gurm et al., 2008b). In light of the study findings, it can be argued that it is important to learn about patients' values and beliefs based on individual assessment and to integrate them into the framework of care. However, the majority of participants (n=13, 65%) were in a post-treatment stage and all were well-educated, thus these findings might not be applicable to other groups of newly diagnosed women or those with various socioeconomic factors, thus: "future studies are warranted to further our understanding of the culturally determined factors that elicit positive responses in coping with distress and that generally are not included in the traditional Eurocentric model of coping" (Gurm et al., 2008b,P.276).

This call was responded to by Israeli scholars examining the cultural and religious context of breast cancer experience among Arab women in Israel (Goldblatt et al., 2013). Using semi-structured interviews with 31 Arab women (comprising 20 Muslims and 11 Christians), it was found that social and religious beliefs were key factors in coping strategies regarding the disease, potentially acting as a source of strength or causing difficulties (Goldblatt et al., 2013). Similar to the findings of (Goldblatt et al., 2013) among Palestinians/Israeli-Arabs, (Azaiza and Cohen, 2008) found that most Arab-American women fatalistically accepted breast cancer diagnosis as an aspect of fate, and thus as something out of their control. However, the study showed that such beliefs did not prevent seeking care and information about treatment, or medication/treatment compliance among the women.

There is broad consensus that spirituality and religious faith are associated with many positive outcomes for physical and mental health (Harandy et al., 2009, Thoresen et al., 2001). Spirituality provides cancer patients with successful means of coping with stressful life events (Heiney et al., 2011) and maximizes optimistic life orientation and social support, while providing a safeguard against stress and negative emotions (Pardini et al., 2000, Bussing et al., 2007). In the same context, breast cancer diagnosis was found to transform the lives of Brazilian women who, because of consequent spirituality and praying due to illness, became more aware of their own condition and mortality, enhancing their sense of individuality and consequently changing their life values (da Costa Vargens and Berterö, 2007, Doumit et al., 2007). These findings fit well with arguments postulating that spirituality is positively associated with personal growth and psychological well-being among women with breast cancer (Harandy et al., 2009, Howard et al., 2007, Bussing et al., 2007).

Other scholars took the general research about ‘spirituality’ forward to consider dimensions such as hope, coping and religiosity among cancer patients. All of these dimensions were associated with positive mood states and the adoption of spiritual coping style was found to be effective for less hopeful women (Choumanova et al., 2006); furthermore, a higher degree of certainty in belief and religious practices was linked to improved ‘fighting spirit’, reflected in improved coping and greater self-efficacy (Lazenby and Khatib, 2012, Stefanek et al., 2004).

However, given the fact that religious and spiritual activities are undertaken in certain cultural frameworks, caution must be exercised when attempting to generalize findings related to this aspect of care, particularly given the large differences in religious and spiritual beliefs and practices between countries worldwide.

Additionally, some negative influences of spirituality and religiosity have been identified by researchers. Although the concept of fatalism can have positive impacts on coping among many patients, as explained previously (i.e. acknowledging illness as something decreed by God or arising from karma), it can also promote negative behaviours among some patients, such as reduced medication compliance or hopelessness (Doumit et al., 2010a, Hasson-Ohayon et al., 2009). As a result of this belief, some women might avoid taking part in breast cancer prevention efforts or activities, thus missing the chance of early diagnosis and ultimately delaying

appropriate treatment (Harandy et al., 2009). In line with this, it is argued that the strong religious beliefs were associated with more avoidance, anxiety, and more fatalistic acceptance (Hasson-Ohayon et al., 2009). Others propose that such beliefs comprise a major barrier to taking part in breast cancer screening and treatment in many parts of the world (Kwok and Sullivan, 2006). It is important that healthcare professionals consider such beliefs and how they affect women's experiences of treatment, including attending social support groups.

It can be summarized, that using religious beliefs as a mechanism for coping with stress is a complex dimension for those women with breast cancer. But many questions remain about how these shape recovery following the diagnosis with breast cancer. Indeed, the above discussion reinforces those calls urging researchers to examine the effect of different religious and spirituality coping strategies on women's experience outcomes in terms of psychological wellbeing, personal growth (Goldblatt et al., 2012, Chida et al., 2009, Goldblatt et al., 2013). However, this section points out that being diagnosed with breast cancer might lead to more multifaceted psychological disturbances, uncertainty and fears. During this critical time the role of healthcare professionals needs to be developed carefully to meet diverse needs and concerns of women with breast cancer.

2.4 The Role of Healthcare Professionals

Given the complexity of being diagnosed with breast cancer, receiving clear and accurate information from healthcare professionals is vital for women with breast cancer to meet their needs (Morgan et al., 2005), understand life changes (Pinquart et al., 2009) and gain a positive attitude for life (da Costa Vargens and Berterö, 2007). Indeed, providing knowledge about women's breast cancer diagnosis and treatment enables them to be actively engaged in the process of shared decision-making, thus empowering them (Nöres et al., 2011).

Healthcare professionals are a vital source of information for service users, particularly nurses, as they spend the most time delivering front-line care and liaising with patients and their families, especially around issues of diagnosis and treatment. Studies have found that most patients (66%) with breast cancer prefer to receive important information from hospital nurses (NHMRC, National Health and Medical

Research Council 2003), and it has been found that patient distress and fear is assuaged by increased communication between healthcare providers, patients and their families (Shields and Rousseau, 2004, Raupach and Hiller, 2002). Therefore, it is important that healthcare providers, especially nurses and social care staff, offer information to patients about living with breast cancer as part of the general importance of effective communication in cancer care (Beaver and Witham, 2007a).

It is argued, however, that the usefulness of a particular type of information and knowledge to women with breast cancer depends on how it is given (Coreil et al., 2012b, Arora et al., 2007). It should be noted that negative responses from and interactions with healthcare professionals were said to be painful by women with breast cancer, in particular during the early phase after diagnosis, when women are particularly vulnerable (Alkhasawneh, 2007, Allard, 2006). Previous research showed that African-American breast cancer patients perceived that healthcare providers were insensitive to their needs and concerns (Moore, 2001). Likewise, others argue that information is not always given to women with breast cancer in a caring way (Saegrov and HALDING, 2004). This highlights the fact that support offered by healthcare professionals for women with breast cancer is critical for them to cope with their disease.

Research has shown when caring for women with breast cancer, healthcare professionals typically give more attention to medical treatment rather than emotional and social support (Saegrov and HALDING, 2004). Similarly, healthcare professionals focus on survival rates of cancer, but rarely consider QoL (Karbani et al., 2011, Lam et al., 2012b).

Similarly, research investigating interventions for breast cancer has mostly focused on anatomical treatment, followed by physiological and psychological factors, while lifestyle interventions or features are usually unconsidered (Brockow et al., 2004), despite the significant psychological impacts of breast cancer on QoL and general health caused by patients' re-evaluation of goals, interests and life values engendered by the illness (Reynolds and Prior, 2006), which can have either positive or negative impacts, depending largely on the degree of social support that women with breast receive, whether formal or informal (Cho et al., 2012, Eisinger et al., 2011).

As shown above, being diagnosed with breast cancer is stressful and often exceeds the coping resources of patients, resulting in symptoms of depression and anxiety and feelings of helplessness, powerlessness and hopelessness. Women with breast cancer therefore require support from their friends and families to facilitate successful coping (Connell et al., 2006) and reduced anxiety and depression (Lazarus and Folkman, 1984, Wassersug and Oliffe, 2009, Brahams, 2011).

These postulations are consistent with the self-regulation model, indicating that patients' conceptualisations of illness shape coping, including perceived cause, duration, life consequences, symptoms and labelling, controllability and curability of the illness (Leventhal et al., 1984). Taking these components together with the fact that survivors of breast cancer experience emotional and physical consequences over the long term, it is proposed that both cognitive and behavioural processes are needed for women to cope with the stress of breast cancer (Arora et al., 2007, Fang et al., 2013).

Based on the above review, it can be argued that changes in QoL affect women's social interactions, mood and overall physical health. Breast cancer has psychological and social impacts on women's health, appearance, relationships and entire way of life. Breast cancer can be a catastrophic change involving self-efficacy, control and trepidation. Thus, it is essential to ensure that sufficient social support is available to meet the challenges of caring for women with breast cancer.

2.5 The Development of Social Support Groups

Social support group is a frequently cited concept by many researchers in the fields of oncology, sociology, psychology and nursing (Arora et al., 2007, Nausheen et al., 2009, Guruge et al., 2011, Munn-Giddings and McVicar, 2007). However, the exact meaning of the concept is contested, with diverse and sometimes conflicting meanings being socially and culturally constructed around it, as explained below. This section presents a brief background of social support groups to examine how the concept of social support group developed from various perspectives, which are used to inform the conceptual framework employed in the current study.

The history of social group work began in the nineteenth century with significant attention given to educational groups and social action interventions for the poor, to help alleviate the severe social, economic, and personal problems produced by industrialisation and urbanisation in Europe and the US (Fobair, 1998). Such philanthropic endeavours offered information, education and support, and encouraged disadvantaged groups such as needy immigrants and ill people to help themselves. These activities were not, however, well planned and organized until 1905 when a group intervention recognised the necessity to care for the psychological status of tuberculosis patients as well as their physical symptoms (Fobair, 1998). The group meetings were held weekly and encouraged by a physician to raise morale. It was found that those patients involved in group meetings became more socially active, more motivated to gain knowledge about the illness and developed a better image about themselves as patients.

Psychiatrists experimented among psychotic patients with group methods in the 1920s. Many of these patients had depression and social groups enabled them to avoid isolation and establish networks with the local community (Fobair, 1998). Over the subsequent decades, social groups have adopted numerous structures but they have generally strived for less formality due to the experience that relaxing atmospheres enable fruitful participation in decision making and participant empowerment (Chinman et al., 2002). Social groups are essentially meetings in which a group of similar people regularly convene to impart and receive psychological support and information (Pistrang et al., 2008, Chinman et al., 2002).

In addition, social support has frequently been studied as a psychological resource in the treatment of various conditions. However, as the next section will consider, there is a lack of consensus about the nature and definition of social support. This lack of consensus is not only restricted to Western countries. For example, in Japan a clear consensus on the definition of support groups has not been reached (Oka, 2011). Likewise, the increasing diversity of contexts and in particular the nature of target population of social support groups makes it hard to reach an operation definition. Whilst many researchers studied social support groups and cancer patients (Chamberlain Wilmoth et al., 2006, Pistrang et al., 2012, Garssen et al., 2011) some scholars focused exclusively on mentally ill patients and those suffering from depression (Griffiths et al., 2009). Others paid attention not to the nature of medical

cases but to the type of support offered, whether emotional or informational (Schroevers et al., 2003, Nöres et al., 2011).

With the above in mind, it is not surprising that social support groups are described in the literature under a variety of labels, including, “mutual aid”, “mutual support” groups, as well as the broader term “self-help groups”. The latter type encapsulates a wide variety of activities (Pistrang et al., 2008) ranging from personal psychological support to developing a sense of family.

However, in this thesis “self-help groups” and “support groups” are worth focusing on because they are informed by distinct paradigms in terms of theory and intended benefits (Helgeson et al., 2000, Borkman and Munn-Giddings, 2001). Whilst there is a lack of agreement about what social support groups are, some writers believe that they can be seen as a group of people sharing same illness, concerns, uncertainty and they care about each other (Chinman et al., 2002, Fallbjork et al., 2012, Seeböhm et al., 2013).

Beyond this somewhat generic view of a support group, some scholars refer to such groups as a space where emotions are dealt with, common experiences are shared and members can improve coping with similar problems, all of which contributes to overcoming feelings of isolation and loneliness (Adamsen and Rasmussen, 2001, Griffiths et al., 2009). In other words, a support group enables members to speak freely with similar people, sharing experiences and having normal social relations with mutual support and a sense of belonging (Cho et al., 2012, Boesen et al., 2011, Pistrang et al., 2012).

The self-help group concept fundamentally presumes that people facing a similar challenge have a self-interest and common need in mutual assistance (Festinger, 1954). Self-help groups were initially an anti-professional alternative to pure medical treatment in the 1960s, but they are not viewed as a supplementary therapy to traditional healthcare methods, with particular utility for improving patients’ psychosocial outcomes (Borkman, 1999, Nöres et al., 2011). This type of self-help group has been known for decades in the USA, UK, Germany, France, Belgium, Austria, the Scandinavian countries and more recently in Jordan. Scholars have claimed that by

the mid-2020s self-help groups will comprise a supplementary treatment for many psycho-pathologies (Stang and Mittelmark, 2009, Pistrang et al., 2012)

Similarly, others argue further that many of the conditions that cannot be treated with bio-medical care will mean a rising burden of morbidity for which self-care and self-help are the most cost-effective solutions (Oka, 2013, Seegers et al., 1998, Munn-Giddings and McVicar, 2007). Thus understanding such a self-support group and their benefits is essential. However, for the sake of conceptual clarity, it is crucial to understand the differences between self-help groups and professional-led support. These differences are illuminated below.

The main difference between self-help and support groups is that the former are led or owned by patients and the latter are directed by professionals (White and Madara, 2002, Borkman, 1999). Clearly, as argued by some scholars (Boesen et al., 2011, Oka, 2013), professional-led groups offer more opportunities to educate patients and impart factually correct information, but this is at the expense of the improved self-efficacy and other psycho-social outcomes associated with self-help groups,, in which patients have more autonomy and empowerment and in which they can creatively offer mutual support to each other outside the confines and dictates of healthcare systems (for example, patients can share practical and pragmatic advice about common challenges that would be under the radar of professionally led support groups).

Professionally led support groups tend to assume a pedagogical atmosphere (Pistrang et al., 2012, Jackson et al., 2011), whereas in self-help groups the independence and autonomy of members is jealously preserved (Borkman, 1999, White and Madara, 2002, Chaudhary et al., 2013), with the belief that the shared experience of participants constitutes a collective wisdom (Davison et al., 2000, Eysenbach et al., 2004, Stang and Mittelmark, 2009). That is members know their medical situation more than someone else who has never experienced it, and thus experiential learning can take place (Oka, 2011). On this basis, it is argued that experiential knowledge can be seen as:

“Truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others... the term ‘experiential knowledge’ denotes a high degree of conviction that the insights learned from direct participation in a situation are truth, because the individual has

faith in the validity and authority of the knowledge obtained by being a part of a phenomenon” (Borkman, 1976,Pp446-447).

While support groups are normally temporary, self-help groups comprise a more natural community, whose members can engage each other outside meetings (Borkman, 1999, White and Madara, 2002), and it has been found that patients in self-help groups often show high engagement and reciprocity with these communities as they offer the scope for social interactions unavailable in the general community (Boesen et al., 2011, Oka, 2013). Additionally, self-help groups are less restricted by time constraints (Jordan and Neimeyer, 2003), which promotes the naturalness of communication and long-term rapport, enabling participants to build mutually trusting relationships:

“Self-help differs from other support services in the way it is based on relationships of mutuality between peers rather than on the more formal, hierarchical relationship between professional and client of mainstream services”(Avis et al., 2008,P 945).

However, the reviewed literature would seem to suggest that although self-help groups are mostly facilitated by members themselves (Coreil et al., 2004, Jackson et al., 2011), sometimes they are coordinated by health professionals or non-professionals and open to people with cancer and their families (Tercyak et al., 2012, Stang and Mittelmark, 2009). In this context, self-help groups are often successfully coordinated through health organizations, under the stewardship of personnel such as counsellors, nurses or social workers. On the other hand, non-professionally led self-help groups or Sanad in this study are facilitated by women who have experienced a cancer threat (Stang and Mittelmark, 2009). Overall, social groups include helping patients articulate and share the psychological, sexual and physical aspects of illness in a safe and supportive context that maintains a realistic yet optimistic outlook (Pistrang et al., 2008, Chinman et al., 2002). However, there is a need to justify in more detail why women with breast cancer need to be engaged in a self-help group in the first place and thus identifying ways of maximizing its success.

2.6 Self-Help Groups and Breast Cancer: Why do we need them?

General social support is critically required in order to facilitate proper psychological adjustment for women with breast cancer. In particular it is agreed that social support,

whether formal or informal, is essential for maintaining treatment regimens and coping with breast cancer, associated fears and uncertainty (Zuidgeest et al., 2011, Taleghani et al., 2006, Wassersug and Oliffe, 2009).

Family and friends contribute most informal support, while formal support is available via community-based support groups (Shannon and Bourque, 2005, Guruge et al., 2011). Nevertheless, whilst a healthcare system might determine how a woman with breast cancer manages her health (Shields and Rousseau, 2004, Baider et al., 2004), published evidence over the years confirms that informal support is generally insufficient in critical times (Doumit et al., 2010a, Erci and Karabulut, 2007, Feather et al., 1988), including breast cancer diagnosis, when the very social relationships that comprise informal support are often severely affected by the general outcomes of the illness (Arora et al., 2007, Boesen et al., 2011).

Therefore, arguably the formal social support networks might minimise the negative women's experiences with breast cancer such as isolation, fears and uncertainty. This need for a formal support group is reinforced by the theory of social comparison processes (Festinger, 1954). According to this theory, in times of anxiety people solicit the opinions, advice and experience of others perceived to have a similar experience, thus affiliative behaviours increase in order to conceptualise how people should think, feel and behave. Formal support is a form of affiliative behaviour that validates emotions, expresses support, promotes finding meaning and eases cognitive processing (Festinger, 1954).

Recent studies showed that most supportive care needs of cancer patients are in the psychological domain (Allard, 2006, Banning et al., 2009, Vos et al., 2012). Due to the prevailing biomedical focus of healthcare workers and organisations when caring for cancer patients, the latter may feel adequately understood only among other patients and survivors (Stang and Mittelmark, 2009, Sandaunet, 2008), particularly for the issues of femininity and sexuality associated with breast cancer (Lam et al., 2012a, Bakht and Najafi, 2010). In dealing with such sensitive issues, cancer support groups can provide a 'separate space' for women with such illness (Ussher et al., 2006), particularly in conservative cultures, enabling a form of social interaction unavailable outside the group (Berger et al., 2010, Bowlby, 2008, Griffiths et al., 2009).

A fundamental point related to the nature and significance of knowledge exchange among members of a support group needs to be reiterated: the authentic experience of illness is more trustworthy than expert knowledge. This is because a peer audience facilitates disclosure about fears and sensitive issues and diminishes embarrassment among members (Cho et al., 2006, Pistrang et al., 2012). Others (Griffiths et al., 2009, Eysenbach et al., 2004, Borkman, 1999) stressed that hearing authentic stories from members with breast cancer and witnessing survivors encourage women to take particular actions and deal with their illness based on consulting others.

Other scholars (Ganz et al., 2002, Wiles et al., 2008) extended this postulation further by arguing that groups reduce uncertainty and trepidation, increasing members' sense of control in their lives and making them feel more secure. Additionally, practical information, particularly about treatment decisions, is highly valued and useful for members of such groups (Coreil et al., 2012b, Goodwin, 2005, Griffiths et al., 2009). The process of participation in self-help groups (e.g. observing behaviour, listening to others' breast cancer experiences, taking part in group activities members) enables the community narrative to be adopted as their own by members.

However, whilst during the initial period following diagnosis women with breast cancer are more interested in information regarding treatment, during the post-treatment period emotional support assumes more importance (Chamberlain Wilmoth et al., 2006, Grimsbo et al., 2012). Regardless of the stage of cancer diagnosis and treatment, research suggests that women were willing to attend the meetings of self-help groups when the focus was heart-to-heart personal and knowledge (Garssen et al., 2011, Goodwin, 2005).

In summary, although self-help groups do not reach all people and populations adequately, they have been shown to provide a highly appreciated form of help for breast cancer patients. Based on evidence cited previously, which indicates that healthcare staff remain preoccupied with biomedical and anatomical aspects of caring for women with breast cancer, and the recognised need that such women have for psycho-social support, self-help groups offer the most expedient and effective method to address this deficit in care. This highlights the importance of exploring and understanding more specifically the benefits of a self-help group of women with breast cancer and their experiences.

2.7 Self-Help Groups: Benefits and difficulties

Although the need for a social support group is justified in the literature (see above), there is some debate regarding the benefits of support group for specifically patients with breast cancer. Although it is agreed that the aim of support groups is not *curing* in orientation, they do offer psycho-social support for stressful health-related events that ultimately has an impact on health outcomes (Bauman et al., 1993, Allard, 2006, Chamberlain Wilmoth et al., 2006, Munn-Giddings and McVicar, 2007).

A few quantitative studies that specifically addressed the issue of social support and breast cancer were identified from the literature search. A questionnaire based cross-sectional survey of 176 Korean women receiving chemotherapy for breast cancer measured experience mood and disturbance and the level of social support (Gurm et al., 2008b, Doumit et al., 2010b); 134 questionnaires were returned (a response rate of 76.14%). It was found that symptoms (e.g. nausea, appetite and sleep) were exacerbated by greater mood disturbance in the context of average or low social support (Gurm et al., 2008b, Doumit et al., 2010b). As confirmed by other research (Lee et al., 2004), these findings are indicative that social support enhances women's mood and reduces the severity of related symptoms. However, the study was focused on Korean patients, the sample was small and the validity of the scales for the sample population was untested. These shortcomings were considered by large web-based surveys in the UK (Reed et al., 2012) and Canada (Jones et al., 2012), wherein researchers examined the QoL of women with metastatic breast cancer, quality of social support provided and health anxiety. It was found that satisfaction with experience of social support and care in general was low in the hospital setting, and the contributions of general practitioners and palliative care services were minimal (Reed et al., 2012, Jones et al., 2012). The complex needs and problems of women with breast cancer are largely unmet (Wyatt et al., 2004, Remmers et al., 2010). However, the conclusion is based on self-reported disease and treatment information and the possibility of bias and the volunteer effect cannot be ruled out. Indeed, because the web-based studies are carried out online, it is not possible to identify the actual medical conditions of participants.

Accumulative evidence on research with breast cancer in the USA, the UK, Japan, Lebanon and Iran confirmed that self-help group participation facilitates adaptation to

illness (Agrawal et al., 2007, Oka, 2013, Doumit et al., 2010b, Heidari Gorji et al., 2012). This adaption included improved coping, education, maintaining treatment regimens (Coreil et al., 2012b, Sammarco, 2003), and thus a significantly lower rate of recurrence and mortality than those in the control group (Goodwin, 2005). Other researchers pointed out that one-year cancer support groups focused on emotional self-disclosure sharing of fears and cohesion among women resulted in improved survival rate and coping behaviours (Sandaunet, 2008, Eysenbach et al., 2004) and better QoL (Gurm et al., 2008b). In other words, support groups promote feeling accepted and less isolated, empowered with greater self-efficacy, and acquiring effective ways to cope with illness and other difficulties (Helgeson et al., 2000, Griffiths et al., 2009).

To date, although the efficacy of self-help groups for people with cancer has been examined frequently in controlled and randomized studies (Garssen et al., 2011, Graves, 2003) the evidence is still unconvincing (Newell et al., 2002, Hersch et al., 2008, Coyne et al., 2006). When the literature is reviewed on support groups, what is clear is that several studies found an improvement with respect to anxiety, depression, worry, confusion, self-esteem, experience and control, but there is limited knowledge about how such groups shape the recovery with its diverse aspects of women with breast cancer. Indeed, the existing benefits of a self-help group are often reported interchangeably with the benefits of other types of group, such as social support groups, psycho-educational interventions for women with breast cancer and cognitive behavioural oriented stress management (Manne et al., 2007, Helgeson et al., 2000).

However, research from the social sciences on self-help and breast cancer advocates focusing attention on a model of the experience of breast cancer related to participants' culture and involvement (Ussher et al., 2006, Griffiths et al., 2009). It is not surprising therefore that a self-help group needs to be informed by the cultural beliefs and practices that impact on the utilization of health and support services (Gurm et al., 2008a). Thus it is important to study how effective social support groups are, and to identify the conditions that enhance their effectiveness.

It would appear that a self-help group for women with breast cancer is a safe and supportive environment to enhance reciprocity and the sharing of cancer experiences is associated with better mental health outcomes, QoL, symptom reduction and

functional status. However, whilst there is an increase in the number of self-help groups, those patients who attend them are still in a minority. Consequently, it is imperative to identify contributing factors to joining a self-help group and what difficulties might be posed by such meetings.

2.8 Factors in Self-Help Group Attendance

The reviewed literature suggested that only a small percentage of cancer patients join such groups (Lieberman and Goldstein, 2006, Avis et al., 2008), and only a few patients become long-term members. Few studies have investigated factors associated with sustained participation (Owen et al., 2007, Munn-Giddings and McVicar, 2007). There are a number of factors found in the literature explaining why self-help groups are attended or not attended by women with breast cancer. These are illuminated below.

The reasons why some ethnic groups are more likely to engage in self-help groups than others was investigated in the UK (Avis et al., 2008). It was found that forming a sense of togetherness, mutuality, learning from one another and developing mutuality are main reasons for attending a self-help or support group. On the other hand, stigma and related cultural barriers to discussing private issues with strangers were identified as blocking people from participation in self-help groups (Avis et al., 2008). Similar findings have been made by numerous studies in recent years, including both quantitative (Sandaunet, 2008) and qualitative research (Oka, 2013, Pistrang et al., 2012, Munn-Giddings and McVicar, 2007).

Others found that the negative consequences of unsupportive social interactions in a self-help group itself might discourage some patients from re-attending the meetings, especially when they are experiencing a life crisis (Figueiredo et al., 2004). Likewise, some women with breast cancer report that social support is either unavailable to them or that the group format is unsuitable to verbalize their feelings (Chantler et al., 2006), and generally attending a self-help group might intensify patient distress (Manne et al., 2005), leading to elevated anxiety and depression (Iwamitsu et al., 2005).

Some researchers take these points even further by arguing that patients are discouraged from attending support groups by some healthcare due to the latter's

belief that such groups promote pessimism, complaints and a negative victim mentality (Carroll et al., 2000); similarly, some individuals might perceive that taking part in a self-help group could contribute to a negative labelling process (Damen et al., 2000).

In line with the above, some research found that retention is influenced by the social and cultural characteristics of members themselves (Bauman et al., 1993, Coreil et al., 2004). It is not surprising therefore that the proliferation of ethnic cancer support groups in the US in recent years is an important factor in achieving the participation of minority ethnic groups in such methods of care delivery (Newman et al., 2002, Sussner et al., 2011). Scholars assert that support groups necessitate a desire to expose private experiences and feelings, which is associated with numerous particular cultural barriers (Ashing-Giwa et al., 2004, Ashing-Giwa et al., 2006, Avis et al., 2008, Borkman and Munn-Giddings, 2001).

However, further examination of the literature revealed that the nature of interactions among members themselves is not the only contributing factor in taking part or remaining in a self-help group. Further evidence would suggest that behaviour about seeking support is influenced by the conceptualisation of illness. For example, when individuals perceive their illness as stigmatizing, they generally become withdrawn and isolated or seek the association and support of others with a similar condition (Davison et al., 2000, Ablon, 2002, Azaiza and Cohen, 2008). However, viewing illness as disfiguring and disabling might not be a strong factor in self-help group attendance. Seeking support is promoted by a desire to share concerns, to compare emotional and physical condition with others and to learn about the illness and treatment options (Krizek et al., 1999, Stang and Mittelmark, 2009). Therefore it is plausible to argue that perceiving less adequate support and experiencing more unsupportive interactions in a self-help group may also be associated with increased health anxiety. These negative effects cannot be ruled out and thus there is an urgent need to understand how the interaction processes among the group members shape overall women's experiences with breast cancer (Shannon and Bourque, 2005).

A main shortcoming of previous studies on social support groups in general is that they have mainly focused on the positive aspects of social relationships, paying little attention to the existent and serious negative aspects of social relationships

characterized by conflict, criticism and interference, all of which are powerfully related to psychological functioning (Kunkel and Chen, 2003, Schroevers et al., 2003, Kwok and White, 2011). Furthermore, whilst the barriers identified in this section are vital in preventing women from joining a self-help group, they are largely descriptive. Indeed, there are some valuable online studies on factors affecting attending a self-help-support group, but it is not clear how observing women's online discussions without examining the body language and non-verbal communication can contribute to credible and comprehensive picture (Sandaunet, 2008, White and Madara, 2002). Existing studies mainly focus on individual factors such as motivation, psychosocial variables and socio-demographic characteristics; few have explored participation with regard to personality characteristics, group dynamics, socialization or social support. Other researchers questioned "whether having the same illness is, in itself, sufficient for people to feel that they have an experience in common"(Avis et al., 2008,P.944).

Researchers have recently begun investigating individual-group fit and group context generally as explanatory variables for understanding support group participation (Plass and Koch, 2001, Sherman et al., 2012, Coreil et al., 2004). This highlights the need for further research identifying, comparing and contrasting motives behind taking part in a self-help group or rejecting the whole idea. However, regardless of whether women with breast cancer attend a self-help group or not, their recovery is usually their ultimate goal. The next section explores this concept and its components.

2.9 Recovery and Women with Breast Cancer

Reviewing literature on "recovery", it is clear that the concept is multidimensional, complex and both socially and culturally constructed. For example, words such as "empowerment," "self-efficacy," "will," and "control" are often used interchangeably to describe recovery concepts (Young and Ensing, 1999). These concepts also were found in more recent recovery related literature (Cho et al., 2012, Davidson et al., 2005, English et al., 2008).

Recovery is a unique and personal process of attitudinal change in feelings, values, skills, goals and/or roles (Fox, 2012, Fox, 2007, Gartner et al., 2010). In other words "it is thought to be a process of adaptation at increasingly higher levels of personal satisfaction and interpersonal functioning" (Hatfield and Lefley, 1993,P.141). In this

context scholars argue that people who experience major illness or other life events search for meaning and satisfaction (Kilgour et al., 2008, Cho et al., 2012, Palmadottir, 2009), which involves internal coping resources and the external environment in a process that can help or hinder recovery.

In other words, the interaction among characteristics of the individual such as hope and characteristics of the environment such as choice can promote or hinder recovery (Gartner et al., 2010, Fox, 2013), involving numerous dimensions of life (Elmir et al., 2010, Coreil et al., 2012b). Individual resources complemented by social and healthcare support have a major impact on recovery. This highlights the need for understanding recovery meanings and experiences from patients' own perspective.

However, against this background, the literature offers conflicting views regarding recovery that are often based on a dictionary definition encapsulating regaining normal health, poise, or status. It is postulated that such views might be unrealistic because recovery is not synonymous with cure; recovery is not necessarily a return to normal health and functioning, rather it can be better adaption to illnesses (Coreil et al., 2004, Elmir et al., 2010). To this end, three main components of recovery are worth further exploration, thus they inform the questions of this study: rebuilding a sense of self, hope and empowerment.

2.9.1 Rebuilding a sense of self

Recovery literature repeatedly mentions the concept of rebuilding a sense of self, after one's 'self' is changed and damaged by a life threatening illness (Coreil et al. 2004; Fox and Widzinski 2003).

This postulation was developed further to indicate that recovery seemed impossible for many patients until a sense of self and reality was reconstructed (Coreil et al., 2012b). A quantitative study examined ethnic differences in recovery narratives among women (n=36) participating in breast cancer support groups in Central Florida, US (Coreil et al., 2012b). It found that the leading feature of recovery for all participants was the importance of maintaining a positive attitude for self. In line with this finding, it is argued that when a patient is discovering a more active and positive self, this discovery appears to offer the person a sense of hope that will provide the

first opening to the road to recovery (Davidson and Strauss, 1992, Wiles et al., 2008). An effective mechanism for sense of self, and thus enhancing recovery, is social support programs (Garssen et al., 2011, Cho et al., 2012).

Providing a supportive social environment for women with breast cancer is associated positively with lower levels of psychological distress (den Heijer et al., 2011, Arora et al., 2007, Wassersug and Oliffe, 2009). On this basis, taking part in a self-help group might enhance self-building skills for those women with breast cancer.

A further element related to building a sense of self is the sense of agency. The latter concept is related to the primacy of self-determination that runs through various aspects of the recovery process (Cook and Jonikas, 2002). Likewise, because it is the woman with breast cancer who recovers, she must direct her goals by choosing her own life path and going along it (Coreil et al., 2012b, Davidson et al., 2005). It can be argued that recovery is closely related to the ability of a woman with breast cancer to establish and work for life meaning. In light of this, it is reasonable to suggest that the new paradigm of recovery is less focused on the individual and more demanding on the environment:

“The new paradigm also changes the nature of solutions and remedies from ‘fixing’ individuals or correcting their deficits to removing barriers and creating access through accommodation and promotion of wellness and well-being”(Onken et al., 2007a,P.18).

This rebuilding process is often facilitated not only by sharing narratives of illness and experiential learning in support groups but also by a sense of hope, another recovery component found in the literature.

2.9.2 Hope

An analysis of numerous accounts by oncology patients in general and in particular those with breast cancer would seem to imply that the process of recovery needs to be driven by hope.

The reviewed literature concurs that the experience of hope is significant in everyday life, and acute in coping with stressful events such as breast cancer. Although it is hard to define, hope involves cognitive and motivational dimensions that include a

future-orientation (Benzein and Saveman, 1998, Wong et al., 2010), related to QoL and well-being (Elliott et al., 2000, Fox, 2012). Others (Wiles et al., 2008, Wengstrom et al., 2001) consider hope to comprise cognitive beliefs a sense of the ability to achieve goals and the determination to do so. Within the perspective of recovery of women with breast cancer, it seems that hope is not a single reaction to a certain episode of illness, but rather it involves orientation to the future. Given the catastrophic impact of breast cancer on women, one might assume that such a condition would cause patients to lose hope; however, research suggests that most women with breast cancer in remission maintained a high level of hope, and that this increased as the illness progressed (De Brabander et al., 1998, Pistrang et al., 2012, Ashing-Giwa et al., 2006).

Taking the above arguments together it can be argued that hope at its most fundamental level means the belief of the patient that recovery is possible (Barbera and Prosa, 2002, Wiles et al., 2008). Hope maximizes the commitments of women with breast cancer to change, focusing on strengths rather than on weaknesses or the possibility of failure, looking forward rather than (Jacobson and Greenley, 2001) backward and enjoying every little achievement rather than longing for a full and speedy recovery (Ashing-Giwa et al., 2006, Hann et al., 2005, Fox, 2012). However, whilst hope is an essential part of recovery for women with breast cancer, it cannot be gained without having a sense of control. This would enable identification of ways to alleviate illness symptoms and reduce psycho-social impacts of stress (Lengacher et al., 2013, Ohaeri et al., 2012). Control itself is an important factor in the next component of recovery.

2.9.3 Empowerment

Finally, a further component of recovery that is frequently cited in the literature and related to the above sections is empowerment. Although there is no single description of empowerment, scholars it includes increased self-confidence, self-reliance, sense of personal control, and self-esteem (Stang and Mittelmark, 2009, Gallagher et al., 2009, Young and Ensing, 1999). Other elements of empowerment seem to be a reduced sense of stigma about having breast cancer (Brahams, 2011) and increased personal agency and self-efficacy to promote recovery (Zorrilla et al., 2005).

Breast cancer recovery is not a crescendo of improvement from sick to well; rather it is a nonlinear and erratic process, involving progress, relapse, regrouping and recommitment with the ultimate goal of recovering (Ralph et al., 2009, Gartner et al., 2010). However, whilst the previous arguments are valued, some theorists go further and view empowerment as overcoming disabling symptoms (Jacobson and Greenley, 2001, Fox, 2013) and reducing the stigmatized status of patients (Lapsley et al., 2002, Ralph et al., 2009). On this basis, it is possible to argue that recovery represents an on-going expression of power (Jacobson and Curtis, 2000, Coreil et al., 2012b, Stang and Mittelmark, 2009).

However, earlier studies found that women with breast cancer are unable to become empowered on their own without a social support system (Coreil et al., 2012b, Lengacher et al., 2013). More specifically, social context and community life were deemed critical to understanding the changes that individuals experienced over time (Meier et al., 2007, Stang and Mittelmark, 2009). For example, participants in self-help groups applied their new participatory competence (e.g. communication, assertiveness, self-monitoring, how to use professionals) to ever-expanding areas of their lives in a safe environment (Doumit et al., 2010a, Cho et al., 2006).

In other words, it can be stated that bringing people together with a common issue opens up possibilities and avenues for future creative health action; recovering individuals may think creatively and develop their own goals in life that positively affect their QoL and health (Cook and Jonikas, 2002, Nausheen et al., 2009).

Whilst a self-help group is not free of possible negativity, as explored earlier in this chapter, being supported and enjoying mutual respect not only empowers members through experiential learning but also creates a positive culture of healing (English et al., 2008, Wright and Bell, 2009). In this context, for women with breast cancer, empowerment connotes the belief among patients that they can make a difference, changing the way they conceptualize breast cancer. To this end, healthcare professionals should work on the assumption that every patient can achieve empowerment, and consequently hope and healing. Thus, for a positive and empowering culture of healing the development, collaborative relationships between women themselves and healthcare professionals are needed. Whilst the involvement

of healthcare professionals is valued, women with breast cancer have the opportunity to make their own choices.

Collaborative relationships among members of a self-help group should allow a meaningful and mutual assumption of responsibility and establishing new connections, which should validate the idea that recovery is possible. Incongruent with the above discussion, women with breast cancer portrayed recovery as an opportunity for personal growth and development (Coreil et al., 2012b, Zorrilla et al., 2005, Coyne and Borbasi, 2009).

Indeed, in light of this chapter it would appear that the majority of earlier reviews focused on a broader range of interventions, such as self-help and management in general (Oka, 2013, Berg et al., 2013, Pistrang et al., 2008) or social support interventions (Arora et al., 2007, Chamberlain Wilmoth et al., 2006), many of which were professionally led. However, patient survivorship and the recovery experience have been considered in terms of disease-free intervals and changes in tumour size (Somlo et al., 2001, LoConte et al., 2008, Hann et al., 2005) and to a lesser extent patients' performance status and experience following attendance of a self-help group (Jones et al., 2012, Kroenke et al., 2006).

Although certain themes and ideas emerge from reviewing literature about recovery, as outlined above, clarification about such concepts in various cultures necessitates further exploratory research (Cho et al., 2012, Fox, 2012, Hsu et al., 2012).

Table 2: Summary of the main studies relevant to women's experiences with breast cancer, support groups and recovery

Focus/aim	Methods	Main findings	Limitations
<i>Palmadottir (2009), Iceland</i>			
The experiences and occupational lives of women with breast cancer	Semi-structured interviews with 18 participants were used. The sample was selected using a convenience sampling method.	Physical and emotional hardship was not avoided but mediated by support and care provided in the social and institutional environments.	The emerging evidence is threatened by a self-selected convenience sample carried out by the managers, who were known to patients.
<i>Obeidat et al. (2012), USA</i>			
The experience of being diagnosed with and undergoing surgical treatment for early-stage breast cancer among Arab American women in USA	A phenomenological approach was used with ten Arab-American women selected purposively.	The majority of Arab-American women accepted breast cancer diagnosis as something in God's hands and thus out of their control.	The study's findings, particularly its external validity, is threatened by the small scale of research (n=10) and lack of adequate description of the analysis process. All participants recruited had high socioeconomic status and as a result the transferability of the findings to those patients with different status is open to debate.
<i>Doumit et al. (2010), Lebanon</i>			
The experience of Lebanese women living with breast cancer	A qualitative phenomenological study was used with ten Lebanese women living with breast cancer. Purposive sampling and unstructured interviews were used.	The analysis identified four major themes describing participants' lived experiences emerged from the interviews, including living with loss, guilt, fears, uncertainty and the need to know and to share that knowledge.	Due to the small sample size (n=10) and possibility of selection bias, the sample might not be representative of the population of Lebanese with breast cancer and in particular the "saturation" of data is an open area for questioning. The study findings offers valuable insights into married women's experiences with breast cancer, such evidence might not be applicable to single patients.
<i>Goldblatt et al. (2013), Israel</i>			
Arab women's experience of coping with breast cancer.	A semi-structured interview was used with 31 participants. The sample was selected purposively.	It was found that social and religious beliefs played a vital role in the women's reactions to their disease as a source of strength.	The study lacks a theoretical background about the recovery concept and thus the findings were examined in narrow context.

Focus/aim	Methods	Main findings	Limitations
<i>Cebeci et al. (2011), Turkey</i>			
The experience of women living with breast cancer.	Semi-structured interviews and purposive sampling.	Because of being diagnosed with breast cancer, all participants were unable to fulfil their domestic roles during surgery, chemotherapy and radiotherapy treatments.	The study focused only on married women; given the social and emotional context of married women, these findings might not be generalizable to single women with breast cancer.
<i>Banning et al. (2010), UK</i>			
Factors that affected the lived experience of breast cancer in Pakistani Muslim women	Semi-structured interviews and purposive sample of 36 participants.	The majority of women in this study felt shock, horror, despair, fear of the unknown, change of image and depression following their initial reaction to the diagnosis of breast cancer.	The total sample (n=36) included 11 patients from London and 25 from Lahore; consequently the sample was dominated by women in Pakistan. In light of this, the reliability of the outcome of comparing and contrasting these two groups can be debated.
<i>Karbani et al. (2009), UK</i>			
A qualitative examination of the breast cancer experience of immigrant Chinese women in the UK	Three focus groups were undertaken with Chinese women (n=23) diagnosed with breast cancer in their native language.	Some Chinese women held the misconception that mammography was a preventive rather than a diagnostic measure. Other women in this study attributed their breast cancer to the effect of the stress of living in Australia due to language barriers and 'culture-shock'.	It included only a small sample from an ethnic minority group from one geographic region, thus the extent and diversity of the breast cancer experience might not be captured. The inclusion criteria included only those women who were diagnosed with breast cancer for the last six months and thus the applicability of the above findings to other sufferers is questionable.
<i>(Gurm et al., 2008b), Canada</i>			
The experiences of Punjabi women with breast cancer.	Four focus group discussions were conducted with 20 women.	The findings showed that all women had a strong spiritual connection and that it was fate or and that their cancer diagnosis was only the will of God.	About 13 (65%) of participants were in a post-treatment stage and all (n=20) were well-educated.

Focus/aim	Methods	Main findings	Limitations
<i>Lee et al. (2004), Korea</i>			
How mood disturbance and social support were related to the symptoms experienced by Korean women with breast cancer	A cross-sectional, correlation design was utilized. The sample included a convenience sample of 134 Korean women receiving chemotherapy for breast cancer. 134 questionnaires were returned (76.14% response rate).	It was found that a higher level of mood disturbance led to a higher level of symptoms (e.g. nausea, pain, appetite and sleep) when the level of social support was average or low.	The study focused on Korean patients and the applicability of the findings to other patients is in doubt. More importantly, although content validity of the scale was established with Cronbach's alpha (0.82), the validity was based on previous studies and not tested with Korean cancer patients.
<i>(Reed et al., 2011), UK</i>			
The QoL of women with metastatic breast cancer and quality of care provided.	QoL examined by an online questionnaire via the Breast Cancer Care website with 235 women with metastatic breast cancer. A number of 136 consented to take part from the two cancer centres. 110 participants completed the questionnaires (80.8% response rate).	It was found that satisfaction with experience of care was low in the hospital setting, with little evidence of involvement of general practitioners and palliative care services. The study revealed that symptom burden was a major problem, with about 34% reporting high levels of pain and other uncontrolled symptoms.	The findings are based on self-reported disease and treatment information and the possibility of bias and the volunteer effect cannot be ruled out. The full scale about QoL is not offered to examine its quality but it would appear from findings cited that it has focused exclusively on women in advanced stages of breast cancer.
<i>Sandaunet (2008), Norway</i>			
Participation and withdrawal from an online self-help group for breast cancer patients.	The study utilized qualitative interviews and participant observation. The participants were recruited through self-selection. Out of 51 women diagnosed with breast cancer who expressed their interest in the self-help group, 40 women agreed to participate in the study and received a password.	The analysis revealed that there are five conditions identified as barriers to use an online-self-help group: to avoid talking about painful details about cancer, the perception of not being 'ill enough' to participate, the challenge of creating a legitimate position in the group, and the organization of everyday life and illness phases that did not motivate for self-help group participation.	It is not clear how women's online discussions were observed without examining paralinguistic communication (e.g. non-verbal, body language), which can contribute to credible and comprehensive understanding.

Focus/aim	Methods	Main findings	Limitations
<i>(Avis et al., 2008), UK</i>			
The possible reasons why people from some ethnic groups did not take part in self-help to the same extent as the rest of the community.	A qualitative interview approach was used with a sample of 68 people who were active in self-help. This included those who attended self-help groups (n=49) and health and social care professionals (n=19).	Participants described three main aspects of the value of being a member of a self-help group: forming a sense of togetherness, learning from one other and developing mutuality. The findings indicated that the stigma attached to an illness and related cultural taboos about disclosing private difficulties to strangers and the inaccessibility of meetings were vital barriers to joining self-help group.	The sample is dominated by black participants, thus the extent to which findings might be applicable to other groups of patients warrants further investigation.
<i>(Jones et al., 2012), Canada</i>			
The role of perceived adequacy of social support and unsupportive social interactions in health anxiety relative to general anxiety, depression, and demographic and cancer-related variables.	A number of 131 participants completed a web-based survey.	The findings showed that perceived adequacy of support and unsupportive interactions were both significant predictors of overall health anxiety.	Although internet-based recruitment is time-efficient, the quality of data might lack credibility because women were asked to self-identify as having a diagnosis of breast cancer and other information (e.g. date of last oncology treatment), consequently it is impossible to identify the actual medical state of participants. The study's sample mainly included highly educated Caucasian women with access to computers, potentially undermining the generalizability of the findings (re. socioeconomic status).
<i>(Coreil et al., 2012b), USA</i>			
The ethnic differences in recovery narratives among women participating in breast cancer support groups in Central Florida.	A semi-structured interview was undertaken with 36 cancer survivors and structured interviews with 64 survivors using an instrument with 66 closed-ended questions were designed.	Analysis showed that the leading feature of recovery for all participants was the importance of maintaining a positive attitude for a good recovery. Faith and spirituality were more significant in recovery for African-American and Latina than for European-American women.	The validity and reliability of the questionnaire cannot be assessed as no copy was offered. The type of observation and its style is not clear, which makes it impossible to evaluate its data

2.10 Summary

This chapter explored women's experiences with breast cancer as a diagnosis, the nature of coping mechanisms used, the role of spirituality and the contribution of healthcare professionals in facilitating or inhibiting positive orientation to such illness. Based on this chapter, it is evident that changes in social interactions, mood and overall physical health affect the QoL of women with breast cancer. Thus there is little wonder that being diagnosed with breast cancer can be seen as a catastrophic change that potentially involves all areas of control, and uncertainty about the future.

As outlined in this chapter, it is unsurprising that the perspective of healthcare professionals on women's experiences with breast cancer contributes to the overall picture about the significance of social support groups and recovery. Moreover, the chapter resonates with calls urging researchers to look at the impact of different religious and spirituality coping strategies on women's experienced outcomes.

Several studies on breast cancer worldwide reported on changes in body image and sexuality (Cebeci et al., 2010, Takahashi and Kai, 2005); experiences from the initial diagnosis (Gurm et al., 2008b, da Costa Vargens and Berterö, 2007); psychological impacts of cancer (Vargens and Berterö, 2007); communication with healthcare professionals (Beaver and Witham, 2007b), family and friends (Howard et al., 2007, Erci and Karabulut, 2007); risk of depressive symptoms (Christensen et al., 2009); and experiences of living with breast cancer and its impact on QoL (Doumit et al., 2010b, Jones et al., 2012) .

Whilst the previous research established some valued groundwork, it included only small samples from ethnic minority groups in specific geographical regions (Obeidat et al., 2012b, Lee et al., 2004), thus their conclusions might be threatened by the possibility of selection bias (Doumit et al., 2010a, Banning et al., 2010, Reed et al., 2011), focusing on women with high socio-economic status (Obeidat et al., 2012b, Gurm et al., 2008b) or a certain stage of breast cancer prognosis, such as early or metastasis (Karbani et al., 2011, Goldblatt et al., 2013). Additionally, their findings have not been adequately duplicated with different methods and sample to verify their evidence (Jones et al., 2012). This

indicates that further research needs to include a more diverse group in terms of the period of living with breast cancer. Indeed, many of studies in the area of breast cancer experience used a qualitative approach, but the methods used reflect the study aims as opposed to the process itself, taking into account the nature of such research (Sandaunet, 2008).

Indeed, the chapter also examined the notion of self-help groups and their development. Likewise, the concept of recovery and its meanings and components such as hope and empowerment were also sketched. The value of social support after a breast cancer diagnosis is well-documented. The chapter revealed that self-help groups provide considerable potential for acquiring illness-related knowledge (Nöres et al., 2011), because some patients feel insufficiently informed about different forms of surgery and adverse effects of treatment (Collins et al., 2004, Keller and Prendergast, 2009). However, the existing experiences and benefits of a self-help group are often reported interchangeably with other types of group such as social support groups, psycho-education, cognitive behavioural and oriented stress management. Similarly, when reviewing literature on self-help groups, it becomes clear that inadequate regard is given to the importance of group processes, which are essential factors in social well-being and patient dynamics in the presence of the breast cancer crisis. This is an important research area but little is known about motives that influence participation. In the light of this, the current available literature poses a dilemma for healthcare professional and researchers alike about what the benefits/shortcomings of a self-help group really are.

As shown in this chapter, there is extensive evidence on the benefits of participation in self-help but such evidence is prone to a self-selection bias – it generally relates to people who choose to join and remain in self-help groups. Indeed, there is some limited evidence of dysfunctional aspects of some groups, and there are issues for further research focusing on participants' involvement and experiences in general. Without doing so it is not possible to design a self-help group that is informed by the cultural beliefs and practices of women with breast cancer.

The chapter argues that recovery is a unique process involving changing attitudes, values and feelings, and it involves the development of new meanings and purposes in life,

enabling adaptation at a higher level of satisfaction. However, one unavoidable question is whether attending or not attending Sanad plays a helpful role for breast cancer women to empower them to express their feelings, cope with such illness, and alleviate feelings of stigmatization. Likewise, the existing studies often offer a bright picture of the types of changes that women experience following attending a self-help group in particular enjoying sense of feeling cared about, but they offer no evidence on how this might shape recovery. To date some evidence about self-help groups and recovery is based randomized controlled trials. Although these studies are useful for the evaluation of evaluating causality and measuring outcomes, a high level of standardization among researchers and the significant degree of control inherent in clinical trials distorts the informal, peer-driven processes that comprise the defining characteristics of mutual help organizations (Humphreys and Rappaport, 1994, Stolberg et al., 2004). Therefore there is a need for a more systematic research exposing the link between a self-help culture like Sanad and its impact on recovery of women with breast cancer.

Considering the literature that has accumulated on women's breast cancer over the past two decades, there is a noticeable gap related to Arab women in the Middle East. More specifically, although many studies have addressed the experience breast cancer in numerous cultural environments, no published research has been related to the Jordanian context. The available studies are still limited and suffer from considerable limitations (see above), and in particular there is a need to verify their findings and examine their applicability to the Jordanian healthcare system. This is due to the nature of healthcare system (i.e. women with breast cancer's beliefs and the nature of Jordanian healthcare system, in the context of increasing numbers of women with breast cancer in the country). Therefore, this study examines how Jordanian women perceive and ascribe meaning to their breast cancer experience following attending a self-help group and how this shapes recovery. In other words, there is a need to understanding the experience of breast cancer among Jordanian women to enable health professionals to provide suitable information and to explore relevant and acceptable interventions tailored to this population's needs and concerns.

CHAPTER 3: METHODOLOGY AND METHODS

3.1 Introduction

The primary purpose of this study was to describe and understand the experience of recovery among Jordanian women with breast cancer following attendance the self-help group (Sanad). More specifically, the study was conducted in Jordan to gather information needed to answer a number of research questions. These included: What are the experiences of breast cancer illness among Jordanian women? What are the roles that self-help groups play in facilitating recovery after treatment for breast cancer women in Jordan? What are the perceptions of recovery experiences between those attending a formal self-help group (e.g. Sanad members) and non-attendees?

With these questions in mind, the key research methods of the investigation needed to be identified. Whilst the terms ‘methodology’ and ‘methods’ are used interchangeably in the literature (Norton, 1999), in this thesis they are separately defined. The term ‘methodology’ concerns how the research project was conducted and the required evidence, while ‘research methods’ relate to the measures used to answer the research question. The current study utilised a naturalistic design with semi-structured interviews. The application of naturalistic criteria to the current study is considered in the following section.

3.1.1 The underpinning epistemology of the study

Prior to formulating the research questions and selecting a certain methodology, attention should be given to the culture (the cumulative deposit of knowledge, experience, beliefs, and meanings acquired by a group of people) being studied (Bowling, 2009). This is because capturing the reality of women’s experiences of breast cancer and their subjectivity may raise ‘difficult questions’ from the epistemological perspective (Benton and Craib, 2001). These include the general ontological issues of the nature of reality, whether it exists, and how it can be examined and understood, and the specific concerns of the perspectives of women with breast cancer (Klein, 2004).

In the light of such questions, it is vital to distinguish between knowledge and mere belief, faith, values and assumptions related to a certain culture (Benton and Craib, 2001), although the value of the latter to human subjects is extremely important. In particular, scholars postulate that the epistemology includes the relationship between the knower (inquirer) and the known (knowable) (Guba and Lincoln, 1994). However, this relationship cannot be clarified until the nature of reality is defined and its subjective elements are highlighted. It is unsurprising therefore that selecting the most suitable research methodology fundamentally depends on understanding one's epistemological assumptions (Mason, 2002, Benton, 2000, Bryman, 2012). In light of this, decisions about selecting the current methodology were based on reviewing and debating epistemological principles found in the body of literature. Specifically, selecting quantitative/positivism or qualitative/naturalistic approach was a focus of the author's thinking during the development of this research (see below).

Although the positivist approach is appropriate to study the link between variables related to breast cancer and recovery (Polit et al., 2006), it cannot elicit a coherent picture about an experience as it occurs in a social-cultural context (Jones and Bugge, 2006). Indeed, whilst a quantitative approach might be effective in identifying the link between patient's knowledge of health and their cultural beliefs, it is difficult to explain the reasons behind that (Foss and Ellefsen, 2002). These arguments acknowledge that the truth is discovered by a positivistic paradigm through the verification and duplication of observable findings (Kumar and Phrommathed, 2005). It includes identifying and explaining the causal relationships between events and therefore it is best suited for testing an existing theory, to examine cause-effect relationships, to predict and control, and to stress the importance of measurement and explanation (Bryman, 2012).

However, it is contended that the meanings of behaviours and interactions in human beings are far more complex than they appear because the possibility of multiple meanings and interpretations behind the same behaviour (Green and Thorogood, 2004). Conversely, qualitative methods focus on understanding how individuals perceive and interpret reality through using words and understand the rationale behind the actions in terms of motives (Greenstein and Davis, 2012). In this context, the paradigm of the

qualitative approach is to explore the nature of reality for certain participants, which could have dissimilar interpretations among individuals, depending on how each interprets the meaning of the interactions with the phenomena involved (Lincoln, 1985).

The issue here is that human beings are able to understand and to reflect on their 'self'; and lived experiences, and so act differently upon them (Lopez and Willis, 2004). Likewise, the sense of 'self' with which humans are endowed enables them to make reflexive assessments of themselves and their positions in society or interactions with others (Delanty and Strydom, 2003). Qualitative researchers view the human world as being characterised by mind, thoughts, consciousness, actions, feelings and purposes, which find their objectifications in languages and beliefs (Van Manen, 1990).

With the current study questions in mind, it can be argued that there are several issues in women's experiences with breast cancer that favour qualitative investigation, due to the socially constructed values highly associated with this particular illness, related to femininity and maternity. On this basis, there is no wonder that qualitative research has gained significant attention and popularity in recent years when it comes to conducting studies in the area of breast cancer (Wiles et al., 2008, Wong-Kim et al., 2005, Doumit et al., 2010b, Fang et al., 2013). This is due to the fact that examining such a complex medical and socio-cultural issue involving treatment, stigma and isolation is not a straightforward process.

The starting point of this thesis is to know more about the Jordanian women's experiences of breast cancer and its treatment, the role of self-help groups in facilitating their recovery, and how attendees of such groups compare to non-attendees. Exploring and understanding human's experiences requires positioning the meaning that they share within the context of their interaction. This epistemology illustrates how humans understand others' behaviours or interactions within any given socio-cultural context (Denzin and Lincoln, 1994). For women with a chronic illness like breast cancer, the disease itself and long term of survivorship is very significant (Williamson et al., 2011). Physical disfigurement and the fear of being socially stigmatised direct women to revise their role in the family and the community (Karbani et al., 2011). The importance of uncovering and examining these complex elements led to the selection of a naturalistic

inquiry as a mechanism of analysis with structural details that inform the conduct of research rather than defining the exact process (Lincoln, 1985). However, undertaking research using the paradigm of naturalistic inquiry requires an understanding of the five axioms that shape naturalistic inquiry (Lincoln, 1985).

The first axiom focused on reality being defined by the participants and influenced by the current researcher. Prediction and control of the outcomes of any experience was impossible. The second axiom addresses the relationship of the knower (i.e. the researcher) as being indivisible from the subject of inquiry, the known. I was a necessary initiator of the study who responded to the women and was guided by them to share what was discovered through the inquiry process (Lincoln, 1985). The third axiom stresses that that generalization of findings applies just to the topic studied, and thus findings do not apply to every situation across all time. That is, understanding gained from this single study defines only this study. On this basis, other studies generate their own unique findings. Scholars argue that these pieces of understanding encourage further research and debate (Guba and Lincoln, 1985).

The fourth axiom in naturalistic study presents the position that cause of a single effect cannot be determined. The goal was to identify as many causes and unique experiences as possible, acknowledging that there may be some unknown factors that may or may not have influenced the ultimate understanding (Guba and Lincoln, 1985). The final axiom presents the role of values in conducting the study. The values of the researcher shaped the study by virtue of the type of questions asked. Incorporated in this study was the qualitative method of naturalistic inquiry for information collection and analysis. Sensitivity of the study to the values of the topic was crucial, which informed the selection of the naturalistic paradigm, and semi-structured interview method, to align the study questions and methods with the women's context (Guba and Lincoln, 1985).

The above axioms were applied to the current thesis. For example, the reality of recovery from breast cancer following attending a self-help group was unknown and was described by each woman as being true for that woman. Collecting a range of unique and individual experiences may enable the discovery of common issues that apply in a variety of different ways to women in similar circumstances, not only regarding the unique

experiences of women with breast cancer but also the common elements in those unique experiences.

I was responsible for gaining as much data as possible, in concert with the willingness and ability of each participant to reveal her experience. Therefore the findings from these interviews are applicable only to these participants. Indeed, the values of this study were the unique combination of the researcher, the questions, the participants, the Jordanian culture and the way in which this study was conducted. Recognizing and emphasizing the importance of the interconnectedness of these values was essential for a productive study (Guba and Lincoln, 1985). The experience of breast cancer patients in terms of their disease, background and religious beliefs may help us understand “How do they think about this illness?” and “What are the perceptions of recovery between Sanad members and none-attendees?”

In conclusion, the suitability of the naturalistic epistemological approach for this study is justified by a number of reasons. In particular, there is little known about how attending a self-help group might shape the recovery process of women with breast cancer, and this research problem cannot be separated from their context where several issues interact in a natural setting. As argued by noted scholars (Guba and Lincoln, 1994), this approach includes both exploring inductively the main constructs or meanings of a certain problem under-investigation and then examining deductively them within the context of the exiting literature. Consideration of how to generate as many constructs as possible from women’s experiences of recovery following attending Sanad is presented in the following section.

3.1.2 The role of researcher as instrument

In this naturalistic inquiry paradigm, I was the instrument. It is recognized that no other recording instrument can capture the minute expressions of human subjects than a person who is sensitive to the participants (Guba and Lincoln, 1985). I tailored questions to each participant’s response to elicit the fullest amount of data. That is, each woman was a partner in this research and affected its course. The direction of study was determined by each participant to the degree she was able to express herself and guide the questions

(Erlandson, 1993). I am a registered Jordanian nurse, and a doctoral candidate in nursing in the United Kingdom. My nursing expertise is diverse, including direct patient care, classroom and clinical instruction of nursing students, and management of several women's outpatient care departments in Jordan. Such roles required significant skills in communication and gathering information. In particular, since I was the tool of data collection and analysis, reflexivity was used to maximise the credibility of this work (Russell and Kelly, 2002). This includes careful thought of the problem under-investigation and taking into account my own assumptions that may affect the current study (Lamb and Huttlinger, 1989). That is reflexivity in this research is considered as "*a method of inquiry, a way of finding out about yourself and your topic*" (Richardson, 2000,P.923).

To this end, during the course of the study I wrote short field notes, including my feelings and challenges involved following meeting women with breast cancer. Moreover, field notes were complemented by using reflective journals in the area of women's experiences with breast cancer. I returned to such journals to reflect back on the current study and thus get a deeper understanding of the women's experience of breast cancer. Drawing on issues/ideas from the journal, links between the literature on methodology, its appropriateness and my understanding of the qualitative research were made (Maxwell, 2012). This was part of the epistemological reflexivity whereby the researcher needs to question how the research question has been defined, and how it could have been investigated differently (Dowling, 2006). This type of the reflexivity enabled the reader to assess the validity of the study findings (Allen, 2004).

However, despite the utilization of reflexivity (see above), data collection and analysis relied largely on the researcher's interpretation of data. While this constricts the validity of the research, it contributes to validity by making it apparent to the reader (Winchester, 2000, Frankfort-Nachmias and Nachmias, 2007). Although bias might affect any study (Gillis and Jackson, 2002), some actions can be taken to reduce its impact. The data in this study were discussed with some women with breast cancer (respondent validation), thus examining whether or not their views are represented in transcribed data.

Moreover I used a framework developed by a qualitative researcher to give a balance between my reflection, assumptions and the real data collected (Frankfort-Nachmias and Nachmias, 2007). These included important questions to be kept in mind and throughout data collection and analysis such as: what are the data telling me? What do I want to know? What is the relationship between one and two? (Guba and Lincoln, 1994, Guba and Lincoln, 1985).

These questions attempt to link between claims and evidence, refocus my attention on the study questions and examine the dynamic interplay between my interpretations and what the data really told me. Therefore, a balanced account between what I interpreted and the reality of a certain experience was kept. However, a full account about how the rigor of this thesis was established is given in subsequent parts of this chapter.

3.2 Research Design and Method

It is argued that the research design cannot be fully identified prior to the data collection process (Bryman, 2012, Maxwell, 2012, Bowling, 2009). This is because understanding any phenomenon develops during the research process, and each data collection and analysis activity informs its design (Grbich, 1999, Silverman, 2003). Thus, this study used as an explorative design that required flexibility to respond to the evolving understanding of the researcher of certain issues, and it did not start with a hypothesis to test (Benton and Craib, 2001). This is effective when the focus is to understand the dynamics of interaction between different individuals in a certain setting. That is, an explorative naturalistic design was used to provide a better understanding of women's experiences of breast cancer; in terms of what is happening and why it is happening. In other words, unlike descriptive design, in this study exploration not only describes the reality of women's experiences of breast cancer, but also explores factors contributing to such experiences. As a result, the explorative design was deemed to be the most suitable to be used in this research.

Although using focus group discussions could present diverse views and dynamic interactions among participants (Kitzinger and Barbour, 1999, Webb and Kevern, 2001), this qualitative method was rejected. Whilst Sanad itself is a form of group meeting, I felt

that getting different women with breast cancer and diverse private issues (e.g. sexuality, body image) to communicate about difficult issues in what is essentially a public forum could limit their ability to take part freely without reservations and thus affect the quality of data.

Likewise, the suitability of employing a standardised method such as questionnaires with participants was also considered but the idea was not accepted. Although anonymity might maximize the validity of data, the questionnaire could raise more questions than answers (Gillis and Jackson, 2002, Gillis and Jackson). In the light of this, an interviewing method was used in this study to further explore women's experiences of breast cancer and to investigate the impact of Sanad on their recovery. Using individual interviews would help the researcher in illuminating unclear statements and therefore gaining a clearer picture of their experiences (Mason, 2002).

The review of related literature revealed three types of interviews: structured, unstructured and semi-structured. Weighing their advantages and disadvantages, the first two types were deemed as inappropriate for this study. It is argued that structured interviews are reliable due to their standardisation (Polit et al., 2001) but they lack flexibility (Grove et al., 2012). Similarly, although unstructured interviews generate richer responses and are recommended when the researcher knows little about the problem under investigation, participants might not be able to focus on the question asked (Jackson et al., 2008), which might lead to lengthy interviews and thus diversions from the focus of the research. Thus there is a need for a type of interview that gives interviewees the freedom of response and description to illustrate the concepts and not only to cover the necessary questions but also to develop their own narratives in each interview (Bryman, 2012). To this end, semi-structured interviews were employed. This type of interview shares the major benefits of structured and unstructured interviews such as flexibility and reliability, while addressing the main questions and affording participants an opportunity to explore other areas of interest that are beyond the schedule (Gillis and Jackson, Frankfort-Nachmias and Nachmias, 2007).

3.2.1 Interview schedule

Overall, the interview schedule was developed in the light of the existing international literature relevant to women with breast cancer, self-help groups and recovery (Chatman and Green, 2011, Cho et al., 2012, Doumit et al., 2007, Cho et al., 2006, Doumit et al., 2010a, Coreil et al., 2012b). However, the majority of questions evolved during the interview time, enabling both the interviewer and the interviewee flexibility to probe for details (Wengraf, 2001). In other words, the interview schedule was created and developed taking into account responses from women obtained in previous interviews.

In this study, the semi-structured interview schedule was composed of open-ended questions with some closed ones. Specifically, the interview schedule included a variety of questions as follows (see Appendix B):

1. How were your reactions and thoughts after being diagnosed with breast cancer?
2. Please tell me how long you have been diagnosed with breast cancer?
3. How would you describe your experiences in relationships with family, friends, and health care professionals during the period from being diagnosed until today?
4. Can you tell me about why you attended Sanad group in KHCC?
5. How did Sanad affect your recovery?

Prior to conducting the interviews, three experts in the qualitative research were invited to examine the content validity of the interview schedule, and the extent to which the questions/items reflect women's experiences of breast cancer. The experts were two Jordanian qualitative researchers holding PhD degrees and one from KHCC who has undertaken projects in the area of breast cancer. The interview schedule was examined by the research supervisors in the UK. Additionally, face-validity (overall interview schedule) was assessed by three non-participants of women with breast cancer (Giorgi, 2002). Accordingly, some modifications were made regarding issues pertinent to women's experiences as well as the clarity of questions. For example, more attention was given to the overall family atmosphere and its impact on women's experiences. Moreover, questions probed further to cover a broader range of aspects related to the impact of attending Sanad on women's recovery.

3.2.2 Sampling strategy

Designing a sample strategy for a qualitative study is as significant as for quantitative inquiry. It is argued that a well-defined sampling strategy, including access and selection of the relevant social units, is a crucial strategic element of qualitative research (Bryman, 2012). In this qualitative study, the researchers' intention was to understand the phenomena and explore unique experiences rather than to generalize findings (Golafshani, 2003). In general, qualitative method is concerned with the quality of the collected data rather than the representativeness of informants who participated (Webb and Kevern, 2001, Munhall, 2011). On this basis, this study selected particular participants who can offer relevant evidence to the phenomena and inform the researcher about the research problem and meet certain criteria (Creswell and Clark, 2007). Purposeful sampling leads the researcher to learn a great deal about issues of central significance to the aim of the study (Winchester, 2000, Frankfort-Nachmias and Nachmias, 2007); in other words, the women in this study were chosen based on their experiences and knowledge of breast cancer self-help groups aiming at addressing the research's questions.

3.3.3 Sample size and selecting procedure

In qualitative studies, there are no definite rules for sample size, although researchers have commonly accepted some considerations when making decisions regarding it (Finfgeld, 2003). As discussed earlier, the main concern of qualitative research is investigating the phenomena under investigation in depth, as well as providing rich data, whereas in quantitative research, the sample size is identified with the generalisability issue in mind (Mason, 2002), which is not the aim of this research. In fact, qualitative samples seem to share a common feature in that the number of cases is often small. It is argued that it is not possible to set out the number of representative sampling in advance for accessing the views and understanding the phenomenon of interest (Sandelowski, 2000). Instead, the sample size should be based on two principles; an aiding tool to understand the process more than representing the population and being dynamic practice (Mason, 2002). Thus, the type of sampling employed is determined by the nature of

methodology selected and the problem under investigation, rather than the need for generating generalisable results (Higginbottom, 2004, Grbich, 1999).

Within the context of the sampling approach in qualitative research, a purposive sample size in this study is determined on the basis of theoretical saturation, when no new data and insights into women's experiences of breast cancer emerge from the data analysis (Glaser, 2001, Marshall, 1996), the threshold point after which no new data result from additional data collection (Selden, 2005). In this study about 90 percent of codes and emerging themes/categories occurred after carrying out 24 out of 28 interviews of women with breast cancer (see below). The last four interviews added minor proprieties to certain concepts such as the state of "getting out of the capsule", as presented in depth in the findings chapters.

It is argued (Patton, 2002) that recruiting a heterogeneous sample of participants enables the researcher to gain high-quality and unique case account together with a shared pattern of commonalities across the participants. In line with this argument, I selected all of the health care professionals who work closely with those women with breast cancer at KHCC (two breast nurse practitioners and four social workers) from diverse backgrounds to help me merge themes from both patients and health care professionals, and to maintain gaining in-depth data from their experiences with self-help groups.

Initially 36 participants agreed to take part in the study but later two of them withdrew (without stating the reason). Eventually, a purposive sample of 34 participants was recruited from the KHCC over a period of six months. The population of the study involved three groups: 15 breast cancer women who participated in Sanad group; 13 women who did not participate in Sanad group; and six health care professionals. The inclusion criteria for selecting women for the first two groups were that they be adult Muslim females (aged 18 or over), diagnosed with early to late stage breast cancer (stage 0-IV), Arabic-speaking, having experienced treatment such as chemotherapy, radiotherapy, hormonal therapy and surgery.

The third group comprised six health care professionals (two nurses and four social workers) from different backgrounds. This group was included to get the perspectives of

health care professionals, enabling data triangulation and thus gain a holistic understanding of the problem under-investigation (Jones and Bugge, 2006, Denzin and Lincoln, 2000). For example, the impact of attending Sanad was exclusively examined from the perspective of women themselves and from the position of health care professionals who meet them on a regular basis. All the available health care professionals (n=6) were selected. Four were social workers and two breast nurse practitioners with a Bachelor's degree and experience of more than one year in working with women with breast cancer.

3.3.4 Research setting

The study was conducted in the KHCC. This hospital is located in Amman, the capital of Jordan. The centre is considered as one of the biggest and advanced hospitals for cancer management centres in the Middle East. It is an independent, non-governmental institution founded by Royal Decree to combat cancer in Jordan (KHCC, 2009a). The centre has a good relationship with other organizations outside the country, particularly in the US. This bond is built to improve the quality of care for oncology patients. Physicians and nurses are sent to some hospitals in the US to gain the advancement skills and competencies that are required for the promotion of cancer care.

The KHCC is the leading centre for cancer care in Jordan and the surrounding region. The study was conducted in a comprehensive cancer centre, as it includes palliative care for inpatients, outpatients, and patients at home. The hospital has 160 beds with a highly specialised section for oncology care. About 2500 new cancer patients are examined in the centre per year (KHCC, 2009b).

3.4 The Nature of Sanad

The word 'Sanad' itself literally means 'support' in Arabic (JBCP, 2009b). In 2003, Sanad group was established in KHCC. It is a vital part of the Psychosocial Unit at KHCC. It is the only self-help group that was established for breast cancer women in Jordan. Six health care professionals (four social workers and two nurses) are responsible for this unit. Their duties include welcoming new breast cancer patients, informing them

know what Sanad is, and explaining its role. The psychosocial health care professionals act as a bridge between the medical care team and those women with breast cancer, such as by explaining the treatment options for their cancer, and helping them to access other resources (e.g. whether they have any financial problems). The unit has a limited budget that could help women in Sanad with their transportation costs and other issues.

The Sanad group was founded by an enthusiastic and dedicated group of breast cancer survivors. The Sanad group is considered a psychosocial-oncology therapy group that works to reduce the psychosocial burden of cancer on patients (KHCC, 2009b). Sanad, based on the 'Reach of Recovery' model, is focused on facilitating breast cancer women's recovery, enhancing patients' coping with the physical and emotional trials of the disease (JBCP, 2009b). These ideas are in-line with recent international calls for integrating women with breast cancer into the community and help them dealing with isolation and release their potential (den Heijer et al., 2011, Heiney et al., 2011)

This self-help group is led by women with breast cancer. Women with at least one years' experience of breast cancer and its treatment were encouraged to take part in Sanad. The one year criterion is to ensure that they would be able to share their experiences with other women in a similar situation. These chosen women were coached in KHCC by health care professionals (facilitators), in order to know how to cope with their disease and give support and knowledge needed to other newly-diagnosed women (see Appendix E).

At the time of data collection of the current research, Sanad has four groups of women with breast cancer. Each group consists of women with different stages of breast cancer, and have had, or are still undergoing different types of treatment. Sanad is open to all women diagnosed with breast cancer, and there are no specific criteria for joining. The Sanad meetings run are weekly, usually in KHCC but sometimes the psychosocial unit prefers to change the venue, and hold it in public places. The aim is to encourage women's attendance, and prevent them becoming bored. The psychosocial unit in KHCC is responsible for organising the meetings, in terms of time and location, so as to create a suitable and safe environment for this group of patients.

According to the Sanad's coordinator, each group consists of 10 to 12 women with breast cancer, but sometimes the number of women could reach 20. Women's attendance or absence depends on their family, and other social and life circumstances which some have been identified in this study. The length of each group meeting is two and a half hours. In the first hour, a relaxation session is provided by a specialist volunteer from KHCC. Yoga and other relaxation techniques are applied in an imaginary journey, so that women can find a new way to relieve their mind and body from stress and the side effects of cancer treatments. After the one-hour relaxation session, the remaining 90 minutes are for the Sanad group meeting. This is an informal meeting only for women with breast cancer. In this meeting, women chat, and share their experiences and concerns, and feel free to talk without any barriers (see Appendix E).

3.5 Accessing Patients and Healthcare Professionals

The study had to follow ethical guidelines set by the University of Nottingham and also the ethical requirements of the KHCC. Ensuring the participants' rights and privacy is a non-negotiable issue. Therefore, I followed predetermined procedures to gain access to the participants. First, I attended some of Sanad's group sessions to introduce myself to the potential participants. This served as an opportunity to invite participants and inform them about the study. Second, a package was sent to the potential participants (Sanad members and non-members) via the health care professionals, which includes an invitation letter explaining the purpose of the study, participant's consent forms, contact details forms and a pre-paid post envelope (see Appendix C). All the documents were translated into Arabic language using a simple but informative style. Participants who agreed to take part in the in-depth interview and who returned their contact details and wished to be interviewed were subsequently asked by telephone or email address if there are any further concerns regarding the study. All health care professionals (n=6) were accessed by arranging a meeting with them at KHCC. Following the explanation of the study aim and procedures, those who agreed to take part (n=6) were listed and permission was obtained to contact them later and thus conduct the interviews.

3.6 Ethical Considerations

A number of ethical issues were identified and addressed in this study. Because the data collection process took place in Jordan while studying in the UK, the study proposal was approved twice (see Appendix A). Key elements of the ethical approval systems were to prevent harm, ensure informed consent, protect personal data and maintain safety. All participants in this study were assured that this research was confidential and there was no personal risk involved. Each participant received an information sheet about the study explaining its aims and procedures. A signed consent prior to participating in the study was obtained prior to undertaking interviews (see Appendix C). All the participants were informed that taking part in this study was completely voluntary and that they could withdraw at any time without giving reasons. In particular, participants were assured that refusing to take part in the study would not affect the quality of care provided to them at KHCC. Moreover, they were informed that they had the right to accept or to refuse recording of their interviews. To achieve the confidentiality, the identified names were replaced with codes during the analysis and writing up this thesis. Indeed, pseudonyms were used when presenting participants' comments and remarks (Smyth and Williamson, 2004). Data security was also considered by using a number of measures. For example, I was the only one who had the transcribed data and the digital recorder. I kept all the records and the transcribed data on my personal computer, which is password-protected. In addition, all of the research diaries and notes, and the translated papers, were kept in a locked cupboard then they will be destroyed at the end of the study (see Appendix C). However, there were some challenges and difficulties. For example, three women displayed suspicion about the study. They felt that there was no need for an interview, and one stated that discussing issues related to private life would cause family problems. With the help of healthcare professionals, those women were re-assured about the aim of the study and its confidentiality and subsequently agreed to take part.

Although I emphasised the confidentiality of data, a health care professional asked for information about how participants perceived the quality of care. I felt that this was ethically unsafe, so the request was politely rejected. In addition to violating the

participants' rights, this could negatively affect the study by undermining the trust and rapport established between me and the participants.

Finally, although my role was a data collector, I sometimes had to act as a support provider on some occasions. For example, during undertaking an interview with a newly married woman, she could not hide her feelings and concerns and started shouting that "I am dead now and your study will not cure my cancer!" At that moment I felt that it is not ethical to continue recording the interview, I stopped it and supported her. We then went to the canteen at KHCC and had a cup of coffee. The interview was re-scheduled for the following week.

3.7 Data Collection: Location and Preparation

In order to improve the validity and reliability of the data obtained, I was involved in all interviews (Wengraf, 2001). After collecting the signed consent forms from all participants, interviews were undertaken. All of the participants preferred to be interviewed at the KHCC when they returned for medical follow-ups and attending Sanad. The interview was undertaken held in KHCC venue that has good illumination and ventilation, and was close to the bathroom, suiting those patients with diabetes or who are taking diuretics. The chosen location allowed the interviewee and interviewer to concentrate without distractions. Prior to undertaking the interviews, demographic information was collected. Moreover, semi-structured interviews gathered information on the age and education of the patients, women's' medical information, types of surgical procedures, staging time since diagnosis and treatment (see Appendix B).

The format of the interviews in followed a 'funnel structure' (see Appendix B). This approach is useful to provide an easy, non-threatening way to begin an interview and is particular effective when the interviewee might feel emotional about the topic (Rubin and Rubin, 2011, Wengraf, 2001). In order to hear participants' overall perspectives, the beginning part of the interview was less structured. The participants were asked to verbalize their initial experience with breast cancer following diagnosis.. The interviews probed to determine how the different environments/support and challenges affected

women's experiences. Finally, questions were narrowed down to address deeper issues related to attending Sanad and its effects on recovery, the main focus of this research.

During face to face meetings with participants, a flexible approach was used in which the interviews were adapted to mirror the real experiences of each participant (Bryman, 2012). Those barriers and facilitators that might affect attending Sanad were also identified by health care professionals.

Although most interviews followed the sequence of the pre-structured guide, a few women tried to lead the whole interview by themselves and discussed a particular issue in great detail. For example, a participant started her interview by blaming and talking negatively about her husband and mother in law. These important responses were given attention, but then I re-focused the discussion in a polite way to encourage exploration of other aspects to interrelationships and their influences on women's decisions and experiences (e.g. Sanad and recovery). Similarly, another woman adopted my role as an interviewer and asked many questions about living and studying in the UK (e.g. housing, weather). Once again, I re-directed the discussions and asked her that we can chat later after conducting the interview.

During the interview process, I did not display greater (professional) knowledge about breast cancer and self-help groups than the participants. This was to prevent leading responses and to improve the flow of the discussion without restricting the emergence of genuine data (Somlo et al., 1997). The format of interviewing was thus low control and high processes, in which control over the interview was minimal but I ensured that all relevant information was covered in a depth way matching the study naturalistic epistemology (Bryman, 2012, Frankfort-Nachmias and Nachmias, 2007). At the end of each interview, a verbal summary with the help of the participants was created. The aim of doing this was to synthesize and confirm noteworthy themes found in the interview.

3.8 Recording Interviews and Field Notes

All participants accepted their interviews to be digitally recorded. This allows events/experiences to be reviewed many times for the analysis process. Nevertheless,

recording the interview does not collect non-verbal communications and thus written notes of non-verbal behaviours (e.g. staring at the floor, physical appearances) were made. The duration of the interview was about an hour and a half to two hours, not tiring participants and allowing adequate focus on the topic and collection of relevant data. However, due to emotional and psychological disturbances that were triggered by the interview for two participants, the duration was about 30 minutes. After completing every interview, the file was transferred to the computer.

3.9 Data Analysis

In this qualitative study data collection and analysis were conducted concurrently. All interviews were conducted in Arabic and the analysis was in English. To facilitate this, it is argued that back-translation is necessary to bring the second language as close as possible in terms of meaning to the original language through translation (Maneesriwongul and Dixon, 2004). The recorded interviews were translated from the Arabic language into English transcriptions. Actions were taken to ensure that the obtained English transcripts were equivalent to the original data. First, translation was made by the current author from Arabic to English. Then, a bilingual researcher was invited to independently back translate randomly selected manuscripts from English into Arabic. The independent researcher was selected on the basis of his recognised experience in back translation of qualitative texts in social and health sciences. The two translated versions were checked by the researchers. The aims were to render a translation that is as close as possible in structure to the original language, carefully taking into account the cultural nuances (Cruz et al., 2000). In case of any dissimilarity, the recorded interviews were re-examined by arranged meetings and using phone calls until consensus was reached. Following this, a thematic analysis approach was used for analysing the qualitative data, which were in English. This approach of analysis was considered appropriate because the emerging responses were about experiences and stories. In this study, thematic analysis studies systematically the woman's experience, concerns and beliefs in order to create an overall picture about how attending Sanad might shape recovery (Lambert and McKevitt, 2002), without de-contextualizing the data

(Braun and Clarke, 2006). In order to manage data effectively and identify related commonalities NVivo 9 was used (Thorne, 2008).

All manuscripts were read through as many times as possible in order to be aware of the main issues/themes and thus, getting a deeper understanding women's experiences of breast cancer (Guba and Lincoln, 1994) (see examples of the preliminary data analysis in Appendix D). The extent to which common themes were really common in the manuscripts was re-checked (Gillis and Jackson). Any statements/ideas that were of significance to the study were coded. This enabled the emergence of themes from the data, and precipitated different 'pieces' of the full story about Jordanian women's life with breast cancer. Once the vital issues/themes have been identified and coded, as many labels as needed were devised. Recurring themes (e.g. joining Sanad to "get out of the capsule") within one transcript and across the dataset were then grouped (Miles and Huberman, 1994). The degree to which some themes are based on real responses were re-checked and confirmed by extracts. For instance, one aspect of Sanad experience was referred to as "from isolation to recharging my battery". This experience was based on real responses among women involving "back to work", "being socially active" and "thinking positively". In order to introduce the reliability component to the categorisation process, a PhD Nursing colleague in Jordan was asked to analyse a randomly selected number of four transcripts without seeing my analysis.

In case of disagreement, each researcher needs to give some extracts from the original manuscript in order to justify a certain category. Overall some minor changes were made to the labels. In order to link themes together, a thematic map was constructed and redefined as patterns of the themes became visible. The map was discussed and debated with my supervisors.

In order to rule out the possibility of selection bias about what was relevant and what was not, the study questions were frequently re-explored with my supervisors in the UK. However, if in doubt about what to exclude from analysis, irrelevant materials were kept in a specific file to be revisited at the end of data analysis and to examine how it might be fitted with the overall emerging evidence. For example, some participants talked a lot about the increasing living costs (e.g. price of food, housing) in Jordan following the

2003 invasion of Iraq. During initial analysis of the data, such information was not given much attention as the main focus was on how Sanad affected women's recovery, but when approaching the end of the analysis process, having revisited the data and discussed the issues with my supervisors, it became clear that such details were of significance to women's recovery and helped the development of the "economic recovery" concept, as explored in the discussion chapter.

3.10 Trustworthiness of Qualitative Data

The trustworthiness of this study - the extent to which its findings reflect the actual experiences of women with breast cancer and perceived recovery was addressed using different considerations (Shenton, 2004). As a researcher from Jordan with significant experience in nursing, there was a possibility for bias that might be caused by my preconceptions of women's experiences of breast cancer. Therefore, as outlined earlier, throughout the study I attempted to use the reflexivity approach during developing the methodology, data collection plan and analysis and interpreting the findings.

Before undertaking the interviews, qualitative research experts (n=3) and non-participants of women (n=3) with breast cancer checked the interview schedule and evaluated its content and face validity. Indeed, the involvement of an independent qualitative researcher in the process of data analysis accomplished a degree of dependability and conformability (Polit and Hungler, Porter, 2007). Moreover, the credibility of qualitative data was taken into account by participants checking the data. A randomly selected number of thirteen women and three health care professionals were asked to check the comprehensiveness and accuracy of the transcribed data in comparison to what they really reported. Indeed, during conducting the semi-structured interviews, all participants were given the opportunity to correct the summaries/reflections, and they were encouraged to add further information. This contributed to semantic validity because participants were able to examine the extent to which the language and expression used had a similar meaning to them. This method was essential as I am from the southern province of Jordan and not fully aware of the meaning of some colloquial Arabic phrases in other areas.

Over the period of six months of data collection in Jordan, I spent prolonged time with participants. This enabled a deeper understanding of participants' culture and language, and thus facilitating the establishment of a trust relationship with them (Gillis and Jackson). This is likely to encourage honest responses and more valid interpretations of women's experiences and views. Moreover, it should be noted that the credibility of findings was maximized by involving health care professionals in the study. This type of data source triangulation strengthens the development of the study conclusion and its comprehensiveness (Foss and Ellefsen, 2002).

Finally, whilst statistical generalisability of current findings is not the aim of this study, the idea of transferability was used. Transferability refers to the extent to which the reader is able to generalize the findings of a study to her or his own context and see "how far a researcher may make claims for a general application of their theory" (Gasson, 2004,p.98). It is recognized here that albeit other women with breast cancer in other settings are not identical to the current sample, there might be some commonalities which might be of relevance. In order to address the transferability criterion of trustworthiness, a number of interventions were used. I provided sufficient information about myself as a researcher and the research context and processes to enable the reader to decide how the current findings may be transferred (Silverman, 2003). Indeed, the transferability was enhanced by offering the reader adequate information about the how the themes were developed as highlighted in the following chapter.

CHAPTER 4: FINDINGS ABOUT DECISION-MAKING AND SELF-HELP GROUPS

4.1 Respondent Characteristics

Of the participants (n=28), fifteen women took part in the Sanad group and thirteen women did not. The age range of women across the sample was 28-68 years, with a mean age of 45.6 years. The majority of women from the sample were between 30 and 60 years of age. Nine women were diagnosed with Stage III of breast cancer, nine women were diagnosed with Stage II, and seven with Stage I. Only three women were diagnosed with Stage IV.

Sixteen of the women were married, five were divorced, five were single and two were widowed. The level of education varied; twelve women had a Bachelor's degree and six had a secondary school certificate. Four had diplomas and postgraduate education. Three women had only completed primary school. Two women had no qualifications. More than half of the sample (n=16) identified themselves as housewives, five were retired and five were workers. Only two women were unemployed.

At the time of data collection, all women (n=28) had received surgery. Twenty were receiving chemotherapy and radiotherapy. Out of the twenty, eight women received mixed treatment (chemotherapy, radiotherapy and hormonal therapy). Eight women were receiving chemotherapy alone, and one woman was receiving radiotherapy. Table 3 below shows the characteristics of the sample and it provides an overall picture about the sample characteristics. Table 4 shows the profile of health care professionals who were included in the research. The total number is six. This includes four social workers and two nurses working in the psychosocial unit in KHCC.

Overall the analysis process showed five categories and thirteen sub-categories, as presented in table 5.

Table 3: Respondent characteristics

Respondents	Age (yrs)	Marital status	Education	Role	No. of children	Stage of breast cancer	Treatment type	Attend Sanad (A) or not (N)
R1	60	married	Diploma	Retired typist	5	III	surgery, chemo, radio, hormonal	A
R2	62	divorced	BSc Arabic language	Retried Arabic teacher	4	I	surgery, chemo	A
R3	48	married	Secondary school	housewife	7	III	surgery, chemo, radio	A
R4	33	married	Secondary school	housewife	5	III	surgery, chemo, radio	N
R5	44	single	BSc Islamic studies	Retired Islamic teacher	---	II	surgery, chemo	N
R6	49	married	No qualification	housewife	7	II	surgery, chemo, radio	A
R7	55	divorced	BSc Arabic	housewife	2	III	surgery, chemo, radio, hormonal	A
R8	45	married	BSc Arabic	Teacher	4	I	surgery, chemo	N
R9	68	married	BSc Administration	Retired headmaster of primary school	5	I	surgery, chemo	A
R10	28	single	BSc Economy	housewife	-----	II	surgery, chemo, radio	N
R11	55	married	No qualification	Farmer	8	II	surgery, chemo, radio	A
R12	47	married	Diploma of Accounting	Retired accountant	5	III	surgery, chemo, radio, hormonal	N
R13	41	married	Secondary school	housewife	3	III	surgery, chemo, radio, hormonal	N
R14	47	widowed	BSc secretary	Unemployed secretary	3	II	surgery, chemo, radio	A
R15	36	married	BSc Law	housewife	4	III	surgery, chemo, radio, hormonal	A
R16	28	single	MSc Business	Teacher	----	I	surgery, chemo, radio	A
R17	68	married	BSc Civil Engineering	housewife	4	II	surgery, chemo, radio	N
R18	32	single	Primary school	Cleaner	----	II	surgery, chemo, radio	A
R19	66	divorced	Secondary school	housewife	3	II	surgery, chemo	A

Respondents	Age (yrs)	Marital status	Education	Role	No. of children	Stage of breast cancer	Treatment type	Attend Sanad (A) or not (N)
R20	29	married	Secondary school	housewife	2	I	surgery, chemo	N
R21	36	married	Postgraduate student MSc Maths	Teacher	2	IV	surgery, chemo, radio	A
R22	55	married (Bedouin woman)	No qualification	housewife	10	II	surgery, chemo, radio	A
R23	44	divorced	Primary school	housewife	2	IV	surgery, chemo, radio, hormonal	N
R24	38	married	BSc Physics	Unemployed (a physics teacher)	1	III	surgery, chemo, radio	N
R25	31	divorced	BSc History	housewife	---	I	surgery, radio	N
R26	54	widowed	Primary school	housewife	7	III	surgery, chemo, radio, hormonal	N
R27	48	married	BSc Electronic Engineering	housewife	3	IV	surgery, chemo, radio, hormonal	N
R28	32	single	Secondary school	housewife	---	I	surgery, chemo	A

Table 4: Health care professional characteristics

Health care professionals Social worker (S), Nurse (N)	Age (yrs)	Experience (yrs)
S1	45	7
S2	55	18
S3	58	21
S4	36	10
N5	27	5
N6	38	12

Table 5: The main category and sub-categories

Category	Sub-categories
Decision-making: “ <i>finding other ways</i> ”	<ul style="list-style-type: none">➤ Influences on making decisions➤ Alternatives
What did Sanad group mean to the women?	<ul style="list-style-type: none">➤ Getting out of the capsule➤ Being part of a new family➤ Learning from each other
Perceived tensions in effective Sanad meetings	<ul style="list-style-type: none">➤ It depends on who attends: behaviours and attributes in Sanad➤ From cohesion to disruption: dealing with loss in Sanad
Ideas of recovery for Sanad members	<ul style="list-style-type: none">➤ From isolation to recharging my battery➤ From reluctance to acceptance➤ From hopelessness to hopefulness
Ideas of recovery for non-attendees	<ul style="list-style-type: none">➤ From being glued to my room to being attached to outside world➤ From hopelessness to depression,➤ From hesitation to rejection of the treatment plan

4.2 Category One: Decision-making - “*Finding other ways*”

This chapter sheds light on women’s experience of breast cancer, their responses to the diagnosis, and eventually how they make a decision about joining Sanad or not. The question and consequent items introduced by the researcher, when discussing with women their overall experiences of breast cancer, generated diverse but interrelated responses. Questions were mainly asked about how women with breast cancer coped with their initial diagnosis and responses were then explored in relation to how this experience had shaped their views about cancer, and impacted their decision about joining Sanad.

The analysis process led to the emergence of the category of “decision-making: finding others ways”. This broad category is made up of two main sub-categories comprising: “influences on making decisions about Sanad” and “alternatives“. The influences on

decision-making included: maintaining a sense of self, the reaction of significant others and stigma. The last two influences acted as both facilitators and inhibitors for joining Sanad. The second sub-category focuses on the “alternatives” which include “strengthening religious beliefs with Allah (God)” and “creating my own support group”.

All categories and sub-categories are shown in Table 6. These are supported by extracts of data collected. It is hoped that this enables the reader to arbitrate for themselves and evaluate the credibility of the findings as discussed in methodology chapter. Although, the two sub-categories are overlapping, for the sake of clarity they are presented separately together with related cluster of meanings.

Table 6: The main category and sub-categories

Category	Sub-categories	Concept and sub-concept
Decision-making: <i>“finding other ways”</i>	Influences on making decisions	<ul style="list-style-type: none"> ➤ Maintaining a sense of self ➤ Self-appraisal and why me? ➤ The reactions of significant others ➤ Stigma: <ul style="list-style-type: none"> • social stigma and “labelling” • physical stigma: the power of body image
	Alternatives	<ul style="list-style-type: none"> ➤ Having my own group and being religious

4.3 Sub-Category One: Influences on making decisions

This subcategory encapsulates different experiences and factors that affected women’s decision to join Sanad. During the interview process, all of the women interviewed, to some extent, talked about how they adapted to the breast cancer diagnosis itself. These data can be considered as a springboard for understanding how women’s experiences shaped the quality of breast cancer journey. Given the qualitative nature of this study, it was not possible to outline correlative links between the type of influences and their impact on women’s decisions to join Sanad or not. Rather, explanation is given of the patterns of those contributing influences and how they eventually contributed to and/or shaped the decision-making process.

For the most part, the onset of diagnosis caused shock and led respondents to search for meaning and find ways to cope with illness. Maintaining a sense of self was seen as an approach for making decisions about how to move on in life. Indeed, under the sub-category of “influences” the analysis identified other factors that emerged from the family and community context. These include how women perceived the reactions of significant others such as husband and mother in law, and stigma facilitated or inhibited decisions to join Sanad. The elements related to the “influences” sub-category are discussed further below.

4.3.1 Maintaining a sense of self

Under this concept, data revealed that following the diagnosis of breast cancer, for various reasons, some women tried to maintain a sense of self by joining Sanad. However, maintaining a sense of self is not a straightforward process. It involves multidimensional feelings, concerns, expectations and self-appraisal that inform women’s decision about joining Sanad and at least accepting it as an idea.

When women were re-counting and exploring their experiences and feelings about being given a cancer diagnosis, they described how shocking it had been to them. Respondents described their first experience of the knowledge they had breast cancer diagnosis in a variety of ways.

“... receiving [the mammogram result] was like grasping a fire ball between my hands so you know how does it feel when you hold such a hot thing... it just keeps burning you... you know this is how I received my disease... when the doctor told me that I have a breast cancer...”. (R5, did not attend Sanad)

The analysis showed that women had a feeling that being diagnosed with breast cancer might end their life or cut off their relationships with loved ones. In particular, this is highly related to the nature of the extended family system in Jordan, where close relatives often live in the same geographical area. This meant that being diagnosed with breast cancer is not only an individual crisis but also a family challenge. Many of the women interviewed reported a greater need for emotional support at the time of the diagnosis

from members of their extended family. However, the reality was that this was not always the case. In some cases some women in this study felt that they had been left alone and some members of the family were scared of the illness and thought that they might catch the illness due to proximity to the sufferer. This situation contributed to women's decisions to find another group of people offering support, which is well understood and accepted:

“I was worried about leaving my family and people I loved... I expected to find the help from them [her family and relatives].... Ugh! You know living in a big family does not always mean you can get help... my expectation was wrong as I found myself a bit lonely and in fact some relatives felt that standing beside me might affect their health and they are [busy] with their own businesses. This kind of feeling directed me to look for assist from other helpful people”. (R7, attended Sanad).

It is worth noting that the overall environment at home and related beliefs played a vital role in defining women's thinking and behaviours. Related to this, there was evidence in the interviews to suggest that, following a breast cancer diagnosis, some women experienced a feeling of losing a vital and leading role in the family and this had a negative effect on women's ability to maintain a sense of self. This feeling appeared to contribute to women's experience of breast cancer. In this context, it is interesting to find that being a mother figure and a source of wisdom in the extended family might place pressure on their ability to express fears and concerns. Statements like “*I am the leader of the family and do not want my relatives to see me weak*” encouraged women to search for another context in which to some extent authority will be protected. More specifically, some women in this study were concerned about their image among family members in a way that they will be looked at as dependent and powerless individuals. This is illuminated in the following response:

“I was afraid of being diagnosed with this [breast cancer]. Ugh! I am the eldest in my family so my sisters and brothers consider me as their mother... I am the consultant of the family for many issues and I feel that sometimes that I will have no control over simple decision in the family due to my illness. For this purpose I decided to cope with my illness and find other ways to get improved.... I liked to join Sanad as I hoped that my role as an older and respected woman will be maintained among other women”. (R1, attended Sanad)

It is interesting to note that that “*the fear of losing leading roles*” was linked to finding other ways to maintain authority. It should be noted that the above evidence highlights the fact that some women adapted positively to the illness and did not segregate themselves, as evidenced by statements such as “*I decided to cope with my illness and find a way to get improved*”. The fear of being rejected in a big family encourages women to start at an early stage to look for another “home”.

The analysis revealed a wide range of diverse responses about women’s experience with breast cancer and how it impacts their decision about Sanad and in particular maintaining a sense of self. For instance, single and younger women in this study articulated several concerns about body image and marriage. This is substantiated by elements such as “*I am still young*” and “*I have not yet got married!*” Other respondents used Arabic and cultural statements to show their sense of disbelief and feeling of loss.

“Each individual has two glasses of life and they are rotating... the first is sweet and the other is bitter and now I have the second glass.... So I decided to join Sanad because we all have the same type of this glass... at least I think that by doing so I would be more able to move on in life!”
(R14, attended Sanad)

These data would imply that women decided to join Sanad as a result of commonality in terms of the medical diagnosis. In this context, maintaining a sense of self was driven by a belief that joining Sanad and sharing experiences with those women suffering from the same medical issue would encourage them to move on in life.

Conversely, evidence revealed that some women had lived their life and strong religious beliefs minimized the impact of the bad news, believing that what happened to them was out of their hands and that what will be, will be. However, whilst some women thought that joining Sanad would help keep their role as a respected source of wisdom (see above), others felt that nothing would change their destiny and skipping treatment sometimes will make no difference.

“...You know... *alhamdu lillah* [thank God]... It is His will and I have to be thankful. What can I do now? It is too late what happened has happened and I think that I need to have good faith in Allah and joining Sanad or not will not give me a brand new breast... my family tells me that I need to

keep the appointments for treatment but I skipped many of them you know, daughter.... I believe sometimes that will stop the chemotherapy in the future and stay at home awaiting my death”. (R26, did not attend Sanad)

When the above findings are compared to responses from single women it can be seen that they were more severely shocked due to the future negative consequences on their lives. Such consequences include inability to get married and have children. Simply, the statement reflects the importance that respondents placed on getting married and having children in judging the successfulness of one’s life in Jordan. Indeed, the decision about joining Sanad was by driven by the fear of being lonely.

“... Finding a life partner and having kids were my dream! This disease [breast cancer] suppressed my feeling!.... I feel that joining Sanad might help me in establishing networks with people”. (R18, attended Sanad)

“.... I didn’t enjoy my life yet. I think it is too early to have such a malignant disease, isn’t it?.... I heard about Sanad and thought it would be nice to chat to other women... I feel loneliness will kill me rather than cancer itself... I am looking for hope and feel that Sanad is the only place where you see active women with breast cancer and living their life normally”. (R16, attended Sanad)

Although under the subcategory maintaining a sense of self, women joined Sanad to feel more socially active and to preserve certain roles in society, others believed that doing so would contribute to bad experience of breast cancer illness. In particular, the decision not to join Sanad was underpinned by the fear that some members would ask embarrassing questions about sexual issues in the group. Whilst stigma will be explored somewhere else in this thesis, it is worth linking this to the current data.

“.... I am still young and I never thought that cancer will be my future diagnosis. My friend has joined Sanad but I feel that such a place is not for me.... I am shy and you know some women just will hit you by their private questions... in particular about [sexual issues]. I am searching for peace”. (R20, did not attend Sanad)

The above findings might suggest that the pre-conceptions about Sanad are powerful influences on the decision-making process about whether to join the group. The term “*searching for peace*” suggests that the decision of joining Sanad is influenced by its

perceived images among women with breast cancer. Although ‘Sanad’ means ‘support’, for some women it is a source of trepidation; the above evidence raises an issue about control in maintaining a sense of self (open to being asked embarrassing questions) and how this might shape women’s ideas about Sanad.

4.3.2 Self-appraisal and “why me”: “I pray and did not do any sin”

A further analysis of some frequently reported statements showed that women suffered from self-blame and the tendency to link past behaviours and lifestyle to the diagnosis. In particular, the “why me?” question was used interchangeably with the process of shaping the goals in life. That is, women in this study invoke a need to understand why they have been diagnosed with breast cancer and its impact on their abilities to maintain a sense of self.

In other words, respondents in this study tried to understand the cause of breast cancer and thus leading them to existential reappraisals of life. According to the analysis, respondents reported that they were healthy and did not suffer before from a serious illness. Common statements reported by women to support self-appraisal include: *“I eat healthy food”, “I never smoked”, and “I do regular exercise”, “no one had it before in my family”, “I pray and did not do any sin”, “why not other women who are fat and not healthy?”*

The quotes below illustrate the way women reacted towards their disease and reflect the above discussion:

“.... I never had done something bad in my life!! No one in my family had a breast cancer, I am not fat, I’m healthy and walk a lot, I never smoked, so why me?.... I felt that meeting other women in Sanad might offer me answers.... alone, I am confused”. (R6, attended Sanad)

Comparisons were made about their medical status and those other friends and colleagues: The following quote illuminates this issue:

“Life is strange my friend does not look after herself very well like me... she smokes and spent her time watching movies and no sport at all, I got cancer and she got nothing!.... nobody will understand my naive

explanations and questions except those women in Sanad”. (R28, attended Sanad)

The above findings demonstrate an important issue that emerged from the data, namely linking the presence of illness to committing a sin. The statement “*I never did something bad in my life*” indicates a type of self-appraisal and reflection among breast cancer respondents. Comparing their illness to other friends’ health might postulate the need for finding the cause. In other words, women during their initial responses to the diagnosis and their adapting mechanisms can be seen as trying to make sense of what has happened to them. However, one respondent (a 54 year-old respondent) believed that bad luck negatively affected her ability to maintain a sense of self:

“The diagnosis of breast cancer was really painful and I kept thinking about my grandsons all the nights.... but you know my husband died aged 34, and one of my daughters passed way in the following year.... so I have bad luck... daughter [referring to the researcher].... I do not think that joining Sanad will give me another soul.... even if I stopped taking the multivitamins tablets and other drugs”. (R26, did not attend Sanad)

It should be noted that whilst of course the breast cancer diagnosis is stressful, maintaining a sense of self and figuring out a cause and effect link between breast cancer, and past behaviours might be attributed to the lack of a sense of mastery (Silva and Lautert, 2010). The statement “*I do not think that joining Sanad will give me another soul.... even if I stopped taking the multivitamins tablets and other drugs*” might demonstrate the lack not only of hope, but also of control over the situation. Likewise, it seems that the lack of sense of mastery leads to negative adjustment. This is substituted by the possibility to avoid the treatment. In other words, whilst some respondents joined Sanad to find themselves, others felt that doing so or not would not change their situation due to the power of bad luck.

In the light of the current analysis, Jordanian breast cancer respondents attempted to find meaning in the cancer experience and appeared to take two forms. A causal form that provides an answer to “why me?”, and is driven by sense making approach leading them to readapt themselves to the reality rather than to a disbelief. For Jordanian women, it seems that using a sense making approach is the way forward not only to understand the

cause of breast cancer but importantly to search for possible positive adapting mechanisms, such as getting involved in Sanad, where exchanging knowledge can take place and hope might be gained. However, joining Sanad was not only an avenue for seeking knowledge, roles, and learning about breast cancer as a disease but also as a way to deal with a significant life challenge which needs complex adaption. In the second form and in contrast to the above, the negative adjustment behaviour exhibited was driven by a lack of a self-mastery, inability to maintain a sense of self, and the tendency of self-blaming approach. This led some women to skip the treatment and to somewhat losing hope in life (i.e. the feeling of being powerlessness and the conviction that nothing can change bad luck or destiny).

4.3.3 Reactions of significant others

Under the concept of influences on decision-making, reactions of significant others have been found to affect women's perceptions of Sanad and influenced whether or not they joined a self-help group. In this study significant others were noted as being the women's husbands and mothers in law.

Just as young single women perceived the negative effects of the illness primarily in terms of matrimony (i.e. preventing them from getting married, as explained above), married women's stories indicate that the husband might play a crucial role in making the experience of the breast cancer journey smooth or otherwise, and may affect the direction of any decision regarding participation in Sanad; women's need for support in making sense of self, and the different responses of their husbands/families pave the way for making a decision about joining Sanad.

Some women in this study had a positive expectation of their husband's reaction and this was confirmed following the diagnosis. Women felt that the strength of their relationship was at the heart of understanding each other and working hand in hand to fight breast cancer. However, whilst some women found that supportive husbands' reactions were enough and they consequently had no need for Sanad, others found that joining Sanad was an opportunity to adopt an advisory role for other women who might face marital problems:

“My lovely husband and children gave me all the support that I need. You know when I had some pain, I may say Argh!... so I find my husband and daughter running very quickly towards me in order to check on me... Thanks to Allah, it is a gift to have someone to take care of you when you sick.... Maybe I feel that there is no need to attend any group meeting in order to get support, because I have already got enough support”. (R17, did not attend Sanad)

“*Shokran ya rabiy* [thank God], my husband is educated and I strongly believe that the strength of the love relationship between us is the best weapon to fight breast cancer... so my husband was very helpful so I didn't feel alone at all through my illness.... he encouraged me to join Sanad... I thought that when I joined Sanad group I might help and give useful advice to other women who had a bad experience with their husbands towards their illness”. (R15, attended Sanad)

These extracts demonstrate that the reality matched the married women's positive expectations of their husband's reaction towards the illness. In the first extract, the respondent felt that her family provided the support and therefore no need for the Sanad group. The family concept expressed by the participants does not only involve the social aspect but importantly caring and unquestioning support and loyalty, as confirmed by the expression: “*when I had some pain, I may say argh!... so I find my husband and daughter running very quickly towards me in order to check on me*”.

On the other hand, the second extract shows that the respondent had adapted a new role through her breast cancer journey, a helping and supporting role towards other breast cancer women, thus she joined Sanad to fulfil her goal. It is not surprising that a strong marital relationship could help both couples looking forward to a future, making husbands rethink life's priorities and maintaining a positive outlook, not ruminating on the illness (Hilton et al. 2000). The term “*best weapon*” is indicative of an effective coping strategy led by the couple themselves. On the basis of findings outlined above, it can be argued that the strength of the marital relationship might contribute to a more empowering husband's reaction regardless the final decision about Sanad. However, further evidence indicates that such a link is not always guaranteed.

In contrast, to the above reaction, other women had a positive expectation but in the reality husbands reacted negatively in particular following visible side effects of the

treatment. The quoted interview below illustrates this kind of experience and the dramatic change in the relationship:

“...For 17 years we’ve lived with each other, we had very nice moments with him so I expected that he could handle the situation and support me.... you know... he was caring for three months after diagnosis but this started to vanish when treatment side effects started to show up.... he got annoyed and had a hot temper and this got worse because he [her husband] stopped understanding my feelings [sadness]... my husband started to sleep alone in a room, and leave me with the kids in the other room. Ohh!! He was afraid that I would infect him with my cancer. I told him many times that my illness was not infectious, but he was not listening to what I was saying. Being alone in that journey was a very bad feeling.... I could not believe that the one I loved, and took care of, treated me like that when I got sick and needed his passion.... I have two cancers! One from Allah and the second is my husband! I think my husband’s behaviour affected me psychologically, more than the disease itself.... after a period of time my husband rewarded me by marrying a second woman [clenched her fists]... Because he was telling me that my body didn’t look like before, and he was not sexually satisfied as a man [sadness and crying].... Ohh! Sanad.... I met a lady from Sanad; she was visiting the chemotherapy clinic. That lady had a nice looking and a smiley face.... I thought if I joined Sanad I will find an alternative source of support had a hope that this group might be a turning point in my life so I could find safety if I joined it.... I was just about to sink”. (R3, attended Sanad).

The above findings showed that the unstable marriage led women to be convinced about Sanad and take part in its meetings. It is interesting to note that although the husband was supportive at the beginning of diagnosis, he could not tolerate the treatment side effects and the long-term process of breast cancer treatment. He was worried that he could get this cancer from his wife thus he started to sleep in separate room and leave her alone.

However, from the data and other aspects of the story it seems that the fear of infection was not the main drive for the negative reaction and behaviours following the diagnosis. Whilst talking about sexual life in Jordan is a taboo, this respondent highlight the fact that a lack of sexual satisfaction negatively affects a long marriage relationship. Describing her husband as the second and real cancer is an explicit way of summarizing how husband’s reactions contribute to women’s decisions and coping effectively with the diagnosis. Indeed, it worth noting that husbands’ reactions not only affected women’ decision to join Sanad, but also their psychological health (see above).

Lack of emotional and psychological support led this particular respondent to look for another place in order to fight her loneliness and find security. It seems that while some women in previous sections joined Sanad for social interactions, others were seeking psychological and emotional support they were not able to access from usual sources. Whilst the husband's reaction might be led by the way he addresses his needs (see above), the interferences of others, in particular the mother in law, in supporting or otherwise such reactions was also apparent. These are interesting findings expressed in the following extracts:

“.... I thought that my husband's reaction would be good and supportive but it was not... Haamati, my mother in law, played an important role in deviating his thinking.... she kept saying that her son should marry another one.... and she didn't know why he keeps me up to now, as I cost him a lot of money.... my mother in law was afraid that I will be infertile and her son's family tree will not survive because of my breast cancer and its treatment.... Ohh!! So she kept blaming me and made me feel like a burden on her and her son's shoulders.... you know this affected my husband's patience and tolerance to my illness.... so I had a bad time with him.... he was just a mummy's boy... I felt that my home is not a home anymore so I hoped that joining Sanad could be my second home”. (R6, attended Sanad)

In the following story, one of the mothers in law prevented her daughter in law from joining Sanad as “*women gathering is not more than nagging and a waste of time*”.

“We all live together, I mean me, my husband, my kids and my mother in law in the same house.... you know, I can't hide anything although it's my own home.... I feel sometimes there is no privacy.... when I got this [breast cancer], I tried to find another woman like me so I could talk to her.... I heard about Sanad from one of the volunteers who usually come to visit the chemo clinics.... I loved the idea because this is what I was looking for. I asked my husband to join that group but my mother in law started to say there is no need... *women gathering is not more than nagging and a waste of time*.... she was saying that good mothers should stay at home to cook, wash and take care of their family, so what it is the point of joining Sanad?! Chatting to other women will not cure the illness.... my husband agreed with her opinion and started telling me that he believes that his mother is right and there is no need to join that group! He thinks that I should stay at home in order to watch my kids!” (R13, did not attend Sanad)

As exemplified above, the role of mother in law in affecting the husband's reaction should be taken into account. In fact her negative interferences might add further stressors to the breast cancer journey. Culturally speaking, in traditional extended families in Jordan it is common for mothers in law to live nearby or even in the same home. Such a housing condition might lead to some troubles between the mother in law and her sons' wife; the wife and husband like to have their own freedom and feel comfortable.

Evidence from the above quotes shows that women who had a troubled relationship with mothers in law were more frequently jobless and/or had limited education. Given these data, this sub-group of women might be more vulnerable to negative interferences from the side of mothers in law. In particular, this relationship is complicated further by the perceptions mothers in law hold of the proper roles of daughters in law, namely being a housewife to carry out daily household activities as opposed as going out to join Sanad. This is supported by the statement "*good mothers should stay at home to cook, wash and take care of their family*". Based on this, it can be concluded that the mother's in law interference could affect the couples' autonomy in dealing with the breast cancer and its future prognosis. The net results could encourage women to find a friendly and supporting environment.

In conclusion, there are issues relating to relationships and the reactions of others that shape involvement in Sanad both in terms of reasons for participating or not. The evidence outlined above might indicate that the significant other relationships had a powerful influence over what happened regarding joining Sanad or not.

However, gathering all related segments of data it would appear that there are other factors within the sphere of breast cancer women themselves. This is manifested by the influence of different forms of stigma, highlighted below.

4.3.4 Stigma

The analysis of collected data revealed that stigma, as a multidimensional factor, played a vital role in shaping women's decisions with regard to joining Sanad. Based on data

gathered about stigma, two main forms have been found to largely discourage women with breast cancer to join Sanad, and to a lesser extent, encourage others to do so. The first form is concerned with the social stigma and “labelling”, and the second form is focused on the body image stigma and its power in influencing the decision-making process. Whilst in some cases these two forms were incentives to join Sanad, in others they were disincentives. The ways in which social and body image stigma affected women’s thoughts and decisions to join or not are explored in the following sections.

- Social stigma and “labelling”

When women were diagnosed with breast cancer in the present study, they reported that their life has been threatened by this “bad illness”. The concern was that breast cancer could be a companion to their daily life forever and thus affect their family and social networks. In the following quote a woman felt shame about her breast cancer and tried to hide it in the beginning from neighbours and relatives, as she was afraid that her breast cancer would give a bad reputation to her family. Thus, breast cancer was dealt with in a furtive and secret way. These findings are congruent with the evidence reported earlier (see above), which suggests that for some women, whilst joining Sanad might encourage them to maintain their social activities and find hope, others believed that doing so would expose their private life.

“.... Oh! No! I don’t want be to have this [breast cancer].... my illness will stick with me forever. I mean when I wake up, do shopping, walk and talk to others... now I don’t want to tell anyone about it.... I am not ready to face this shame! I am afraid that my disease will stay as a landmark and people will start to recognize me from it. I don’t want to cause any trouble for my family... I am afraid that my illness will stick not only with me but also with my family surname. Now, I prefer to keep it for myself and don’t share it with others.... I didn’t like the idea of joining Sanad group”. (R24, did not attend Sanad)

Another participant had a previous experience with “*women’s gathering*” in general that gave her a negative preconception about Sanad. She remembered the time when one of her friends had hysterectomy, so women visited her and kept talking and asking many private questions that led the lady with the hysterectomy to ask them to leave the house and not to come back again. The respondent drew the lesson from the story that joining

Sanad would create more troubles than solutions. In her opinion, the purpose of Sanad might be misused by some women and cause more harm than benefits for others. In other words, thinking about being socially involved in Sanad triggered fears of appearing weak in the eyes of other women in the group. This was a driving force for not accepting the idea of joining Sanad.

“.... I have a group of women, you can call us friends.... you know women, they have big mouths... they like to find something to talk about it. I remembered one of our friends did a hysterectomy and women decided to visit her.... during our visit women started to look at her in a pity look and keep saying ‘oh dear you are too young’, ‘*Ya Haram!* [poor you]’... and what made our visit worse when one of the visitors started to ask some private questions about sex and how does she deal with this with her husband after having that surgery.... oh dear! You cannot imagine the response of the lady who had the hysterectomy! She asked all the group to leave her home and never ask about her again! So when I was diagnosed with breast cancer and had the surgery this story just went through my head and thus I decided not to join any group of women in the future... I don’t want to feel that I am not able to live my life normally as I used to be ... I heard about Sanad but I decided to stay at home and keep my illness and suffering for myself... (R12, did not attend Sanad)

Some women expressed a number of assumptions about the role and functioning of Sanad. These presumptions have been largely influenced by previous experiences with episode of illness. That is, each participant has their own world and her decisions might not be unpredictable. Whilst stigma was not verbalized and stated clearly, related issues were reported. The preferences of isolation and avoidance of pity are the signs of social stigma (Fife & Wright 2000) and thus the idea of defining individuals by their illness in a group might be unacceptable.

In contrary to above findings, one participant felt that the fear of not being accepted socially due to her illness encouraged her to join Sanad, where “*birds like to fly with other birds from the same family*”. This decision was reinforced by her fear of not being accepted by society and a future life partner. In her opinion, she hoped to find a welcoming place where she belongs.

“....When I had the surgery and left with one breast.... I felt how much I am weak and life is so silly [laughing].... last year I was healthy, sitting

with my friends chatting about my wedding dreams and how it would look like! Now I am afraid of telling anyone about my illness as I am scared that no one can accept me as I am! You know sometimes people just do not like you... Without reasons I think the chance to find a man to accept me as I am is too weak... I was in need to find women like me to talk with them and share my story with them... Sanad in KHCC.... I thought it might be a good idea to speak about my experience and meet new people.... you know, birds like to fly with other birds from the same family!” (R16, attended Sanad)

Other participants were not happy about the label ‘breast cancer’ itself. This was part of labelling stigma which refers to sick individuals who need lots of care. However, Fatimah (47 years old) in the following story highlights a somewhat more positive influence of the term on joining Sanad:

“I am not happy about the word ‘cancer’ itself! It is a bad name that if anyone heard about will link it straight away to the end of life! You know, I wish if there was another word that could be used instead of it [cancer] so it could help in accepting this disease more in our society.... I decided to join Sanad group because I want to proof that we could change some of people’s views that my breast cancer is a not shameful illness.... and move on in life”. (R14, attended Sanad)

Although the expectation was that the stigma of the labelling itself might discourage women from joining Sanad, it was not the case in the above scenario. Self-determination is evident and joining a group of other women was seen as a tool for correcting people’s beliefs. Not only was Sanad seen as a possible supportive method as outlined earlier, but also as a community changing agent. However, this finding should be regarded with caution. A further analysis of the participant’s background found that this particular woman has participated before in a campaign for raising public awareness of breast cancer. Consequently, it is possible to postulate that such campaigns have affected her decision-making process, maximized her self-determination and advocacy role on behalf of other women. Nevertheless, some other data showed that the breast cancer label might have a damaging impact not only on breast cancer women but also their extended kin networks (see below).

Although the importance of tribal affiliations is decreased in the modern world (except in the exigencies of war), certain mores and patterns of conduct endure, and the general

importance attached to extended families and kinship networks remains relatively strong in Arab societies. According to ((Goffman, 1963), tribal stigma could include issues of religion, race and culture. In this study, data showed that the tribal stigma could affect one's social activities and relationships in public. From recalling some of the women's experiences, it appeared that being ill with cancer is connected to a hereditary disease in Jordanian society. This cultural belief could influence marriage in future because of the fear of transferring illness traits to subsequent generations. It is not surprising therefore that some women in this study were more worried about the impacts of breast cancer on their daughters' future (i.e. getting married and bearing children) than about the immediate physical and psychological effects of the disease itself. The idea of joining Sanad was seen by participants like "*putting the family as a headline in the newspapers*" and "*disfiguring the tribe gene*". Such descriptions were reported frequently by participants during interviews. Further concerns are expressed in the following extract:

"No, I didn't join Sanad group.... it is good to find someone to talk to and share experiences with.... you know, I would love to express my feelings, but at the same time I don't want to bring future troubles for my daughters.... some link breast cancer to hereditary disease, and this could prevent my daughters getting the chance to marry and live normal lives like their counterparts.... I feel that some people stopped talking to me as I heard that some thought that they will have breast cancer and I felt that they do not like me anymore; eventually I forgot myself and the illness and kept thinking about the future of my daughters". (R27, did not attend Sanad).

As outlined above, it would appear that reasons for not joining Sanad might include the fear of "hurting" the tribal reputation. Furthermore, the evidence is indicative of limited public knowledge about breast cancer. This is exemplified by dealing with the illness as contagious, despite widespread education in Jordan. Consequently, this might lead to the creation of isolated sub-communities within the community and thus living in isolation and adding further stress on the shoulders of breast cancer patients. A final comment to be made is the link between the fear of tribal stigma and prejudice as a barrier for joining Sanad. The above extracts suggest that some people with their poor understanding of breast cancer and irrational dislike led some women to cut off their social networks. This situation is complicated further by the next form of emerging stigma.

- Physical stigma: the power of body image

Although labelling, social stigma and body image are closely interconnected in the current study, some respondents focused exclusively on their body image and appearance, and how this affected their decision regarding joining Sanad or not. With this in mind, it was decided to present all relevant data under this form of stigma. As part of the breast cancer journey, having different types of treatment was difficult and demanding. Such demands revolve around the physical stigma and how to get back to the normal physical appearance and strength.

Some women acknowledged that physical stigma in general, as an obstacle to normal life, is a sign of weakness that could be seen as a “burden on their family”. The analysis revealed a cluster of meanings such as “*being ugly*”, “*being bald*”, “*putting on or losing weight*”, “*the feeling of dependency*”, “*being unfeminine like other women*” and “*looking yellowish like a lemon*”. These findings are explained further by the following extracts:

“When my husband was not at home, my mum and dad were helping me. I felt ashamed to ask my parents for help, especially when I needed the toilet. It was embarrassing, oh!! My parents were old and barely walking, so they needed to be looked after more than me.... you know, I was worried who would look after me when I become very fragile... I feel that joining Sanad will put me under the spotlight.. and let other women see how much I became weak and a bit not attractive”. (R4, did not attend Sanad)

Likewise, a respondent felt that joining Sanad will put her in a beauty competition in relation to other women who might be more attractive than her.

“.... my family considered my body shape as a role model in contrast to my other sisters.... you know this is sad that breast cancer left me only with one [breast].... I look deformed, ugly not attractive like other women.... I came from a poor village and I think that in Sanad I will see lots of city women who are more attractive than me! [tears in the eyes]”. (R8, did not attend Sanad)

With the above findings in mind, it would seem that there is a fear of the social class of some women who might join Sanad. In Jordan, women in Amman are perceived as metropolitan fashion figures compared to villagers and those from provincial cities. This

led some women to avoid Sanad in the first place, which is located in the capital where the rhythm of life and styles are different to those in rural areas. This issue was also a factor behind having a bad Sanad experience, as discussed in the second chapter of this thesis and examined further in the discussion chapter.

Meanwhile, in the context of physical stigma, some participants reported that having breast cancer led them to lack confidence. The lack of confidence related to body changes, which could comprise a barrier to joining Sanad. In the following extracts, Hadieah (a 44 year-old teacher), was too shy to join Sanad. Putting on weight and hair loss affected her body image and lowered her self-esteem and confidence. This self-stigma discouraged her to join Sanad due to deterioration in her psychological health:

“Because of chemo treatment my hair, eyebrows, and eyelashes fell down. I looked awful. I used to put a wig or hair dress in order to hide the baldness, in front of my family and relatives. At that period I preferred to stay at home and don’t go outside home.... I was a dynamic person but now I barely can practice my daily life... Also when I started the hormonal therapy I gained some kilos so I didn’t like my body shape at all... I gave some of my *galabeeb* [the single of gelbab: an Arabic word which means a long dress that covers the whole body except the head and feet] to my sister.... my body shape was stressful for me.... a friend of mine works in KHCC and told me about Sanad group but I didn’t like the idea because I couldn’t meet anyone with this body shape and appearance... I do not feel confident and sometimes I start stuttering [looking at ceiling]... when I talk to other people!” (R5, did not attend Sanad)

The above evidence adds further illuminates how the perceived body changes and images might negatively affect women’s decision-making process itself. It also shows that some participants were not well informed about how Sanad might help them cope with breast cancer. For the first glance of this analysis, it was felt that the fear of being rejected and the power of physical stigma may have inhibited women from joining Sanad. However, further evidence showed that this is not always the case. For some women, the physical stigma itself encouraged them to join Sanad to feel normal in the community.

Further analysis of some relevant data indicated that some women have used different actions to minimize the impact of physical stigma on their social life. One of the participants stuffed her bra with some tissues or cotton and did not know that she could

use an artificial breast in the future. Thinking about her body shape and finding the suitable clothes and feeling inferior to other normal people made her feel unwanted, thus she joined Sanad. The social and physical stigma left her alone and she found Sanad the suitable group to join. On this basis, it can be postulated that the power of groups in this study informed and challenged the fear and isolation through offering choice over appearance and self-presentation.

“Losing one of my sexual parts was a bad thing... this was giving me the feeling that I am not a whole female.... I was shy to meet people with this figure!... Sometimes I preferred to stay at home and stop going outside as I used to be before. I was embarrassed that they could recognize that I am stuffing my bra with some tissues or cotton.... just thinking about how do I look like and how people might look at me made me curious about my clothes.... you know having a normal breast does not look like a stuffed bra! Feeling shy and uncomfortable in seeing friends and relatives made me think of other alternatives that could help to overcome my suffering... Sanad group!.... frankly I was not looking for knowledge about breast cancer, rather it was about gathering ideas on how to improve my appearance...”. (R18, attended Sanad)

In line with the above findings, another participant joined Sanad to chat with other women who have the same sorts of stigma and specifically to find a suitable shop for wigs.

“....Alhamdu lillah [thank God] I was optimistic to join the group because I and my family were unhappy about my being without hair.... I used to follow the new hair style but when my hair started to fall down I was so shy to go outside like this.... you know it was difficult for me to see others just staring at me.... I was feeling I am a strange creature... this encouraged me to join Sanad so they are women like me, and I am sure they are gonna help me find the good shops that sell nice wigs and other important stuff I might need to my condition!” (R19, attended Sanad)

To sum up, stigma is a complex factor that affected women’s decision to join Sanad. Stigma in this study ranged from social, tribal to body image. Whilst feelings of stigma were an inhibitor for joining Sanad, for some women they were a facilitator, and to some extent these feelings are influenced by social status. It seems that stigma occurs at different levels, and has implications for informing women’s decisions about joining Sanad. It is not necessarily that the stigma of breast cancer is the main concern for

women; rather, it is the fear of its impact on their families and self-esteem, confidence and private life. Due to this shame and concern, some women decided not to disclose to close relatives and other women with breast cancer and thus they rejected the idea of Sanad. Others preferred to disclose to Sanad members who might help them cope better with breast cancer and stigma related body changes. However, these findings need to be taken with care due to the unique nature of each participant's situation. Although stigma is a complex problem with no easy solution, its impact on women's decision to join Sanad should not be underestimated.

4.4 Sub-Category Two: Alternatives

4.4.1 Having my own group and being religious

Some women with breast cancer who did not join Sanad group in KHCC created their own supportive environment. The supportive environment created primarily consisted of two alternatives: "having stronger religious beliefs", and "creating my own support group". Findings related to these alternatives are discussed below.

Following the diagnosis with breast cancer, a few women became more religious, believing that Allah is the only one who could help them to overcome their disease as opposed to joining Sanad. Although some of the religious beliefs have been referred to in previous sections, further analysis showed that such beliefs appeared to be a driving force for not joining Sanad.

During the interviews, women who did not join the Sanad group talked about other ways to cope with their breast cancer. In the following quote, one woman explained that praying supererogatory prayers (i.e. more than five times a day) and reading the Qur'an helped her to cope with her disease. Through practicing these customs she decreased the feeling of being isolated as she remembered that Allah stood beside her. She believes that being religious helped to decrease the level of tension that she had during her illness. Thus, joining Sanad or not does not make a difference for her because of strong faith (which can be understood as self-efficacy):

“I became more religious than before, I pray more than five times a day and read the Holy Qur’an every time when I feel free.... My breast cancer has influenced me so bad but by practicing the prayers and reciting *al-Qur’an al-Kareem* [the Bounteous Qur’an] I can tell you that I am getting better and not feeling isolated anymore. I woke up relaxed with no tension... I always believe that Allah with me and will never leave me alone in this crisis.... you know Sanad or nor Sanad will not change the fact of my breast cancer.... Sanad in KHCC might be good but I have a strong faith no one can help me except Allah...”. (R12, did not attend Sanad)

In the following quote this woman reported that turning to Allah, keeping her prayers, and maintaining reading Qur’an were better than doing anything else. Thus, joining Sanad was not the good choice for her as she was afraid of being neglected by the group and unable to express her concerns and feelings:

Nothing can be better rather than being close to Allah... death and life are between His hands, and I am sure that Allah will bring me a better life after this disease. You know, when I read the Qur’an I have a strange feeling that empowers me and strengthens my will to fight my illness. I didn’t join Sanad because I like to discuss some religious issues that will not be accepted by women.... or they might laugh at me... I didn’t feel alone because Allah was listening to me when I talk to him. I think this is the best way for curing and speaking to someone secretly.... Like this I feel there is no barriers to the one I speak to.... I didn’t join Sanad because I was afraid that no one can understand or listen to what I am going to express.... as you know each lady will be busy in her case and stressing the issues she feels that important to discuss!” (R5, did not attend Sanad)

The above findings are indicative of the powerful influences of religious beliefs on not attending Sanad. For instance, evidence suggests that some women believe that joining Sanad might restrict their freedom to express and discuss their religious beliefs in a group. These beliefs are based on their preconceptions of Sanad rather than actual involvement in discussion and activities. Whilst in previous sections (see above) isolation was deemed as one of driving forces for joining Sanad, the problem here is addressed by over-maintaining religious duties. Statements reported by some women (n=10) such as “*when I read the Qur’an I have a strange feeling that empowers me and strengthens my will to fight my illness*” demonstrates the positive impact of the religious activity on

women's morale and determination to move on in life. Simply, some women in this study thought that these benefits will not be gained from Sanad.

Another alternative adopted by a few of women was to create their own groups. The process of establishing relatively "private" groups was underpinned by the geographical and financial barriers to attending Sanad in Amman, as explained below:

.... I have my own group, and we visit each other at home sometimes. I trust them. I know KHCC offers good support but I cannot be committed to Sanad as the time when survivors meet up is not suitable to me. Plus I am not from Amman and coming by transport from my small town is expensive. I think that talking about the illness at home is more convenient to some cancer sufferers. You know you can look after your family while at the same time you verbalize your feelings and concerns about the illness. I wish KHCC offered us a free transport service to see other women with breast cancer". (R8, did not attend Sanad)

Another participant added that:

"I and four women have established an especial group for us. All from the same town and live close to each other so there is no need to go to the capital in order to attend Sanad! Transportation is quite expensive and our economic status is not that good. We [their group of women] found that meeting once every week is useful to chat and express our feeling and concerns.... sometimes I think this might be better than attending Sanad as you might meet some women you can't get on well.... they might be strangers..." (R20 , did not attend Sanad).

Evidence from the above findings suggests that some women did not attend Sanad not only due the difficult and cost of transportation, but also as a result the fear of not getting along with other "strange" women (which could be related to the perception of women in Amman being a cosmopolitan elite alluded to previously). It would appear that women's own groups offer the support needed in a convenient time and place. Thus, the alternative of establishing autonomous groups is an alternative to Sanad, which is essentially located in the capital (although not always in KHCC itself), and expressing feelings and concerns might not be possible. Although such groups seem efficacious as expressed in the foregoing quotes, they might not benefit from a framework or guidance from health care professionals.

4.5 Chapter Summary

This chapter presented findings pertinent to women's experiences with breast cancer, and how as a result of the diagnosis, feelings and fears, decisions were made to join a formal self-help group with health care professional support (e.g. Sanad), set up a group of one's own or not be part of any self-help group. Influences on decision-making and the processes involved was a major theme identified in the data and together with related factors shaped women's thoughts, expectations and roles.

It would appear that, from the women interviewed that maintaining a sense of self and self-appraisal were found to a large extent a powerful drive for joining Sanad. This was in order to gain knowledge about breast cancer, create social interactions, and share their beliefs and learn from others. On the other hand, the feeling of powerlessness and the belief that nothing can change the bad luck or destiny were linked to the rejection of the Sanad concept.

A further cluster of related micro-factors were explored under the sub-category of "the reactions of significant others", it was found that the nature of the husband's reactions and the relationship between mothers in law and the women with breast cancer played a vital role in women's decisions regarding Sanad. Although evidence is limited, it suggests that some daughters in law, in particular those from lower socioeconomic groups (i.e. jobless and uneducated), might be more vulnerable to negative interferences of the mother in law. Underestimating the importance of Sanad and asking the participants to focus only on household work are examples of such interferences by family members (i.e. mothers in law, with the compliance of the spouses of women with breast cancer) that negatively inform the decision process.

Moreover, analysis of the interviews revealed that stigma appeared to be a central factor that affected women's decision to join Sanad. Interestingly, although feelings of stigma were for some women an inhibitor for joining Sanad, for others they were considered as a facilitator. Some women decided not to disclose their breast cancer status with close relatives and other women with breast cancer, and thus they rejected the idea of Sanad.

Finally the analysis of the interviews indicates that a few women found that “alternatives” might be a more effective and convenient way to joining the formally organized Sanad group. These included being more committed to religious beliefs and duties, and creating their own private self-help group of women. Women felt that joining Sanad in Amman is not only costly in terms of the transportation but there was a fear that its composition might not be suitable. The next chapter focuses on women’s experiences of participating in Sanad.

CHAPTER 5: WOMEN’S EXPERIENCES OF BEING MEMBERS OF THE SANAD GROUP

5.1 Introduction

This chapter presents the women’s experiences of participating in the Sanad group, and explores a range of factors that appear to both contribute to and inhibit interactions within the group and its effectiveness as a self-help group. These findings are based on fifteen interviews with women who had decided to join Sanad and relevant responses from health care professionals. Whilst the previous chapter dealt largely with the decision-making process about joining Sanad, this chapter draws on the actual encounters, feelings and challenges women experienced during their weekly meetings at the group. The theme “women’s experiences of being a member of Sanad group” is made up of two categories: the meaning of Sanad to participating women and barriers to effective meetings. All the categories and sub-categories are shown in Table 7.

Table 7: The main categories and sub-categories

Category	Sub-categories
What did Sanad group mean to the women?	<ul style="list-style-type: none">➤ “Getting out of the capsule”➤ Being part of a new family➤ Learning from each other
Perceived tensions in effective Sanad meetings	<ul style="list-style-type: none">➤ “It depends on who attends”: behaviours and attributes in Sanad➤ From cohesion to disruption: dealing with loss in Sanad

5.2 Category One: What Did Sanad Group Mean to the Women?

In response to the question about women’s experiences of Sanad, women reported a mixture of feelings, thoughts, and beliefs. Women kept comparing and contrasting aspects of their situation and concerns before and after joining Sanad. Their experiences related to Sanad were organized into three sub-categories presented below. These

meanings of Sanad represent how women see and experience such a group from their own perspective.

5.2.1 *“Getting out of the capsule”*

The previous chapter suggests that, following the diagnosis of breast cancer, some women preferred to be left alone and avoided social interaction in particular as a result of fears from being stigmatized in society. In this analysis there appeared to be a transitional stage from isolation and loneliness to a social network and engagement in Sanad. Women highlighted the fact that joining Sanad was a “gateway” that enabled them to express their feelings, concerns and experiences without barriers and fear of being misunderstood. Women used a number of words and phrases which supported this idea of *“getting out of a capsule”*. These include *“meeting the outside world”*, *“being socially active”*, *“stop hiding myself”*, *“it worked as a bridge between myself and outside world”* and *“being aware that I am not the only one who suffers from breast cancer”*. The meaning of Sanad is captured in the quote below:

“....joining Sanad means support and this is what I found once I joined that group.... I started to establish new social networks.... meet new people and deal with different personalities and share with them my story.... It was the right place for me.... It helped me rethink that I should get out of the capsule that I chose to live in, in the beginning of my illness...”. (R2, attended Sanad)

The sense of isolation that women can experience after treatment for breast cancer is illustrated by one participant who initially felt that she was the only person with breast cancer, but following her meetings with other women she became more aware that there were other individuals who might share her experiences and concerns. This is highlighted below:

“I thought that I am the only woman in the world with such a health problem but when I saw more women in Sanad group suffering from the same nightmare I felt a bit more relaxed and came out of my shell and started chatting and sharing my experiences with them!” (R11, attended Sanad).

Whilst changes in women's appearance following the treatment of breast cancer contributed to social isolation (see chapter two), meeting other women in Sanad enabled them, to some extent, to stop seeing themselves as abnormal individuals within society:

“....Sanad was the mean to get out of my social isolation and boredom... it worked as a bridge between myself and oust side world.... This made me feel more comfortable to talk about my illness without any barriers because all women in Sanad group share the same illness so I didn't feel that I am not the only one who is abnormal like what I felt before deciding to join Sanad!” (R14, attended Sanad)

It is worth noting that membership of Sanad addressed women's sense of isolation and differences through creating a social network where they felt accepted. As one women stated, she felt free to express herself as a result of being engaged in Sanad's meetings:

“This group [Sanad] gave me the chance to express my feelings or opinions whatever they are. So I felt I'm accepted as I am... I don't have to hide anything I felt that all the group act as one body attached with one bond...”. (R7, attended Sanad)

This feeling of freedom to express oneself is highlighted further in the following case. One particular participant described how she tried to hide herself behind dark glasses due to her diagnosis and fear of the outside world. However, since having joined Sanad, she subsequently experienced a feeling of being confident:

“Sanad group was a miracle. In my point of view, it is the place that opened the door for any woman with breast cancer, going through depression or a hard time from the disease or its treatment. Joining this group was a helpful way to overcome the loneliness and isolation that I was suffering from. I used to wear big dark glasses to hide myself when I went out of the home... now I can chat regularly with other women in the group.... Joining Sanad and chatting to other women is unique... you know it is not like chatting with a friend on the phone or face to face for a couple of minutes... in Sanad meetings we spend more time with other members and discuss things in details”. (R3, attended Sanad).

This evidence would imply that a key element of women's experiences of Sanad is related to how women felt accepted, understood, and had their experiences recognized by others and thus felt more confident in expressing needs and concerns. Although the ways in which Sanad affected women's recovery is presented in the following chapter, it is

interesting to note here how women's confidence changed from "hiding" and isolating themselves in society to being exposed and involved in Sanad. However, women's responses add further illumination about the link between reasons for joining Sanad, the expectations and the real experience. Feelings of isolation encouraged women to join Sanad in order to promote some kind of social life following a breast cancer diagnosis. The nature of such social life was an essential requirement for the development of the experience of 'being part of a new family', which goes beyond only establishing social networks as illuminated below.

5.2.2 Being part of a new family

When women were asked about how the experience of "*getting out of the capsule*" influenced their sense of Sanad membership and relationships, more complex responses emerged. The analysis revealed that women did not only get out of the isolation status but also became an integrated part of a new family to which they belonged. Whilst "*getting out of the capsule*" has to a large extent a social dimension as manifested by creating networks with other members, being part of a new family is underpinning a sense of belonging. The experience of being part of a new family was developed and supported in the light of some of elements and descriptions. These included "*being in the same boat*", seeing Sanad as "*a second home*", "*a shoulder to cry on*", and "*a place where you can relieve your stress*", "*feeling secure*". Thus, the family as a building unit of a community involves feelings of emotional support and problems to be dealt with. These findings are illuminated further by the following responses.

"Umm... it does mean a lot to me. Sanad.... means support, help, strength and happiness. I am attending the Sanad group up to now; I consider it as a second family for me in KHCC. I think it is the best place for any woman with breast cancer. In Sanad we worked as one team to help each other, and to overcome our problems, challenges and concerns..... I believe that Sanad is the suitable place to help any woman in need of a friendly face or a shoulder to cry on". (R1, attended Sanad)

"it [Sanad group] is considered as my second family because it is the place where my story is heard and people accepted me as I am. we share the same illness so I think we [Sanad group] are all in the same boat. We are

equal...even I feel more comfortable with my appearance!” (R2, attended Sanad)

In line with this, a further participant stated that as part of a sense of belonging, Sanad gave her a feeling of security and safety.

“Sanad was a secure place where I can talk about my illness freely without any hesitation... I was talking about my experience to the whole group without feeling that I am unsafe like other places in the community where some people stare at you... members of Sanad made the atmosphere enjoyable and like being living with your sisters... Sanad is our small community where it is accessible to all those women with breast cancer”. (R19, attended Sanad)

The overall evidence would imply that participating in Sanad encouraged women to develop a sense of belonging as an outcome of being part of a new family. Such a family provided fellowship and opportunities to share in a group setting, with others in a similar situation. Talking openly, feeling comfortable in a group where all members share similar experiences and feeling that they are validated by others have strengthened relationships in the group. Seemingly, this nature of strength comes from the cohesion and connectedness that Sanad members had in their informal meetings. The majority of participants in this study experienced a high degree of social integration in contexts described as secure. Shared experiences and equality in terms of contributions and roles facilitated the dynamic interactions among Sanad’s members. Nevertheless, it is worth noting that belonging and being part of a new family here is not only and purely about a “feeling”; it is also about integration, teamwork and a shared effort. Indeed, in this context referring to Sanad as “*our small community*” and a “*secure place*” is indicative of how being connected to other members inform the development of a cohesive sub-community in which knowledge exchange takes place.

5.2.3 *Learning from each other*

When women were asked about their overall experience of Sanad and its link to gaining knowledge, the concept of learning dominated their responses. Further analysis of gathered data in this study demonstrates that being a member in the Sanad group had

maximized knowledge exchange. In particular, a joint learning process, as distinct from learning from health professionals was emphasized by many participants. Learning from each other as an experience applied to Sanad is based on a number of elements identified in the analysis. These include: actions to deal with side effects of treatment, and correcting beliefs and assumptions. The following anecdote reflects on how joint learning and sharing a stock of knowledge in Sanad helped a woman to deal with some health concerns:

“...Sanad is a good tool, I learnt through it some advice and knowledge that health care professionals might not give to me.... From my personal experience, after having the fourth dose of chemotherapy my nose started to bleed and that bleeding was continuous.... I went to my doctor in the KHCC and he prescribed an ointment... It didn't work! So I went to our weekly meeting [Sanad group]... we were chatting so I told the other ladies what happened to me... one of them said that she had the same thing as a side effect of having the chemotherapy so she advised me only to apply some olive oil.... You cannot imagine when I went home I did what my Sanad colleague asked me... and it really worked... It was like magic, because after a couple of hours the bleeding stopped....” (R15, attended Sanad)

In addition to learning about simple ways to address the problems of side effects of a certain treatment, being in Sanad the self-help group was almost a health education session, as noted in the following quote:

“...you know, I thought that educated women could not learn any knowledge from those less educated! I was wrong in my assumption because when I joined Sanad group I met women from different backgrounds... I learned from women who are less educated than me.... We were sharing our experiences and problems!.... being a member in Sanad made me discover that some foods should not be eaten while I am having the chemotherapy... raw tomato is one of the vegetables that I should not eat when I have the chemotherapy because it might irritate and increase the acidity of the stomach. You know, I gained very useful comments and advice from other colleagues in Sanad...”. (R16, attended Sanad)

Likewise, learning from each other in Sanad helped women to improve their appearance by debating, advising, and suggesting methods to cope with stressful changes that occurred following a breast cancer diagnosis. This is pointed out in the following story:

“In the group [Sanad] we used to talk about other alternatives rather than medicine that could help us to improve our appearance or our health in general. When I started taking the chemotherapy, after a couple of doses my hair started to fall out, and my nails looked dried and terrible. I felt bad about that... I discussed what happened to me with other friends in Sanad, and one of the members told me that applying some Henna on my hair and finger nails would be a good solution.... I just asked her why and how could it be suitable and affective? She answered me that Henna would increase the ability of hair to grow up again because it is strengthens hair roots. Henna works as a moisture for nails and this prevents any fungal infection..... I did what she advised me and I was surprised with the results...My hair has become a bit thicker and I felt that my nails got better and brighter..... See, a simple advice could make your day! This is what I found in Sanad.... doctors and nurses offer us loads of information but not all the details! You know we [women] in general like to know everything in a specific detail [laughing]!” (R11, attended Sanad)

These findings suggest that, although health care professionals are a good source for information, joint learning and shared experiences in Sanad meet specific and detailed identified needs. This often occurs through conferring with other women and discussing knowledge, and breaking it down into small details that become easier to understand and use. Indeed, it is interesting to note that because joint learning is based on real experiences, women’s receptivity to advice is maximized in the group. Additionally, homeopathic/folk remedies that women found useful (e.g. the cases of olive oil and henna narrated above) were communicated via Sanad members that would not otherwise be disseminated in conventional health care contexts.

However, in one case, learning from others was harmful and this is worth exploration. While the general picture that emerges from the data suggests that experiential learning in Sanad contributed positively to the experience of members, the following case suggests that learning from others might contribute to ill health:

“I spent nice moments in Sanad! In fact I knew that some information could be gained not only from health care professionals but also from sharing my experience with Sanad members.... But also what I learned from Sanad group that not everything women advise I should take immediately, because this might be useful or harmful to my health.... I remember that in one of our weekly meetings, I had a general weakness.... it might be because of the different medications and treatment I had, so one of the members saw me and advised me to buy some multivitamins

that she took when she was suffering from the same thing. I bought the multivitamins tablets and started having them... in the next day I had severe nausea and changes in bowel movements... following my visit to the doctor I was told that I need to stop these tablets and never take any medication without prescriptions!” (R7, attended Sanad).

The findings generally reflect how experiential learning in Sanad helped some women to deal with health concerns. These finding highlights the fact that being a member of Sanad not only enhances social life and the feeling of being part of a new family, (see previous sections), but also contributes to women’s understanding of their condition and to dealing with problems which might arise. Although most of the information patients receive about cancer and its treatment is probably provided by staff in KHCC, it seems that if patients do not get sufficient information there is a potential risk that they might rely on nonmedical sources to satisfy their learning needs. One finding from the interviews was that patients actively sought information about cancer only to a limited degree, but the majority of women take an interest when cancer issues are presented in Sanad meetings. It would appear that the concern is when members got some unhelpful and inaccurate information that might be used by others and thus affect their health status.

5.3 Category Two: Perceived Tensions in Effective Sanad Meetings

Although the emergent evidence from the previous category showed women’s experiences of Sanad were positive overall, further analysis of responses found that this there were also challenges associated with being part of the group. This category focuses on those tensions that affected Sanad’s meetings, namely “*It depends on who attends*”: behaviours and attributes in Sanad; and from cohesion to disruption: dealing with loss in Sanad. Therefore such sub-categories provide opportunities to examine how the overall group atmosphere, micro-relationships, and perceptions among members shaped their experiences. Some relevant responses from health care professionals are integrated into the current analysis. This triangulated analysis procedure was used to examine the level of congruence among different datasets, and thus maximize the credibility of evidence. All relevant responses from health care professionals and women were grouped together in the light of study objectives, then the main issues were drawn together, analysed and discussed, with some extracts presented below.

5.3.1 *“It depends on who attends”*: behaviours and attributes in Sanad

This sub-category illustrates how some women’s behaviours led to negative Sanad experiences. Although women in the study generally reported that Sanad experiences were positive and diverse, ranging from *“getting out of the capsule”* to learning from each other, the analysis also uncovered some tensions worth highlighting. These tensions are reflected into two issues.

Some women felt that they were not given adequate time and an opportunity to express themselves in Sanad meetings. This was as a result of the discussions being dominated by a small number of participants. According to the elicited responses and related attributes, perceived dominance takes different forms and behaviours. These include: *“eyebrow movement”*, *“interrupting others”* and *“undervaluing others’ suggestions/information”*. Whilst perceived dominating behaviours affected the dynamics of Sanad meetings, they also encouraged some participants to maximize their confidence and strongly express themselves.

“....sometimes I found it is difficult to talk whenever you want.... in some Sanad’s meetings I found that a talkative woman did not stop discussing her story... I believe that it is a kind of showing off to prove that she has a strong personality and this might lead to a noisy environment... once I attended Sanad and the same woman undervalued my feelings about the impact of breast cancer on my daily life she kept moving her eyebrow in a way that I felt that what I was talking about was silly.... but now I got used to her and in fact her behaviour allowed me to try harder to express myself and increase my confidence you know it has advantages! [laughing] Sometimes you need to strongly defend your point of view...”. (R3, attended Sanad)

Additionally, analysis of women’s responses and stories indicates that dominating the group was attributed to certain characteristics. Related to this, a participant argued that some married women often try to dominate the meetings more than single ones. Family problems and children’s needs were largely the core of the discussions of this sub-group of women. As a result a single lady felt that sometimes single women’s thoughts, emotions and concerns were not given much attention.

“I spent lovely moments in Sanad, although I faced a small difficulty.... I have a friend, her name is [X] in the Sanad group.... we are both single.... when we attend together the weekly Sanad meeting... I feel that married women dominate the discussions and keep talking about their concerns, problems, husbands and children’s needs... Many of these issues are not of interest to us as single ladies.... in fact this made me uncomfortable.... I felt that they have their own clique!” (R18, attended Sanad)

The analysis of responses from health care professionals lend validity to how the nature of Sanad’s composition affects women’s perceptions and experiences.

“... You know women come from different backgrounds and cultural beliefs.... This might affect the way they communicate in the group. According to the feedback from women, some did not feel comfortable in some of meetings. You know some women are not married and might find it not interesting to talk keep talking about children and husbands...”.
(Nurse 5)

In addition to the communication dominance in the group, being sarcastic was perceived as a barrier for comfortable conversation and therefore knowledge and experience exchange. Although the previous section reveals that learning from each other was a valuable experience for Sanad, to some extent the scope of this positive experience is affected by “*nasty behaviours*” and “*a bad sense of humour*”. Whilst such behaviours and descriptions were limited in the data, they contributed to women’s negative feelings and experiences in Sanad meetings. It appears that such experiences are triggered by the situation of women who were already suffering from the diagnosis of breast cancer, and thus it is unsurprising that some women felt oversensitive and vulnerable to inappropriate remarks;

“....I learned a lot from Sanad but you know I feel that sometimes its success depends on who attends... yes, we are one family, but not all members behave in a good manner. One day I was talking about my experience with breast cancer and told others that I used olive oil for the mass in my breast in the beginning of my journey with [breast cancer]... all women in the group were supportive except one of them who suddenly started laughing in a sarcastic way and said that ‘I know olive oil is used for roasting chicken and not for treating breast cancer!’.... I felt terrible, maybe she tried to be funny but I was suffering and not ready to hear nasty comments. This made me think twice before uncovering and discussing

anything related to my experience... This was the only problem I had”.
(R22, attended Sanad)

A further perceived tension to effective Sanad meetings, and under the sub-category “*it depends on who attends*”, was the lack of empathy from some members in Sanad. Although all members considered themselves as being “*in the same boat*”, some participants felt that they were not shown adequate empathy in some of the meetings and felt that “*I was outside that boat*”. A frequently reported meaning attached to empathy was “*not understanding my situation*”. The following response indicates that empathy does not only mean being sorry for others, but also involves understanding, listening carefully, and offering solutions and ways of coping with a certain crisis.

“I am convinced that Sanad is a priceless way to express our feelings and experiences.... I attended all the meetings and made lots of friends but on a couple of occasions I felt that I am sinking alone in my financial crisis and problems.... I was talking about how the lack of money made me work so hard in the local shop in the past.... whilst many of members were empathic, two did not pay attention to my story... they did not listen carefully, one kept texting messages.... I felt they were emotionless.... I expected solutions based on their experiences.... it is not only about feeling sorry for my situation.... yes, we are all in the same boat, but sometimes I felt that I was outside it”. (R14, attended Sanad)

Finally, when women were asked to offer a more detailed account about how the nature of Sanad’s composition shaped their experience, a complex picture of perceived tension was noted. It seems that there was a power imbalance among members, and a hierarchical approach was occasionally used. The emergence of the concept “inferiority” might imply that this is natural to families. One aspect of hierarchy was the notion of “attractiveness”. Attractiveness in this study is a subjective concept and some participants judged others from their appearance and body language behaviours. Related elements to perceived attractiveness involve “*sexy eyes, nice body shape and expensive wigs*”. Likewise, behaviours such as “*leading the discussions*”, “*making decisions*” and “*behaving like a queen*” are the manifestations of practicing power within the group.

“I am a regular member of Sanad [smiling], and it was very helpful in many ways.... I think it is a great idea I can say that all members are ok, but in one incident I felt that an attractive lady misbehaved and looked at

me as someone who came from another world.... Yes, we are all having breast cancer and we go through similar experiences, but you know some women are more attractive than others.... you know, sexy eyes, nice body shape and makeup... that attractive lady avoided me.... She behaved like a queen and kept showing off her expensive wig.... she tried to lead the discussion like a TV presenter.... sometimes if there is any social activity for the group she decides on behalf of the whole group without giving us the chance to share her our decision.... I felt sometimes that I am a bit inferior to her... This made me feel odd and uncomfortable, but thanks to Allah that woman went back to Dubai and the group become even more enjoyable [laughing]”. (R9, attended Sanad)

Complementary and confirmative data from health care professionals indicate that the social class of some women, in particular those with a high economic status, negatively affected Sanad meetings by according them dominance and leading roles (as identified previously, some women did not attend because of perceptions that this would be the milieu of Sanad):

“....Some women told us that one of the things that might sometimes affect Sanad interaction is the level of economic status of Sanad members.... they found that women who tried to dominate the speech are most likely the attractive ones who can buy expensive clothes, wigs and apply the modern makeup.... women told me that this was creating some stress in the Sanad environment...” (Social worker 2)

In summary, it would appear that perceived dominance together with being sarcastic and the absence of empathetic behaviours might hinder women’s abilities to express themselves freely without the fear of being perceived as inferior and undervalued members of Sanad. Although women in Sanad have many things in common, it seems that this does not necessarily and always guarantee its positive experience, and in particular learning from each other. The evidence suggests that most women found Sanad meetings positive, but there were aspects and behaviours less helpful and sometimes negative to the achievement of a positive experience. In particular, imbalances in power and socio-economic status sometimes conferred superiority and inferiority on members, thereby inhibiting the process of sharing experiences and gaining support. However, equally these findings showed that despite some undesirable behaviours and attributes contributing negatively to Sanad experiences, they encouraged others to be more assertive in verbalizing their feelings and concerns.

5.3.2 From cohesion to disruption: dealing with loss in Sanad

Earlier findings in this chapter showed that women experienced the feeling of being part of a new family where they belong to and learn from each other, and thus it is unsurprising that losing a member of Sanad was seen by some participants as “*a sudden earthquake*” and a “*very traumatic time*”. These powerful descriptions are indicative of changes in Sanad’s atmosphere and often the quality of meetings. The cohesion of Sanad as one family therefore is prone to disruption. However, the examination of emerging responses would imply that coping with losing a member in Sanad was a deeply personal experience. Withdrawing temporally from Sanad was a frequently reported reaction to the death of a member from Sanad. Additionally, some members started questioning the importance of Sanad as a social network and preferred to be alone. These findings to some extent contradict, at least temporarily, the experience of “*getting out of the capsule*” which is largely underpinned by establishing social network with other members. In other words, it would seem that a death of a member of Sanad transferred women back the status of isolation, but to a lesser extent than before attending the group:

“....You know in Sanad we act as one family.... I remembered a woman who was only on the hormonal therapy and survived breast cancer.... she looked nice and healthy.... after a period of time the cancer just came back to her and was very aggressive so she passed away... it was not easy to lose a member after being together for quite long time... it was like a sudden earthquake... you know I was surprised because her annual tests showed that she was free from cancer and suddenly she died.... this affected me [sadness].... I started to worry about myself that cancer might come back again to me... I preferred to be alone for a while and skipped a few Sanad meetings... I may die, so what’s the point of the treatment and attending Sanad?!.... But when we [Sanad group] got back together, I felt more relaxed and become more accepting of the fact of death, as it is the end of any human...”. (R16, attended Sanad)

“When one of close members in Sanad just died.... I felt bad and this was not only my feeling but most of Sanad group felt in the same way.... I remembered that when we received the news of her death, we spent the whole meeting just talking and remembering her.... Oh!!! Such a shame to lose her.... I just had all the negative thoughts.... I might die even if I feel okay, and [my medical prognosis] is good... you know I just thought that Sanad is not worthy.... I kept going to Sanad although I was not convinced that I can be cured from cancer.... but at least I feel more comfortable to

keep going to Sanad and talk with those women who are suffering from breast cancer...”. (R19, attended Sanad)

Likewise, based on participants’ views and experiences, the worst nightmare was the thought about “*who will be the next on list?*” These feelings led to poor appetite, feeling depressed, and being obsessed with the idea of death. In turn, these components negatively affected Sanad’s cohesion, and sometimes after a negative event like losing a member of Sanad group, attendees skipped some Sanad meetings. Although dealing with the death of a member from Sanad was hard to cope with in the beginning, a woman felt that temporarily abstaining from taking part in Sanad would not make her life better. However, the following response illustrates how Sanad members generally behaved in the crisis of losing a member.

“You know I kept going to Sanad, but I looked so sad and depressed.... I looked at Sanad members and stared at them with one question in my mind.... who will be the next on the list? [looking fear in the face].... That one, or that one, or me?.... My appetite was very bad, I stopped eating well and carrying out daily life activities in a proper way.... I went back to Sanad because being alone will not protect me from death... but then I realized that other members felt the same; in fact some meetings were cancelled due to the lack of adequate members... So losing a member of Sanad was the worst experience.... it was difficult to handle... but even at that terrible time we acted as one family and went to the funeral of our colleague.... we talked to her daughters and supported them”. (R2, attended Sanad)

When health professionals were asked about factors that affect Sanad’s meetings, the analysis of relevant responses adds significant weight to the validity of above evidence. Feedback from women about their meetings, and contributing factors reported to health care professionals confirm that losing a member of Sanad affected them psychologically, and the number of meetings they joined.

“...yes, from the feedback that we [as health care professionals] received from women who are attending Sanad... the recurrence of breast cancer to one of the members can affect the whole group... I remembered an incident that a lady who had completed her treatment and been a successful survivor for four or six years suddenly had a recurrent growth of malignant cells and passed away.... Her loss affected some Sanad members and they were afraid that one day they would end like her....

some Sanad members instead of talking about their experiences kept their minds busy with her death and worrying about their health condition in future! Some stopped coming to Sanad for a while and others just skipped some of meetings!.... This didn't last forever, because women felt they still need to meet and talk more about their experiences! It was amazing that they coped with this dilemma by re-gathering again after their friend's death!" (Social worker 3)

In summary, evidence from women who took part in Sanad, and confirmative responses from health care professionals, are indicative of how losing a member of Sanad shaped women's experiences and beliefs. Elicited responses showed that the death of a member of Sanad often leaves a large hole in the life of others. It is interesting to note that whilst taking part in Sanad exposed members to such a traumatic time, it helped them to regroup themselves and better cope with the death reality, and in particular accepting their destiny. The ability of regrouping itself might lend validity to the experience of Sanad as being part of a new family. Although there is no doubt that losing a member of Sanad is stressful for all members, regrouping and supporting each other in a crisis is a true meaning of being part of a new family.

5.4 Chapter Summary

This chapter explored women's experiences of being a member of the Sanad group. In the eyes of women who took part in Sanad's meetings, such a group contributed to their sense of being part of a new family and learning from each other. In particular, it would appear that "*getting out of the capsule*" was deemed by participants as a gateway for exploring experiences, sharing concerns and networking with other members. That is, as reported by participants, Sanad was a cohesive sub-community within a larger local community. However, in light of the current data, the effectiveness of the meetings and the way Sanad runs are subject to a cluster of tensions. These were organized in this chapter under two sub-categories comprising "*it depends on who attends*": behaviors and attributes in Sanad; and from cohesion to disruption: dealing with loss in Sanad.

It was found that dominating the meetings, being sarcastic, and underestimating/undervaluing the feelings of others play a major negative role in shaping discussions and create communication difficulties in Sanad meetings. Indeed, it was

interesting to note that the social class, being powerful and a leading personality to some extent created the feeling of being inferior to others among other group members, and thus minimized the willingness of some members to fully take part in the discussions.

Evidence from this chapter argues that losing a member from Sanad temporarily disturbed the cohesion of the group. Such tragic events affected members, both psychologically and physically. However, whilst these tensions are recognized, women often recovered, regrouped and became more accepting of the fact of a death. These findings lend validity to the meaning of being part of the new family, whereby Sanad is the only breast cancer home to belong to and share what might not be possible to share with others, as explored in the previous chapter. These findings can be used as a platform for exploring the images of recovery presented in the following chapter.

CHAPTER 6: THE IMPACT OF SANAD ON WOMEN'S RECOVERY

6.1 Introduction

Whilst the previous chapters focused on the decision-making process about joining Sanad and related experiences, this chapter sheds light on how being a member in Sanad affected the recovery of women with breast cancer. Perceived recovery is also examined from the perspective of non-attendees. perceptions of recovery among those two groups of women are compared and contrasted.

However, in order to place women's perceived recovery in a context, experiences of Sanad from the interviews with women together with related data from health care professionals are integrated in this analysis. When women were asked about the impact of Sanad on their recovery, many of their responses, stories, and comparisons would suggest that women experienced a transitional stage. The analysis showed that women's perceptions and experience of recovery can be addressed under three main ideas and transitional stages. This led to the development of the category "ideas of recovery". In the light of evidence emergent from the data, it was decided to use the phrase "from and to" in order to illuminate how joining Sanad contributed to women's recovery and enabled them to move from one stage to another. The main category and sub-categories are shown in Table 8, and explored below.

Table 8: The main categories and sub-categories

Category	Sub-categories
Ideas of recovery for Sanad members	<ul style="list-style-type: none">➤ From isolation to "recharging my battery"➤ From reluctance to acceptance➤ From hopelessness to hopefulness
Ideas of recovery for non-attendees	<ul style="list-style-type: none">➤ From "being glued to my room to being attached to outside world"➤ From hopelessness to depression,➤ From hesitation to rejection of the treatment plan

6.2 Category One: Ideas of Recovery for Sanad Members

6.2.1 From isolation to “recharging my battery”

Findings from the previous chapter would suggest that social isolation was an important factor for joining Sanad. This included the experiences of “getting out of the capsule” and the feeling of being part of a new family. Under the theme? ‘from isolation to re-charging my battery’ women identified specifically what was involved in such a transitional stage of recovery. Whilst aspects of isolation before joining Sanad have been explored elsewhere in this thesis (see chapter five), “recharging my battery” involves three elements which are based on women’s descriptions of how taking part in Sanad had influenced them. These included, “*setting out goals*”, “*being independent*” and “*thinking positively*”. As a result of being socially engaged in Sanad, and exposed to various experiences, women felt that they became more able to release their potential in life. In fact, as shown below, one woman postulated that Sanad was like a “compass” for her recovery:

“... I feel more energetic to continue my postgraduate education.... When I was diagnosed with breast cancer I stopped my BSc program, I felt down.... what is the point of having a BSc when you will die soon? I was wrong, as I met a lady in Sanad and she was doing her MSc.... you know, I started setting out my goals in order to get my degree... I will get it within a couple of months.... we will have a big party [smiling].... Sanad contributed to my personal development. It is like a compass that guides you in the desert!” (R15, attended Sanad)

A member of Sanad stressed that getting back to her work as a teacher made her feel independent again. In the beginning of her journey with breast cancer, she stopped teaching for nine months and thus her salary was reduced. Meeting other women in Sanad who work despite having breast cancer encouraged her to “*recharge her battery*” and get back to her school to fulfil her role in the society. The ability to act as an independent individual needed knowledge and self-confidence, which she felt she nourished in Sanad:

“....I stopped teaching following the diagnosis of breast cancer.... I was alone in my room for a long time.... I did not like to see other people.... even I hated my work, and despite my health status it was not that bad. I

tried to leave the school and skipped many of my teaching classes... because of that I used to be given half of my salary.... I met other women in Sanad... we talked a lot about working while having breast cancer... frankly, I felt that Sanad recharged my battery. I am more knowledgeable about my illness... I accepted it as it is and started thinking positively.... I feel now that I am independent and have a role in the society.... I am not a handicapped person". (R16, attended Sanad)

Whilst the concept of self-actualization itself has not been explicitly cited by women, some references and responses are of relevance. In the context of self-actualization, one aspect of the impact of self-help group on women's recovery was the realization of a person's full potential. With the above findings in mind, it would appear that this can only be achieved when all Sanad members feel socially active, thinking positively and well supported by other members. These findings fit well with evidence from the previous chapter, which suggests that being part of a new family maximized women's confidence and a sense of belonging.

However, an important finding to note is the fact that having goals in mind and working towards achieving them cannot occur without accepting the problem itself in the first place and "recharging the battery". Although it is recognized that doing so in reality is not easy, evidence would seem to suggest that women gained some power from Sanad and thus were able to get back on the track. When women felt in an isolated state, they might lose sight of what their potential is. This is confirmed by some actions that women adopted before taking part in Sanad such as "I used to close the door of my room and sit alone". The evidence from the first image of recovery revealed by the analysis of the interview material would imply that some women experienced a transitional stage from some level of personal imprisonment towards achieving their own goals and reaching a status of self-actualisation. That is recovery in terms of "*recharging my battery*" and self-actualization is measured by participants by reaching certain levels of recovery. These included moving to independency, revitalizing specific roles in society, thinking positively about women themselves in particular and life in general. All of these experiences might be addressed under psychosocial recovery which is a pre-requisite to medical recovery as illuminated in the next section. In a broader health care context,

these components are needed to foster women's compliance with the prescribed treatment plan.

6.2.2 From reluctance to acceptance

In addition to working towards “*setting out goals*” and “*recharging my battery*”, some participants paid attention to how Sanad contributed to better medical recovery. By comparing and contrasting women's responses before joining Sanad and after doing so, it was found that they became more accepting of their treatment plan and related interventions. This finding supports the idea of recovery as a medical transition from reluctance in the beginning of diagnosis to acceptance following joining Sanad. This transitional stage cannot be separated from the experience of “learning from each other”, as illuminated in the previous chapter, whereby participants shared knowledge and experience about addressing a certain health or complication issue. The analysis revealed that women in the beginning of their journey with breast cancer were largely reluctant to accept cancer treatment, in particular chemotherapy. Treatment itself was often associated with negative changes to the body and thus contributed to social stigma and “labelling” (see chapter five).

Although it is acknowledged here that Sanad itself does not cure breast cancer, evidence from the interviews would seem to indicate that being a member has maximized women's willingness to become more accepting of the medical and nursing treatment regimens:

“....when I was diagnosed with this [breast cancer].... I refused even cannulation procedure... the chemotherapy was completely rejected.... I felt that I am dying and it is the end and no need for more suffering.... taking part in Sanad exposed me to a community where I was better understood and supported... many women told me about the side effects of medication and how to cope with them... we compared different types of cancer treatment and day by day I felt that I became more accepting of the [medical regime] of breast cancer... on some occasions I reminded medical staff about my previous lab results.... and investigations...”. (R2, attended Sanad)

Interestingly, a further examination of data might suggest that being more accepting was associated with the intention to see other women in Sanad. In other words, some women

in this study visit KHCC not only to get treatment but also to “*have a cup of tea*” with other members, as elaborated below:

“...having breast cancer was such a disaster when I was diagnosed I refused any medical care.... meeting other women in Sanad encouraged me to stick to the treatment plan.... in fact sometimes I feel that I go to KHCC not only to get [medically] treated, but importantly to have a cup of tea with other women and update each other about many things in life, including the treatment itself.... so my visits have two goals... [laughing]”. (R21, attended Sanad)

As part of data analysis, the idea of recovery “from reluctance to acceptance” was supported by health care professionals who work closely with women with breast cancer. Based on their observations, health care professionals pointed out that many members of Sanad “*have changed*” following their attendance at several meetings. The change involves becoming keener to know more about breast cancer treatment, committed to the medical appointment and more cooperative with nursing staff. In fact some health care professionals referred to Sanad as “*anti-resistance to the treatment*” (i.e. a facilitating factor in treatment compliance):

“... I have been working with women with breast cancer for 12 years.... so I can see any changes in their behaviours.... Three women were very reluctant to have breast cancer treatment... they used to reject everything... Never came on time for their appointments.... after joining Sanad I felt that that they became more responsible and keen to gain information about each medical intervention.... Sanad was like anti-resistance to the treatment [laughing]”. (Nurse 6)

Further analysis from health care professionals would seem to indicate that joining Sanad affected women’s adherence to the treatment plan at their own homes. It should be noted that many women with breast cancer are accompanied by a number of their relatives when they visit KHCC. A health care professional reported that women’s families have witnessed changes in Sanad member’s behaviours in terms of paying more attention to their illness and its treatment:

“As you know... we get to know both patients and their families in KHCC.... many of them [families] keep in touch with us for advice and what to do in case of medical deterioration of their beloved ones. Many

relatives told me that women with breast cancer [in Sanad] became more aware of their diagnosis and very careful in taking some medications at home. Others [Sanad members] bought timers so they would not miss an appointment” (Nurse 5)

Although running Sanad meetings is not free from pitfalls, as explored in the previous chapter (e.g. speech dominance), evidence would seem to demonstrate that taking part helped women cope better with the idea of breast cancer treatment. This finding is reinforced by data from health care professionals. It is worth noting that according to health care professionals, members of Sanad displayed information-seeking and behaviours that seemed to inform their compliance and recovery. It is interesting here to note that the impact of Sanad on women’s medical recovery goes beyond KHCC to include serious commitments and adherence to the treatment plan at home.

6.2.3 From hopelessness to hopefulness

A further idea relating to the experience of recovery among women with breast cancer was the transitional stage from hopelessness to hopefulness. Perceived hope was reflected in a number of thoughts and referred to by certain events and changes. Although in the beginning of women’s journey with breast cancer many felt like it was like “*the end*”, Sanad and related experiences gave them hope. According to women, hope was reflected in a number of thoughts and expectations. These included the possibility of finding a modern medication for breast cancer, being realistic about the future, the idea that “*everyone will die one day*” and enjoying life as a healthy individual:

“After the mammogram test and [knowing] that I have breast cancer.... I felt that I will die very soon.... it is the end.... there is no need to tell myself some lies that I will survive.... I was alone and isolated in tears [sadness]... there was no hope.. not only for finding a cure for breast cancer but also to get back to living normally- as before... Sanad did not cure my illness, but at least it made me think positively and it gave me some hope.... Last time I read online that there are many good types of treatment for HIV and diabetes now, and I hope that scientists will make an effective drug for breast cancer soon...”. (R7, attended Sanad)

“Before joining Sanad I was obsessed with the idea of death... [asking myself] when will I will pass away like other cancer patients?... Who will

look after my children?... Sanad does not cure my breast cancer, as it is still here [pointing at her breast]... I feel my soul has recovered and I enjoy my life as a healthy person, go shopping, visiting neighbours and having fun with my family [smiling]!” (R3, attended Sanad)

Some participants went further to argue that following taking part in Sanad, they not only gained hope, but also their expectations became more realistic. In this context, visiting other patients, as part of Sanad social activities, and discussing some tragic stories about them, enabled some women with breast cancer (n=8) to be more accepting of their illness. The following participant asserts that “*death might be from breast cancer, but recovery is by Sanad*”:

“Before joining Sanad my expectations were a bit unrealistic... I wanted to wake up in the morning and find that [breast cancer] has gone.... I know that it is still with me... but my soul is full with hope it is not the end.... Umm, Sanad group was arranging some social visits in order to meet people who are sicker than us.... I mean meeting some handicapped people who lost their hearing, vision or some parts of their bodies!.... You know, these visits were very important for me because I found that these people challenged their illness and faced their difficulties in order to success in their life.... So I started to compare my health condition with this group of people and discovered that my health status is better than them... eventually I will die one day anyway, so what is the point of hating life and getting depressed?... You know I believe death might be from breast cancer, but recovery is by Sanad!” (R1, attended Sanad)

The overall evidence would seem to imply that there is no consistent meaning of recovery in terms of gaining hope among Sanad members despite suffering from the same illness; hope has a personal meaning for each member. However, it is worth noting that having hope is underlined by the idea that recovery is not synonymous with cure. This implies that women were cognizant of reaching hope rather than complete cure by developing realistic goals and greater functional capacity, despite on-going symptoms and possible suffering. This is in particular supported by statements such as “*Sanad does not cure my breast cancer... but I feel my soul has recovered*”.

Data from health care professionals adds further weight to the validity of the recovery idea (from hopelessness to hopefulness). Given their close contacts with those women with breast cancer, one health care professional noted that some women following joining

Sanad changed their appearance and became full of hope and vitality. In particular, whilst a couple of them “*looked like cinema stars*”, others behaved with high self-esteem and confidence.

“I have long experience with women with breast cancer... I noted that some of them and after taking part in Sanad have become more attractive, confident and with higher self-esteem, despite in the beginning being hopeless and not paying attention to the way they look.... A new doctor was employed last week and when he saw a member of Sanad he could not believe that she has breast cancer.... she entered the clinic like a cinema star [laughing]... nice wig, high heels and extremely stylish and tidy. I think that Sanad has not only have them hope but also confidence and a belief in themselves and their potential!” (Social worker 2)

Another health care professional noted that the perceived hope of recovery impacted not only Sanad members but also their families:

“In the beginning I believed that Sanad will give hope only to its members... but I noted that their families became more involved in the treatment plan and indirectly gained some hope from their loved ones’ experiences of Sanad... a mum of one of the patients told me that her daughter who was diagnosed with breast cancer comes back from Sanad meetings full of ideas and hope... the mum reported to us that her daughter acts in an optimistic way at home and the family became more accepting of the illness and they recognized that it is not the end... you know, I think that if the family does not have hope and they are resistant to the treatment plan, this will badly affect breast cancer sufferers. We [health care professionals] cannot do everything... therefore Sanad meetings contributed to the family recovery!” (Social worker 4)

These findings would seem to imply that as a result of hope, Sanad members, and to some extent their families, challenged the illness of breast cancer and related negative changes at the personal and social levels. Apparently hope involves an idea that women with breast cancer may be able to escape from some negative thoughts and feelings of hopelessness, and by doing so more energy is generated to build self-esteem.

6.3 Category Two: Ideas of Recovery for Non-Attendees

In the first chapter, data showed that there was a number of women (n=13 in this study) who chose not to join Sanad. Instead, these members of this sub-group of women created

their own small self-help group outside KHCC. Four participants in this study did not attend any group and focused exclusively on practicing religious activities such as praying.

Women who did not join Sanad were also asked to express their perceived recovery. Whilst the impact of Sanad on women's recovery was an overwhelmingly positive transition (as described above), women who had their own group or did not attend any group appeared to have more problems. Generally speaking the analysis revealed only one positive idea of recovery: *"from being glued to my room to being attached to outside world"*. The recovery of some of those non-attendees was hampered by two negative transitions, including from hopelessness to depression and from hesitation to rejection of the treatment plan. These sub-categories together with related meanings are illuminated below.

6.3.1 *"From being glued to my room to being attached to outside world"*

This sub-category illuminates how the social group outside KHCC arranged by those non-attendees affected their recovery. Recalling women's experiences and comparing them to aspects of recovery for Sanad members, some similarities were found. The analysis revealed that all women who joined Sanad or social groups created by non-attendees experience a transaction from isolation to *"recharging my battery"*. That is, the sub-category *"getting outside the capsule"* for Sanad members- to some extent echoes the sub-category *"from being glued to my room to being attached to outside world"* for those who created their own group. As shown in chapter five, women who did not attend Sanad either refused the idea itself or felt more comfortable to have their own group that matched their timetable and home location.

When women were asked about how their own group affected their recovery, the analysis of related data found that such effects revolve around being socially active. According to the current analysis, social activities involved: *"chatting"*, *"watching movies"*, *"cooking"*, *"helping in washing"* and visiting Jordanian historical places such as Jarash. Women felt that having their own self-help group gave them an opportunity to cope with isolation. These findings are encapsulated in the following extracts:

“I live in Karak [a city in southern Jordan], and it is not that close to Amman, so I joined the social group we created in my area which involves four women with breast cancer... in the beginning of my diagnosis I felt so isolated I was just depressed and lonely.... Every time we arrange a meeting in a different home, we chat and watch funny Egyptian movies together.... It affected my recovery by enabling me to feel that I am physically and socially capable to do things. It was like I went from being glued to my room to being attached to outside world...”. (R8, did not attend Sanad)

“We arrange two meetings a month... we cook together and sometimes we go out and visit some places such as Jarash... one of us has many children, so we help her in washing and dusting. It is least it is better than staying alone in my room”. (R10, did not attend Sanad)

These findings would seem to indicate that joining a self-help group created autonomously by women themselves contributed largely to their social health. Whilst it is recognised that the above findings are based on a small number of those women who did not attend Sanad, no reference was made to their capability to realise their potential in life, achieving objectives and planning ahead. What seems clear from this analysis is that socialisation positively affected women’s physical and social abilities to carry out basic tasks such as washing and visiting places. However, the current analysis would seem to suggest that the involvement of healthy women in the social group created a different atmosphere. For example, a participant expressed her concerns that occasionally “*healthy women*” joined them from the neighbourhood. Whilst this might enhance the diversity of the social group, it restricted the freedom of expression for some women with breast cancer. This freedom is exemplified by talking freely about private issues without being misunderstood by “*foreigners*”. This affected the recovery by skipping some meetings and getting back to “*loneliness*”.

“In many meetings I felt that I became more socially active... No more tears... But on a couple of occasions we conducted a meeting in my home but some members invited other neighbours and relatives who do not have breast cancer... I felt down as I could not talk about the chemotherapy and my hair and the way I look... I thought women, the foreigners, without breast cancer would laugh at me or not believe my story... because they did not go through the same experiences.... So I stopped joining the meetings and preferred to get back to my loneliness and I hated myself... I

returned to the question of why me, why not that fat woman without breast cancer?” (R20, did not attend Sanad)

The above evidence is a recognition of the importance of the group homogeneity in terms of addressing the medical problem. Unlike members of Sanad, some women felt that they are not in the same boat and this affected their attendance, participation and importantly self-value as reinforced by the statement “I preferred to get back to my loneliness and I hated myself”. Taking the analysis as a full picture of women’s recovery, it can be said that whilst having a self-help group outside KHCC is positive as it enhances social recovery, it might also contribute further to social isolation, and perhaps self-blaming. Indeed, with the ideas of recovery of Sanad members in mind, it would appear that moving from isolation towards socialisation for those women who created their own social group is narrow in its scope and limited in its impact on women’s recovery, in particular in terms of planning ahead.

6.3.2 From hopelessness to depression

Although women who decided to join their own social group, and others who preferred to be exclusively engaged in religious activities, became more socially active, better connected to the physical and spiritual world, and ultimately accepting their faith (see chapter five), some of the women experienced depression. With the help of health care professionals and their observations of how women behaved following the diagnosis with breast cancer, it was found that some women who did not attend Sanad often had problems with depression. Although it is not possible to offer correlative evidence in this study between attending Sanad and depression, due to its aims and qualitative nature, these findings are worth elaborating.

Whilst the majority of participants went through self-appraisal and disbelief in the beginning of their experience with breast cancer, those who refused to attend any social group were more likely to suffer from hopelessness, isolation, self-blaming, and thus put themselves at high risk for depression. In other words, their transitional journey was from hopelessness to depression, as opposed to from hopelessness to hopefulness, the latter of which was the case with Sanad members. Lack of hope and depression in this analysis

included elements such as “*I am just waiting my death*” and “*I feel always down*”, “*I might kill myself*” and “*my life is getting from bad to worse*”. These quotes do not sit well with the ethos of recovery encapsulating hope and moving on (Schrank & Slade 2007). This is illuminated further by the following self-reported changes following the diagnosis with breast cancer:

“I did not attend Sanad and I’m not interested in arranging social groups with other women.... Breast cancer was such a catastrophic event in my life... many of those women with breast cancer will pass away sooner or later... I am just waiting for my death... my life is going from bad to worse... I look terrible, fragile, and I always feel down. I take anti-depressants but if suicide was not [religiously] prohibited, I might kill myself.... Nothing worth living for!” (R24, did not attend Sanad)

“Listen daughter [referring to the researcher], I’ve been on loads and loads of medications and what I see in the mirror is just a dying tree... I am very weak, if I sit down I cannot stand, I feel that I will die while I am asleep, the graveyard is close to my house I saw many funerals for those women with breast cancer... Sanad nor any group in the world can give me back my health... I am just praying to Allah that I die in peace!” (R26, did not attend Sanad)

These powerful insights into women’s world of recovery from breast cancer would imply that some of them, in particular those who were not involved in any sort of social group, were unable to obtain protective benefits such as adopting better coping mechanisms for breast cancer, unlike Sanad members. It was particularly interesting to note the impact of physical environment on women’s psychological status and the overall recovery journey. This is illustrated by the second extract in which the participant’s home location and its closeness to a graveyard contributed to a lack of hope.

It is worth noting the emergence of the term “*suicide*”, which might be seen as an indicator of reaching a frustrating and hopeless level. Having said that, however, this is not to postulate that Sanad members are protected from such a serious psychological change. Based on this analysis, it would appear that the failure to cope with breast cancer diagnosis and to be armed with hope are key drivers for depression and committing suicide. This analysis is validated by responses from health care professionals. When they were asked about how women with breast cancer recover in general from cancer, it was

found that those non-attendees of Sanad in general are most likely to suffer from depression. Although some members of Sanad occasionally had issues with depression, this did not seem to be as severe as for those who did not attend any social group:

“...You know, we [health care professionals] cannot say that if you attend Sanad you will not have depression... but I believe being isolated and not getting involved with social activities with other women with breast cancer might lead to depression... and [the isolated patients] will never recover... Those who did not join Sanad or any social group come back to us [the psychosocial unit in KHCC] not for treating breast cancer but for coping with depression.... Many of them have withdrawn from society and sit alone at home thinking negative thoughts!” (Social worker 4)

“In general, many women with breast cancer start taking anti-depressants such as Prozac. We [health care professionals] meet up with all of them regardless of whether they attended Sanad or not. According to my long experience with them, the problem is not only with having depression but also with being motivated to confess the problem and work hard to deal with it... this requires having hope... those who did not attend Sanad often have [troubles] with these issues and often they prefer to suffer in silence and stay alone as victims to depression. Sanad members are support seekers and they celebrate any progress in their health, even if it is small!” (Nurse 6)

These findings would seem indicate that the recovery journey of those women who did not attend Sanad was inhibited by the lack of hope, as manifested by avoidance and the preference for loneliness as opposed to being engaged in social groups and connected to outside world. However, lack of hope in this context is not only about limited social connections and willingness but also valuing any progress. That is, the overall data from non-attendees to Sanad, together with complementary evidence from health care professionals, would propose that the recovery process was largely compromised by depression and lack of hope. This state of affairs is opposed to Sanad members' experience of “*getting out of the capsule*” and recovery idea of “from hopelessness to hopefulness”, whereby participants felt confident, driven by hope and goal achievement. However, in this thesis, the focus should not only be on differences and similarities in terms of recovery among different groups. Rather, responses from all participants, whether they attended Sanad or not, should be seen as valid in their own right. That is, as

evident in this analysis, the recovery process is individually shaped and facilitated or inhabited by a certain environment.

6.3.3 From uncertainty to rejection of the treatment plan

A further component related to the recovery of those women who did not join Sanad is related to the acceptance of, and compliance to prescribed treatment plans. The analysis showed that the women involved in this study were uncertain and doubtful about the effectiveness of the treatment plans for breast cancer. However, as outlined in the beginning of this chapter, Sanad members were more motivated and largely engaged in knowledge sharing, and this enabled them to become more accepting of the treatment plan over time. Whilst women who did not attend Sanad and joined their own social group felt physically and socially active, it would appear that no positive changes were found to the level of compliance with the treatment plan. Instead, some responses would imply that uncertainty about the success of breast cancer treatment has changed into rejection of the idea itself, reflecting negatively on recovery. Others refused “chemical stuff” and adhered exclusively to folk medicine, self-medicating themselves with dietary choices:

“...I was uncertain if my breast cancer would be treated... doctors and nurses told me that there is always hope, but I could not believe them... I skipped some treatment courses and instead I joined our own group... we chat and enjoy ourselves... I rejected many treatment plans because you will die anyway, so just have fun in the remainder [of one’s life]... cancer is cancer, so why to have lots of useless and dangerous bills [from medical treatment]?... I know now I have severe anaemia, but I eat lamb liver and I will be fine!” (R25, did not attend Sanad).

“In the beginning I was a bit convinced about the treatment plan but I did not see any progress so I stopped it... I joined our social group in the village and day by day I became more obsessed with the folk medicine... I boil sage leaves and drink three glasses every day... I have a problem with the calcium level but I eat lots of eggs... I did not like the big calcium tablets so I threw them away... they are just chemicals, and not natural. I refused giving blood samples to check my [minerals]...” (R 23, did not attend Sanad)

These interesting findings are largely inconsistent with Sanad members' perceived recovery encapsulating learning from each other, and being willing to become more accepting of the medical regime. The current analysis does not only show a lack of hope among non-attendees of Sanad group but also negative attitudes towards treatment itself which led to poor recovery. For instance "eating eggs" was used as a way to address the lack of calcium problem; albeit this might be a useful homeopathic complement to traditional medicine, and evidence of self-efficacy, no medical follow-up and lab investigations were carried out, thus this represents a very serious disregard of medical advice. This evidence is substantiated by the observations of health care professionals which highlight the recurrent admission of cancer patients due to the rejection of treatment. Health care workers asserted that ignoring and rejecting the treatment plans are often done by those women with breast cancer who did not attend Sanad:

"...I am familiar with all sorts of things related to breast cancer treatment... I know sometimes we have problems with Sanad members, such as not being convinced about the treatment... but eventually they [women in Sanad group] support each other and become more interested in knowing everything and comparing their recovery to each other.... Those who did not attend Sanad are a bit careless and would like to skip the treatment as soon as they can.. I think Sanad members are much more cooperative when it comes to compliance with the treatment plan... some of them chase us up in the corridor for a piece of health education... unlike women who create their social groups outside KHCC... We as health care professionals are always handy and there to help all women with breast cancer!" (Nurse 5).

Some of non-attendees went further to convince Sanad members about rejecting the medical care and considering folk medicine.

"...you know, rejecting the treatment plan is eventually a patient choice, but we noted that those who did not attend Sanad tried to convince Sanad members to ignore some aspects of the treatment plan and to exclusively focus on praying and adhering to folk medicine...." (Social worker 1)

The overall evidence is indicative of how the nature of Sanad group itself, compared to other types of social groups, shapes women's recovery. Whilst it is acknowledged here that those women with breast cancer who attended their own group gained socialization benefits, the above two extracts might imply that Sanad contributed more to women's

recovery in terms of acceptance to the treatment. That is, both types of groups maximized women's social involvement, but in the case of Sanad, seemingly, such involvement is underpinned by an educative and cooperative approach among its members. Consequently, the analysis might argue that the extent to which such an approach affected women's compliance with breast cancer treatment cannot be ruled out.

6.4 Chapter Summary

This chapter addresses findings related to the overall perceived participant's ideas of recovery. The word recovery in this analysis refers both to internal conditions (the attitudes, experiences, and processes of change of women with breast cancer who are recovering) and external conditions (the events, and practices that may facilitate or inhibit recovery). Ideas of recovery emerging from the data, as portrayed in this chapter, represent a state of transition that involves a complex world of thoughts, feelings, and goals. Complementary and confirmative findings regarding the impact of Sanad on women's recovery were also offered by health care professionals. Under the idea "from isolation to recharging my battery" women identify specifically how Sanad shaped "*setting out goals*" and led them to think positively. The analysis shows that Sanad members were more motivated and largely engaged in knowledge sharing, and thus they became more accepting of the treatment plan. Conversely, responses from women who did not attend Sanad, whilst they felt physically and socially active in their own social groups, demonstrated no positive changes in the level of acceptance with the treatment plan and planning ahead.

Indeed, the chapter revealed that as a result of hope, Sanad members challenged the illness of breast cancer and related negative changes at the personal and social levels. In particular, data triangulation with health professionals confirmed that joining Sanad contributed positively to women's appearance and vitality. In contrast to this, the current analysis shows a lack of hope among non-attendees of Sanad, feelings of helplessness, and negative attitudes towards treatment itself. However, responses from all women with breast cancer regardless of their attendance to Sanad contributed in different ways to the overall picture or "puzzle" of recovery following the diagnosis with breast cancer. The

overall emergent evidence from this chapter will inform the discussion chapter, in particular the impact of Sanad on women's recovery.

CHAPTER 7: DISCUSSION CHAPTER

The thesis explored the women's experience of breast cancer in Jordan through semi-structured interviews, and investigated the impact of the self-help group (Sanad) on their recovery. The findings offer a number of issues of use for practice, policy and research that will contribute to the limited body of knowledge of this largely unexplored area. The relevant literature at the national and international level will contextualize the main findings, and implications for nursing practice and recommendations for future research will be highlighted.

The overall evidence suggests that women's experience of breast cancer in Jordan is socially and culturally constructed and has a multi-dimensional nature that goes beyond medical associations and meanings. These findings are consistent with the international literature in that cancer is considered as a major cause of panic because it symbolize death and demanding treatment procedures (Cebeci et al., 2011, Doumit et al., 2010b, Gurm et al., 2008b, Amasha, 2013). Likewise, various concerns, uncertainty, shock and change of image reported by Jordanian women resonate with findings from previous studies carried out in USA, UK, Lebanon, Turkey and Pakistan (Browall et al., 2006, Doumit et al., 2007, Doumit et al., 2010a, Banning et al., 2010, Fox, 2013). With this in mind, it is reasonable to argue that evidence about women's experiences of breast cancer is well established and confirms that such women may experience similar emotions, feelings and concerns towards the diagnosis and treatment of the illness. Although these aspects of women's experiences of breast cancer are shared worldwide, there are also nuances in specific socio-cultural experiences of the illness identified in this thesis. In particular, this work highlighted differences among the decisions of women with breast cancer concerning the decision-making process about taking part in Sanad and their motives, reasons and alternatives.

On the basis of current findings, I would argue that it is more important to clarify the deeper reasons behind taking part in Sanad or not and the consequences of such decisions, rather than purely focusing on the symptoms of women' experiences of breast

cancer which have been given more attention the international literature over the last decade.

For the sake of clarify and the logical flow of women's narratives of the journey from breast cancer diagnosis to joining Sanad and reaching perceived recovery status, the discussion chapter is divided into four parts. The first focuses on the motives and influences affecting participation in Sanad and explores the issue of social stigma and the influence of the family in shaping decisions about joining self-help groups. The second part focuses on the role that a self-help group plays in ideas of recovery and how this compares with the experience of non-attendees. The third part discusses problems within Sanad itself as a self-help group and identifies future recommendations for such groups. The final part of this chapter presents a conceptual model about the impact of Sanad on recovery, taking into consideration difficulties involved in women's meetings and alternatives adopted by non-attendees.

7.1 Motives and Influences in Sanad Participation

7.1.1 Social stigmatization and Sanad participation

The last decade witnessed increasing recognition of the importance of stigma and its negative psycho-social impacts such as isolation and self-blaming among patients with cancer in general (Chatman and Green, 2011, den Heijer et al., 2011, Else-Quest et al., 2009), but in this study it seems that it takes a stronger form and plays a powerful role in informing women's decisions about Sanad that later shapes the recovery process at least at the individual level. In this research, stigma was seen by women as a cluster of feelings, experiences, perceptions and actions that includes fears of telling others about the diagnosis, hiding changes in appearance following medical treatment and avoiding being seen in public.

Stigma and social support groups have extensively been studied with patients with HIV (Phillips et al., 2000, Yoshioka and Schustack, 2001), prostate cancer (Else-Quest et al., 2009) and evidence showed that stigma prevents them from seeking medical help and contributes to social isolation (Brahams, 2011, Vos et al., 2012). These findings apply to

the emerging evidence from this thesis, in particular the role of stigma in social integration.

However, previous research on stigma and self-help groups has focused on men with prostate cancer, mental patients, cardiac rehabilitation programmes (Davison et al., 2000, Else-Quest et al., 2009, Walker, 2005, Bloom et al., 2001) and patients from different cultural and religious contexts from those in this study. What is clear from this study is that the fear of social discrimination among Jordanian women with breast cancer limits the possibility of participation in any social group such as Sanad. It should be noted that stigma is a complex social issue that can delay diagnosis, and thus receiving the medical treatment needed (Sussner et al., 2011, Ablon, 2002, Skinner and Mfecane, 2004).

Self-help groups require a readiness to disclose personal experience, feelings and concerns and it seems that there are socio-cultural barriers to doing this (Ashing-Giwa et al., 2004, Fang et al., 2013, Guruge et al., 2011). Referring to taking part in Sanad as *“putting the family as a headline in the newspapers”* is indicative of the fear of social stigma contributed to women’s decisions. A British study illuminates this point, confirming that having a condition that people perceive as stigmatising means that people feel fearful of the judgments of others (Munn-Giddings and McVicar, 2007), and this in turn informs the decision process of not taking part in self-help groups (Avis et al., 2008). It is not surprising therefore that only a small percentage of cancer patients in general join support groups (Lieberman and Goldstein, 2006, Oka, 2013), as mirrored by this research.

However, the thesis offers some conflicting findings about the impact of stigma on women’s decisions to join Sanad. Whilst stigma played a vital role in inhibiting women from taking part in Sanad, it also encouraged others to seek support and become members of the self-help group. The emergence of this interesting and unexpected positive impact of the perception of stigma might be explained by a number of factors.

First, the findings reveal that women with breast cancer can experience some difficulties affecting their sense of femininity, sexual functioning and fertility. These challenges were cited and confirmed elsewhere in the literature (Kunkel and Chen, 2003, Broeckel et al.,

2002, Chatman and Green, 2011). Sensitive issues such as sexual functioning and fertility may better be understood by those who suffer from breast cancer (Boesen et al., 2011, Cho et al., 2006, Avis et al., 2008, Lam et al., 2012a); in other words, for some participants the power of the sensitivity of certain topics that need to be shared with those “*in the same boat*” in Sanad was a main driver for taking part in the group because of the presence of social stigma among outsiders.

This reflects that social stigma can act to isolate people and cut them off from support, but when patients identify the illness as disfiguring, embarrassing, and stigmatizing, this leads to seeking the support of others, who share common experiences without the fear of being stigmatised and looked at as abnormal (Davison et al., 2000, Fang et al., 2013, Graves et al., 2012). When women share their concerns about social stigma and body image and how to deal with them, this leads to better mental health outcomes and symptom reduction (Coreil et al., 2012a, Goodwin, 2005, Sammarco, 2003). For instance, practitioners are urged to recognize that the stigma suffered by patients with breast cancer could influence decisions to join Sanad, and such issues should be explored and discussed carefully with them without projecting assumptions and pre-conceptions onto patient feelings and preferences.

The current discussion offers health professionals a better understanding of women’s need for support, and of their concerns during diagnosis and treatment, highlighting the need for sound counselling services. This study concurs with other research arguing that the belief that information and knowledge are adequate to modify stigma attached to illness is erroneous (Skinner and Mfecane, 2004, Arora et al., 2007). It would appear therefore that social stigma and “labelling” and its impact on taking part in Sanad is a complex issue that desires to be understood from both individual and family perspectives. It can be suggested that the perception of not being accepted by society or even families due to the social stigma encouraged some women to take part in Sanad, in which relationships constitute a ‘separate space’ for those women suffering from breast cancer (Ussher et al., 2006). Women’s efforts were directed towards such a separate space where they left behind all sorts of fears of being lonely, being treated as infectious and feeling themselves (or being perceived to be) an added burden on the family. In short, the

findings show that the feeling of being stigmatized by family and society induced women to take part in Sanad in order to get a sense of feeling normality.

Perhaps the most interesting issue to emerge in the context of motives behind deciding whether to take part in Sanad is the perception that not being married will be regarded by others as a flaw or reason to be ashamed. Some single women felt that Sanad would expose their private lives and thus lead to feeling embarrassed in front of married women, and that being a member might reduce their chances of getting married. To some extent the available evidence is inconsistent with the current findings. For example, a quantitative American study with a sample of 549 women with breast cancer aged 22-50 found that women with breast cancer believe that being married is associated with more body image concerns, fears and social acceptability than those who are singles (Fobair et al., 2005). Whilst it is recognized that the sample size in this research is small, the occurrence of the fear of negative marital affects arising from participation in a breast cancer self-help group found in this particular study is attributable to numerous reasons.

First, many participants with breast cancer in the previous studies included exclusively married women with children (Cebeci et al., 2011, Chamberlain Wilmoth et al., 2006, Baider et al., 2004), and consequently the experience of single women in decisions regarding social groups have not been well understood. Second, although the utilization of a quantitative method would most likely enhance the generalisability of this finding, this approach might restrict the emergence of complex and in-depth subjective experiences of women with breast cancer. Third, it seems that single and younger women in this study are aware of their stigmatised status but this is triggered further in Sanad when married women explore marriage- and children-related issues.

In line with this, I agree with other researchers who found that commonality in terms of illness alone is not enough for joining a self-help group and each individual's experience is diverse and complex (Avis et al., 2008). Accordingly, it might be beneficial in the future to create a sub-group of Sanad that is homogeneous in terms of some demographics such as marital status and age groups that better promote interactions among the members, minimize stigmatization and contribute to a more relaxing atmosphere and thus experience open and comfortable exchanges.

However, it is clear that more empirical work is needed in future to draw attention to the experiences of single and younger women with breast cancer and its impact on their lives. To date, many research studies used qualitative methodologies to explore women's experiences of breast cancer, stigma and self-help groups; whilst such methodologies are valuable, there is a need to examine women's demographics and decisions about joining Sanad through quantitative means and thus sharpen the generalisability of issues identified in the qualitative data.

7.1.2 The role of family: a facilitator or inhibitor for Sanad?

Although the family was found to play an important part in encouraging and empowering participants to join Sanad and cope better with illness, in line with previous research, it was noted that some women were motivated to join Sanad due to the lack of emotional and psychological support available at home; in short, many women joined the group to escape from domestic loneliness and isolation. More specifically, the situation of women with breast cancer in this research was affected by their significant others, particularly their husbands and mothers' in law who were not always understanding and supportive. Breast cancer impacts the functioning of the family because the relationships/roles are dramatically changed (Julkunen et al., 2009, Coyne et al., 2012). Whilst this affected women's psychological status and maximized the feeling of being unaccepted, as shown in this study, it contributed positively and indirectly to taking part in Sanad.

The family-related fears of "disfiguring the family tree" informed women's decision to join Sanad, where their needs are better understood by its members and concerns are freely verbalized. Women's health concerns may be trivialized and superseded by family concerns (Im et al., 2002, Oka, 2011), thus encouraging women to seek a different source of support. In other words, feeling less supported, being given little attention, and feeling lonely within the family context convinced women to take part in Sanad meetings where they hope to overcome the problem of self "capsulation". This discussion is explained further by the cognitive-behavioural model of health anxiety, which argues that that health anxiety results from (and is maintained by) dysfunctional beliefs about illness, and

that these beliefs are partly shaped by interactions with the patient's family circle (Salkovskis and Warwick, 2001, Sussner et al., 2011).

On the other hand, some women did not join Sanad due to inadequate support offered by the family, in particular from the husband and children. On this basis, it is possible to claim that encouragement from significant others is likely to be a contributory factor to not joining Sanad rather than a fundamental determinant. This discussion is reinforced by previous research. Whilst the differences in culture and sample are acknowledged, earlier findings showed that informal support from family and friends play a vital role in refusing taking part in a self-help group in general (Jackson et al., 2011, Jones et al., 2007) and in particular among those patients from certain ethnic groups (Avis et al., 2008).

In the light of this, one can argue that being well supported from the family, whether nuclear or extended might minimize the possibility of joining a self-help group like Sanad. This is a natural consequence of the situation whereby if some women receive greater support from their families, they perceive less need of joining self-help groups to obtain such support. However, other women who reported being well supported by their families still decided to join Sanad, often because it is difficult in Jordanian culture to discuss and share the intricacies and intimate details of the sensitive subjects surrounding breast cancer with family members. This corroborates the findings of a study conducted in the UK, which also indicated that sharing intimate details about personal experiences of cancer might be deemed as shameful and culturally inappropriate to patients' families (Avis et al., 2008). Thus, the decision about joining a self-help group is closely related to the family context rather than the individual factors affecting patients themselves.

Self-help groups directed towards women with breast cancer assume that the latter can make independent decisions about their health and whether or not to take part in such groups (Chamberlain Wilmoth et al., 2006, Stang and Mittelmark, 2009, Pistrang et al., 2012). In fact, although the family plays a vital role in facilitating or inhibiting patients' taking part in self-help groups, family members are seldom included in research studies (Northouse et al., 2006). Whilst this reflects the fundamental importance of focusing on patients themselves, the findings of this study emphasized the value of developing Sanad

groups to include family members, in particular their husbands and their husbands' mothers. Increasing awareness of families about the value of Sanad is needed so that they are not 'threatened' by the group, and so that they are therefore more likely to support patients' participation in Sanad.

In order to enhance self-help groups for women with breast cancer in a way that suits the culture, structure and family beliefs/roles, the emerging idea of establishing Sanad in the context of patients' families is worth consideration. In general, it was found that a self-help group for family members of women with breast cancer is a successful and an effective therapeutic strategy (Liu et al., 2008, Shields and Rousseau, 2004), however developing and focusing on self-help groups that include family members needs to be carefully planned, with much attention to be given the complexity of relationships within individual families.

For example, it is vital to note that the role of significant others in this study varied among women. Although health care professionals need to be aware of the significance of family in a certain culture and its role in shaping women's decisions about Sanad, they need to avoid making assumptions about how that translates into action in individual cases. That is, each family situation constitutes a micro community system, unique in its own right and requiring to be understood individually within a specific context.

7.2 Recovery Among Sanad Members

Three main unique dimensions of recovery have emerged from this thesis, comprising economic recovery, realistic hope and gaining power and feeling less depressed.

7.2.1 Economic recovery

My findings demonstrate that Sanad members experienced an important transitional stage from isolation and loneliness to a social engagement and experiential learning. Consistent with international studies, taking part in Sanad maximized the sense of belonging and sense of empowerment for Jordanian women with breast cancer, consequently enabling them to feel more understood, less isolated and coping better with difficulties and

problems specially regarding hair loss and body image (Helgeson et al., 2000, Avis et al., 2008, Coreil et al., 2012b, Stang and Mittelmark, 2009). It would appear therefore that there are similar patterns of experiences and perceptions of recovery among women worldwide with breast cancer. However, when the findings are carefully examined and compared to the existing literature, the evidence offers two dimensions to the recovery that worth highlighting.

First, stigma is attached to cancer in Jordan and there is a possibility of not surviving such an illness, the current researcher's expectation was that Sanad members' perceptions of recovery would be dominated by reaching an optimum level of medical status (i.e. biomedical outcomes) and greater social acceptance; this was only partially realized, and other factors proved more important than anticipated. For example, perceiving recovery as "*recharging my battery*" and getting back to work in order to be economically independent was a key criterion against which recovery was measured by Jordanian women in this sample. That is, being part of Sanad, feeling valued, and learning from others enhanced patients' sense of being independent in financial terms because participants in the self-help group rebuilt their self-confidence and self-esteem and enabled them to cope with challenges, to feel normal and to move on (Giddens, 1991, Stang and Mittelmark, 2009, White and Madara, 2002). However, the question that follows from this discussion is *why* women with breast cancer view Sanad and its impact on the recovery from an economic point of view.

First, in Jordan there is a dramatic shift in the roles for both men and women. While throughout the Arab world, as in Europe and most areas of the world, males are seen as the natural and traditional breadwinners for families, this is changing throughout the world. In the Middle East region this change is more evident in Jordan than in other countries due to the instability of the region (e.g. the on-going Arab Spring, the civil war in Syria and conflict in Iraq), limited natural resources and successive waves of refugees. It is reported that the two-thirds of Jordan's inflation in 2010, 2011, and, 2012 was due to rising food prices. The recent influx of almost a million Syrian refugees has compounded the high demand for food and housing (Lozi, 2013). To meet such dramatic economic changes, the role of Jordanian women in improving families' income has become vital.

With this in mind, this necessitates the need for recovery that leads not only to better economic status but to fulfilment of new roles and expectations of women in Jordanian culture.

Second, although the medical treatment is free for cancer patients, women still need and are willing to be economically independent to cover issues related to changes in the body image, for example buying good quality of wigs. These accessories were part of Sanad discussions that resulted in better adaption to the breast cancer diagnosis and maximized women's confidence.

Taking these reasons together, it can be argued that the establishment of Sanad or any type of self-help group driven by the philosophy of responsibility for one's own situation might lead to "economic recovery" that in turn contributes to positive overall health (County and Chepchirchir, 2013). The concept of economic recovery is new in the world of self-help groups and needs to be examined further by focusing on how such groups help women not only to fight cancer, but also the resultant economic crisis that often leaves women highly stressed.

7.2.2 Realistic hope

Emerging evidence from this study confirms that Sanad, when driven by reciprocity and its social benefits, fostered women's capability to move on from the stage of hopelessness to hopefulness. The importance of women perceiving hope as a vital element of recovery is unsurprising, given its basic importance for cancer narratives in general (Ehrenreich, 2010, Kromm et al., 2007), but the prominence of realistic hope in women's stories is particularly remarkable. Although being cured from cancer (i.e. remission status) is the ultimate wish for cancer patients, the women in this study displayed remarkable self-efficacy in developing realistic goals and aspiring to greater functional capacity. Previous studies found that women with breast cancer and related stressful treatments typically lose hope (Hann et al., 2005, Wiles et al., 2008), but the opposite conclusion was reached by this study concerning Sanad members, who gained and developed realistic hope. Whilst the differences in methodologies, samples and the stage of cancer are recognized, this disparity in findings might be explained by what Sanad adds to women's quality of

life; as explained in the previous section, “*getting out of the capsule*” and “*recharge my battery*” are manifestations of hope.

Interestingly, these manifestations are critical in launching the journey from despairing about a life circumstance to hoping for a better future (Andresen et al., 2003), and for this reason the establishment of particular hopes and aspirations needs to be seen as an initial step in the process of recovery (Onken et al., 2007b). However, healthcare professionals do not necessarily possess expert information about what it is or is not realistic hope and recovery (Phillips and Sowell, 2000, De Brabander et al., 1998, Ashing-Giwa et al., 2006). What is needed here is more recognition of the fact that recovering individuals may have aspirations to challenge the status quo in ways that free them to think productively (Cook and Jonikas, 2002).

Therefore, it is vital that healthcare professionals understand the role of hope and its aspects as an integrated experience of illness and how this might be maximized by attending Sanad. This needs to be coupled with more focus on themes such as empowerment, becoming a better person, and pride in being a survivor of breast cancer (Coreil et al., 2012b). However, the circumstances under which hope is a positive and realistic power versus when it can be harmful are issues that remain to be answered in future studies.

7.2.3 Gaining power and feeling less depressed

Although economic recovery and realistic hope are the main impacts of Sanad on women’s perceived recovery, other psychological effects were manifest. Being in control of illness, moving forward and dealing effectively with depression were significant to the perceived recovery of Sanad members.

Overall, evidence would seem to imply that being a member of Sanad and believing in empowerment and hope may counteract any tendency to become depressed. This is largely due to the closeness found in Sanad and previous forms of recovery, including economic recovery and realistic hope (as discussed previously). Gaining power and feeling less depressed is a recognition of the personhood retained by the individual and

the mastery of symptoms during the process of being ill, diagnosed and in treatment (Onken et al., 2007b, Metcalfe et al., 2012).

Regression analyses from previous studies confirmed that lack of social support in general and self-esteem were independently associated with depressive symptoms; lower levels of social support and self-esteem are strongly related to higher levels of depressive symptoms, and thus poor recovery (Schroevers et al., 2003, Hann et al., 2002). This is why there is an increased prevalence of depressive symptoms and major depression among women with breast cancer, particularly during the initial period following diagnosis (Christensen et al., 2009).

On this basis, one could suggest that taking part in Sanad is a means to address the main social factors associated with depression after initiating treatment of breast cancer. However, this linear analysis might suggest that evidence of association does not mean that there is a direct causal link, it is possible that the association could indicate a causal link in the opposite direction, that symptoms of depression may prevent women from joining social support groups such as Sanad. For instance, the presence of depressive symptoms among Jordanian women (e.g. "staying alone in my room") may lead to increased rejection of Sanad as a social support group. This is in-line with previous studies reporting that having severe anxiety and depressive symptoms may prevent people from seeking out social support that could provide a solution to the feeling of isolation, which is known to contribute to depression (Jones et al., 2012) and poor quality of life (Grassi et al., 2004, Reed et al., 2012). The current findings contribute to the literature by illuminating that perceiving an adequate social support system such as Sanad is associated with fewer depressive symptoms, lower health anxiety and greater support-seeking behaviour to alleviate health worries.

7.3 Recovery Among Non-Sanad Members

Being religious and believing that Allah (God) is the only one who could help them to overcome their disease was found to be a crucial barrier to taking part in Sanad. It is interesting to note the powerful impact of religious practices such praying as a perceived alternative to Sanad. An increasing body of the literature illustrates that the absence of a

social support network is linked to severe stress (Lutgendorf et al., 2005), and thus to increased cancer progression (Nausheen et al., 2009) and poor quality of life (Grassi et al., 2004). Evidence from this thesis suggests that religious practices may be a form of social support for some of women with breast cancer. Earlier findings have shown that spirituality and religious practice often lead to better adaption and psychological health among women with breast cancer (Bussing et al., 2007, Howard et al., 2007, Choumanova et al., 2006, Harandy et al., 2009). In this study, both groups of women (Sanad members and non-attendees) experienced recovery in terms of readjusting positively to the change in their appearance and life. These findings agree with earlier work confirming the positive relationship between religiosity, psychological well-being and adaptive coping for patients with cancer (Lynn Gall and Cornblat, 2002, Reynolds, 2006, Hasson-Ohayon et al., 2009).

Given their frequent contacts with KHCC, non-attendees had the opportunity to take part in Sanad but they did not. This decision might be explained by the general-attribution theory. The theory proposes that the religious framework used by some patients serves as a source for explaining various life events (Spilka et al., 1985), particularly “why me?” issues in this study. It is not surprising that the current findings are congruent with those of previous research showing that the religiosity of patients can increase after a diagnosis of cancer, as exemplified by behaviours such as praying (Bussing et al., 2007, Howard et al., 2007, Harandy et al., 2009). Overall, this made women feel less depressed due to the negative dramatic changes following diagnosis, such as body appearance.

However, excessive focus on religiosity at the expense of other treatment methods and self-help groups options can negatively affect patient outcomes, as manifest in the fatalistic belief that breast cancer is from God, and no one can change their fate. Among non-attendees, such beliefs were found to be a barrier to participating in Sanad and to ignoring treatment plans, as confirmed by women and health care professionals. In addition to hindering treatment, religious beliefs such as fatalism can prevent patients from taking part in efforts to diagnose cancer early (Doumit et al., 2010a, Harandy et al., 2009) and from seeking help and support (Harandy et al., 2009, Kwok and Sullivan, 2006), thus preventing or delaying the overall recovery.

Currently, Sanad in Jordan is concerned about exchanging knowledge and experiences and learning from others, but little attention is given to the religious dimension and practices such as praying and reciting the Quran, which have been found to be helpful in improving patient outcomes (Hasson-Ohayon et al., 2009; Lynn Gall and Cornblat, 2002; Reynolds, 2006). In this context, it seems therefore that there is a need to explore, understand and incorporate women's beliefs into the framework of Sanad structure in order to reduce the identified barriers to participation in the group to enable more patients to benefit. However, this requires great sensitivity as some women with breast cancer in Jordan are from other religious backgrounds (e.g. Christians). A possible option to pursue this strategy would be to establish a sub-group of Sanad more religiously focused, whose members can benefit from the dynamic benefits inherent in Sanad along with religious practices and perspectives.

7.4 Sanad Culture and Challenges

In general, findings from this thesis revealed that women participating in Sanad along with others sharing the same medical diagnosis alleviated the sense of loneliness and isolation (and thus of depression), and promoted a feeling of being normal (i.e. increased self-esteem). Although several studies confirmed the benefits of a self-help group like Sanad (Garssen et al., 2011, Guruge et al., 2011, Arora et al., 2007, Munn-Giddings and McVicar, 2007), the importance of a group culture in creating social well-being and mutual member interactions is lacking in the literature. For instance, the possible domination of the group by one person or a small coalition of participants and the reluctance of some individuals to verbalize their feelings are all obstacles for a dynamic Sanad group. These findings are similar to those cited in the literature focusing on group behaviour (Adamsen et al., 2001, Sim, 1998, Kitzinger and Barbour, 1999, Borkman and Munn-Giddings, 2001). Despite the potential for social problems among members, the overall perceptions and experiences among participants were positive.

The significance of self-help groups as learning environments for exchanging information and giving and receiving psychological support needed for recovery is well documented (Chinman et al., 2002, Pistrang et al., 2012). Although the health professionals at KHCC

present a large volume of information about breast cancer support groups, women typically relied on their own information-seeking efforts and informal networks with other women in the group. The long-term treatments and therapies used for many women with breast cancer lead to serious effects, including fatigue, pain, nausea, vomiting and hormonal changes that in turn affect their overall quality of life (Vargens and Berterö, 2007, Erci and Karabulut, 2007). What is clear from this study is that when patients do not get sufficient information about cancer-related treatment, there is a potential risk that they might rely on non-medical sources to satisfy their learning needs. Although traditional folk remedies and holistic therapy methods sometimes assist in care and usually do no active harm, this study found that some patients abstained from medical treatment due to perceiving a dichotomy between traditional/non-medical methods and official treatment regimens. In the light of this, it is not surprising that experiential learning in Sanad might lead to poor recovery as a result of following harmful homemade recipes. In the absence of health care professionals in Sanad, learning might affect negatively women's recovery. This evidence raises the question of how much involvement is needed from health care professionals to ensure that information exchange is beneficial for Sanad members while preventing a formal (and off-putting) lecture situation from arising.

It is reasonable to argue that information about the disease's signs and symptoms and treatment interventions is required throughout the journey of being diagnosed with breast cancer (Fujimori and Uchitomi, 2009). Access to appropriate health education would endow Sanad members with the information, skills and mechanisms to help alleviate symptoms and cope with the consequences of cancer treatments. Scholars argue that mutual relationships between health care professionals and women with breast cancer would empower parties, allowing meaningful sharing of responsibility (Jacobson and Greenley, 2001, Banning et al., 2010, Alkhasawneh et al., 2009). Given the above findings, it is reasonable to argue that rather than having participants report either the presence or absence of social support information it is vital to understand how negative exchanges between patients and their social networks affect recovery.

A further issue that affects the dynamics and cohesion of Sanad is the situation in which members lose one of their counterparts due to breast cancer. Some Sanad members skipped some meetings, felt depressed and were more concerned about death. This tipping point in the Sanad culture needs to be given attention if the group is to run effectively. A according to a meta-analysis of 30 qualitative research papers conducted between 1990 and 2003 found that the acknowledgment of women's own mortality made them live in fear and expecting death, thus negatively affecting their recovery (Berterö and Wilmoth, 2007). However, women in this study were not paralyzed permanently by fears of death and a "who is next?" ideation; instead, they regrouped and shared existential questions to expand their psychological resilience (Landmark et al., 2002). The main argument to emerge here is what ties a Sanad-type group together is the joint happiness and sadness of its members and their general unconditional acceptance of one another, which in turn offers members a feeling of empowerment and control. Therefore, it is important to study how participants of a self-help group behave/adjust in the light of losing a member and the conditions that enhance the group recovery in more depth. Taking the findings together, it is clear that, whilst valued, the significance of the biomedical explanation model of health and illness needs of those suffering from breast cancer needs to be reconsidered, and concrete efforts are required to explore the nature of self-help group participation, process and culture. To this end, a conceptual model was developed from the current thesis that illuminates the nature of recovery for those who attended Sanad that reflects the complexity involved.

7.5 Recovery Conceptual Model

The international literature reviewed in earlier chapter urges health care professionals to understand better the experiences of recovery of women with breast cancer following attending a self-help group. Whilst more attention has consequently been paid to this field of research, empirical efforts to create a conceptual model integrating influences on decisions about taking part in such groups and various aspects of recovery are limited.

Existing models on recovery and support groups accord significance to faith and spirituality, empowerment, the idea of becoming a better person through the journey of

recovery (Coreil et al., 2012b), hope, healing and connection (Coreil et al., 2004, Jacobson and Greenley, 2001). Although some of these valuable concepts have been confirmed by the current research and further debated from a cultural perspective, the previous models are largely driven by illness-medical approach, developed in Western countries, focused on mentally ill patients and support groups mainly led by health care professionals. The picture about the links/paths between decisions and motives behind taking part in a self-help group and its effects on recovery is unclear. Likewise, the applicability of the available models to the Jordanian context where the health care system/religion are different might be questioned.

In this thesis, the proposed conceptual model is driven by the word recovery that involves attitudes, experiences, alternatives, decisions of change of women who are recovering and the conditions may facilitate/inhibit recovery. Therefore, recovery involves acknowledgement not only that personal change but also awareness that one may be at various stages in the change process (Cook et al., 2004). The model involved three spheres comprising family, Sanad and recovery (Figure 2). In line with related literature (Jacobson and Greenley, 2001), not only the proposed multi-sphere model focuses on the experience of recovery and those who attended Sanad, but importantly the decisions, alternatives used by non-attendees, and processes involved. This model has been designed as a process model that can help nurses and other health care professionals in understanding the phases and factors that women with breast cancer might confront when they consider joining Sanad.

Overall, the present recovery model both adds support and is confirmed by the existing recovery literature, although the current thesis shows that there are some distinctive aspects of perceived recovery that are important but underrepresented in the literature. The only concepts of the present model that were not contained in most of the recovery literature were realistic hope and economic recovery. By understanding how the components of the model affect each other, health professionals can draw on what individual and social factors influence women's recovery. Collaborative relationships between health care professionals and women with breast cancer will empower both parties, allowing a more mutual assumption of responsibility.

The model consequently is multi-dimensional spherical and addresses diverse issues. Recovery is expressed in this model as a social process. Related to the social aspect, the model might enable cross-cultural comparisons to be made about women's recovery following taking part in a self-help group. Future and continued empirical work is needed to test the model and explore how addressing different factors might foster the recovery of women with breast cancer.

7.6 Study Limitations

This research represents one of few studies (and the only one in Jordan) exploring women's experience of breast cancer and the impact of self-help groups on their recovery. The current study provides unique insights on women's perspectives of their experiences of breast cancer and Sanad in Jordan. This empirical work expands on previous research that has predominantly explored the experiences of women with breast cancer in other countries (Heidari Gorji et al., 2012, Denieffe and Gooney, 2011, Doumit et al., 2010a). However, there are some limitations to be taken into account when the current findings are interpreted and implications are put forward.

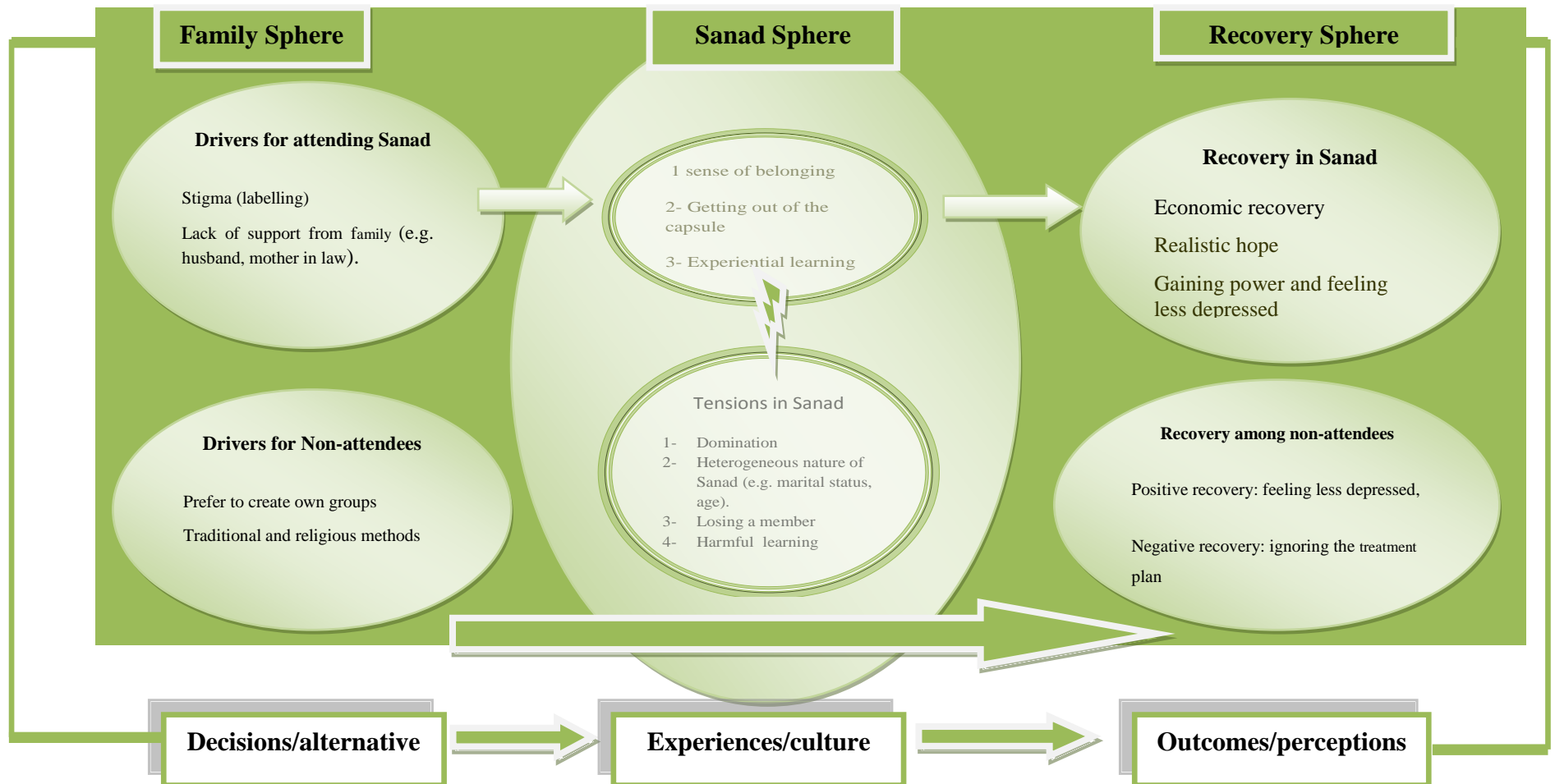


Figure 2: Conceptual model of recovery among Sanad and non Sanad members in Jordan

In particular, qualitative research was a subject of criticisms in the literature on the grounds of ignoring issues of sample size, reliability, and for being anecdotal (Benton, 2000). The reliability of this study was enhanced by respondents' checking of the findings and the involvement of an independent researcher during the analysis process (Chapter three) in other words, measures were taken in this thesis to maintain rigor in the research processes and to ensure that the identified themes were genuinely reflective of the views of participants (Coyne et al., 2012).

Participants were purposively selected in order to meet certain inclusion criteria, and the sample itself might not be representative of all patients with breast cancer in Jordan. The study design and method of data collection may have skewed the sample toward women who find it easier to talk about breast cancer, or those who felt well enough to participate and verbalize their concerns. In particular, it was not convenient for those women who live outside Amman to take part in the research. The members of Sanad included both past and present members. This may have affected the data, as past members may have different responses from current members on their perceptions of Sanad and of their illness.

Additionally, the sample in the study comprised only Muslim women, therefore in order to arrive at more generalized conclusions, studies should be done with other participants of other religions (particularly Christians in the Jordanian context). This is an important issue because the current findings highlighted the role of religion and spirituality in shaping women's decisions about joining Sanad and overall recovery. Moreover, the health care system in Jordan is complex and diverse, including private hospitals, public hospitals, and military hospitals. Whilst the self-help group at KHCC is the only one in Jordan, many women with breast cancer are admitted to surgical wards in different sectors, thus vigilance must be exercised against extrapolating the study's findings to other hospitals.

The generalizability of the findings in this thesis should be interpreted with caution. It is argued that the small sample size of participants in qualitative research is less significant than the depth and richness of the data obtained (Bradshaw and Stratford, 2010). This is because that such research does not aim at representing the experiences of all women with breast cancer (Winchester, 2000) or generating findings that are generalizable (Curtis et al., 2000), but rather offering in detail understanding of how

women's experiences and self-help groups affect their recovery (English et al., 2008). Indeed, the transferability of the current qualitative findings needs to be taken into account (Guba and Lincoln, 1985). As shown in this research, a woman's personal experience cannot become identical to another woman's experience due to the multi-dimensional nature of breast cancer illness and contributing factors involved. Nevertheless, it is postulated that what can be transferred from one individual to another is not the experience "*as experienced, but its meaning*"; in other words, the experience remains personal, but its connotations and importance becomes public (Ricoeur, 1976).

Despite the limitations outlined above, the findings of this study comprise a contribution to the on-going attempt to fill the gap in the literature of breast cancer and self-help groups. Indeed, the current findings might be considered as a benchmark against which multiple case study design can be developed in the future, thus sharpening the generalizability of this research. Building on the themes and issues identified in this thesis, future studies using a standardized measurement method would maximize the reliability of the data collected. A longitudinal study approach could also offer information about the types of support and services which would be most useful and acceptable to Sanad members at different stages of the illness, and enable long-term comparison of outcomes for women who attend a self-help group and those who do not.

7.7 Conclusion

This study provides an important contribution to the impact of self-help groups on women's recovery research and the experiences of Jordanian women with breast cancer. The findings reveal that there are many complex issues involved in consideration of the impact of Sanad on women's recovery. The study differs from much previous research on this area in that it offers findings from an under-represented population (Jordanian Muslim women) and it compares and contrasts the perceptions of recovery from the perspectives of self-help group members and non-attendees.

The study highlighted the fact that women with breast cancer go through a complex decision-making process involving personal, family and social issues. Whilst the

study outlined some difficulties in running Sanad effectively, health care professionals may play a vital role in raising awareness of the potential benefits of self-help groups, both for women in the early stages of cancer-making treatment decisions and their family (or those referred to in this thesis as "significant others"). Evidence would imply that members of Sanad observed more benefits than non-members, which might suggest that non-members may not fully understand or value the benefits of Sanad or perceive the group as a threat to their private lives. Additionally, findings are suggestive of the vitality of Sanad and its heterogonous nature in terms of marital status, age groups and its impact on the group dynamic interactions, and how these factors relate to creating a relaxing atmosphere needed for women to verbalize/exchange experiences and concerns. Whilst tensions that might take place in Sanad are recognized, the main argument to emerge from this thesis is what ties such a group jointly is the shared happiness/sadness of its members and the prevailing ethos of mutual unconditional acceptance, which in turn bridges the gap of isolation and offers members a feeling of being in control, improving self-efficacy and reducing depression. An interesting avenue for future research identified in this study is the way in which members of a self-help group behave/adjust and cope in the light of losing a member and the conditions that promote group recovery.

The proposed conceptual model in this thesis might be considered as a benchmark against which future strategies aiming at maximizing women's recovery can be designed for both Sanad members and non-attendees. Finally, it is important to individually and sporadically examine women's values/beliefs and needs, because the group is not homogeneous; commonality of diagnosis is an insufficient basis upon which to build socio-cultural assumptions. Although Sanad is a group of women with the same illness, each of them has unique experiences that need to be understood by other group members as well as health care professionals.

APPENDICES

Appendix A: Ethical approval

From the University of Nottingham

Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk

17th December 2010

Ms Deema Mahasneh
PhD Student
Sue Ryder Care Centre for Palliative and end of
Life Studies
School of Nursing Midwifery & Physiotherapy
B Floor (South Block Link)
QMC Campus
Nottingham University Hospitals
Nottingham
NG7 2UH



Medical School Research Ethics
Committee
Division of Therapeutics &
Molecular Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham
NG7 2UH

Tel: +44 (0) 115 8231063
Fax: +44 (0) 115 8231059

Dear Ms Mahasneh

Ethics Reference No: 10 KHCC 74 - Please quote this number on all correspondence

Title of Project: The Role of Self-help groups in Jordan following treatment for breast cancer

Lead Investigator: Dr Bassam Kamal, Principal Deputy Director, Psychosocial Oncology Program, Director, Social Work Services, King Hussein Cancer Centre, Amman, Jordan

Co Investigators: Professor Karen Cox, Professor of Cancer & Palliative Care, Ms Deema Mahasneh, PhD Student, Sue Ryder Care Centre for Palliative and end of Life Studies, Professor Mark Avis, Head of School of Nursing Midwifery and Physiotherapy.

Thank you for your application which has already been reviewed and approved by the King Hussain Cancer Centre, Amman, Jordan on 12th December 2010 which is where the study will take place and enclosing:

- KHCC Institutional Review Board Application form B version 1.2 dated February 2010
- Letter of approval from KHCC Institutional Review Board dated 12 December 2010

These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethic's Committee approval.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be

performed on the study which may arise in the process of publication and peer review.


You promptly inform the Chairman of the Ethic's Committee of

- (i) Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.
- (ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.
- (iii) All adverse drug reactions that are both serious and unexpected.
- (iv) New information that may affect adversely the safety of the subjects or the conduct of the study.
- (v) The attached End of Project Progress Report is completed and returned when the study has finished.

Yours sincerely

A handwritten signature in purple ink, appearing to read 'R C Spiller', is written above the printed name.

Professor R C Spiller
Chairman, Nottingham University Medical School Research Ethics
Committee

	King Hussein Cancer Center	مركز الحسين للسرطان
	Institutional Review Board	مجلس تقييم الأبحاث

Date: 12/December/2010

Dear Dr. Bassam Kamal and Ms. Deema Mahasneh,

In reference to the proposal entitled: The role of self-help groups in Jordan following treatment for breast cancer (Proposal #: 10 KHCC 74).

You are kindly informed that the IRB has reviewed and approved your submitted documents which include the following:

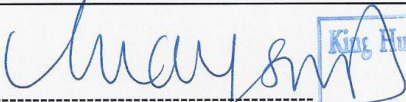
1. IRB Submission FORM B
2. English Research Proposal
3. Arabic Consent Form
4. Arabic Research Poster
5. Arabic Breast Cancer Women Interview Schedule
6. Arabic Healthcare Professionals Interview Schedule
7. The University of Nottingham Confirmation Letter for Completing "B74QRM Qualitative Research Issues and Methods" and "B74EHS Evidence for Health and Social Care" Modules
8. Syllabus for "Qualitative Research Issues and Methods"
9. Syllabus for "Evidence for Health and Social Care"

Kindly Note, that this proposal was approved by convened IRB review.


Kindly note that if the study will extend beyond one year you have to submit a renewal form and an interim update on the study. At the end of the study, you are requested to submit end of study report to IRB.

Please inform the IRB office of any publications/ abstracts that may result from this research.

On behalf of all members of KHCC IRB, I would like to wish you a very successful study.



Dr. Maysa Al-Hussaini
Chairman, Institutional Review Board.
King Hussein Cancer Center



Date: 12/December/2010

The IRB consists of members of medical and non medical background including public, lawyers, nurses and pharmacists. It is the policy of the IRB to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the IRB considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the IRB may request the principal investigator to provide an outcomes report, including information on follow up of participants.
KHCC-IRB is compliant with GCP Guidelines.

Appendix B: Interview guides

Interview schedule for breast cancer self-help group attendees

Before I start the interview, I would like to thank you for being willing to take part in this study. All of the information you give will be kept confidential and remain anonymous, and will be used only for the academic purpose. During the interview, please, don't hesitate to pause for a break. You can also withdraw from the study at any stage if you want to.

- a. This statement will be given before each interview.
- b. Permission to digital record will be obtained from the subject
- c. Please will you fill out this form for me before we start? (5 minutes)

General information about you

To get started I wonder if you could tell me about yourself and family? Please would you tell me:

- a) How old are you?
- b) Are you single, married (for how long), divorced, remarried?
- c) Do you have any children?
- d) Do you have any dependents?
- e) Are you in paid employment?
 - What job?
 - How many hours?

Your experience of breast cancer and its treatment

Please tell me how long you have been diagnosed with breast cancer?

How was your reaction and thoughts after being diagnosed with breast cancer?

What have you experienced in relationships to family, friends, and healthcare professionals during the period from being diagnosed and up till today?

How does treatment affect your life? What impact did it have on yourself and family?

What are the psychosocial consequences of disease and its treatment?

How do your religion and cultural beliefs affect your experience as a woman with breast cancer?

The group site and interactions

What make you join the self-help group in KHCC?

What does that term self-help group mean to you?

Did you participate in Sanad regularly? How often did attend per month?

How do your religion and cultural beliefs affect your decision to join the Sanad group?

What are your expectations from the Sanad group? <Prompts>

- Their hopes and worries
- difficulties

Did each one of you have the chance to speak about things being important there and then?

Did you feel comfortable to talk part in Sanad?

Tell me about the relationship between members of the group.

How do you decide what gets talked about/programs in the group?

Are there things you cannot talk about, or feel uncomfortable talking about?

What does the group do when someone is having a really rough time?

What does the group do when someone asks for information or advice?

What happens when members disagree?

How did you experience getting support from the other members?

Learning

Do you feel that you learned anything in the group? What (example)?

Please tell us about positive or negative experiences from group participation?

What do you think members learn to cope emotionally in the group?

How you understand recovery?

Did you reach such a state?

How do you think that taking part in Sanad affect your recovery?

Is there any role model who influenced your behaviour in the Sanad group?

What have you learned about yourself? (Probe: one thing you have learned).

What have you learned about others in the group?

What have you learned about relationships with others in your life?

Change in Self and Others

What are some changes that you have experienced since being in the group, about yourself and others in your social networks? (Probe: family members' relationships (husband and wife), friends, co-workers, others you talk to/see in the course of a day?)

Has what you learned in the group has increased your awareness of your abilities and strengths?

Would you recommend others to participate in self-help groups?

Is there anything else you would like to tell me, or think that I should know?

Interview schedule for women not attending breast cancer self-help groups

Before I start the interview, I would like to thank you for being willing to take part in this study. All of the information you give will be kept confidential and remain anonymous, and will be used only for the academic purpose. During the interview, please, don't hesitate to pause for a break. You can also withdraw from the study at any stage if you want to.

- d. This statement will be given before each interview.
- e. Permission to tape record will be obtained from the subject
- f. Please will you fill out this form for me before we start? (5 minutes)

General information about you

To get started I wonder if you could tell me about yourself and family? Please would you tell me:

- f) How old are you,
- g) Are you single, married (for how long), divorced, remarried,
- h) Any child you have,
- i) Any dependents – you look after
- j) Are you in paid employment?
 - What job
 - How many hours

Your experience of breast cancer and its treatment

Please tell me how long you have been diagnosed with breast cancer?

How was your reaction and thoughts after being diagnosed with breast cancer?

What have you experienced in relationships to family, friends, and healthcare professionals during the period from being diagnosed and up till today?

How does treatment affect your life? What impact did it have on yourself and family?

What are the psychosocial consequences of disease and its treatment?

How do your religion and cultural beliefs affect your experience as a woman with breast cancer?

Why did you not attend Sanad group in KHCC?

What did you do to cope with the challenges of breast cancer and its treatment?

What sustained you during your disease experience?

Did you need any kind of psychological support and where did you get it from? (E.g. husband, family, friends, co-workers or social networks)

What do you think of the support you get? Prompts:

- Is it the type of support you need, and can you access that support when and where you need it?
- How might it be improved?

Would you recommend others to participate in any social networks rather than Sanad group?

Did you feel that the other kind of support that affect you positively or negatively? Please can you tell me how?

How you understand recovery?

Did you reach such a state?

What factors affect your recovery? How? Any experiences?

Is there anything else you would like to tell me, or think that I should know?

Interview schedule for healthcare professionals

Before I start the interview, I would like to thank you for being willing to take part in this study. All of the information you give will be kept confidential and remain anonymous, and will be used only for the academic purpose. During the interview, please, don't hesitate to pause for a break. You can also withdraw from the study at any stage if you want to.

- g. This statement will be given before each interview.
- h. Permission to tape record will be obtained from the subject
- i. Please will you fill out this form for me before we start? (5 minutes)

General information about you

Would you mind telling me how old you are?

How long have you been qualified as a (nurse and a social worker)?

What is your role in Sanad group in KHCC?

Your experience of Breast Cancer Sanad group

In your experience, what are the key questions/problems for patients with breast cancer, when they are first diagnosed?

When interacting with women, who are experiencing breast cancer and its treatment, what kinds of information do you provide?

Do you ask any specific information regarding their family situation, what they see as their most specific concern at this time- such as who is available to help them?

Do you discuss the psychosocial impact of their illness and its treatment both for them and their families? (Prompt)

- Do you do currently utilize any type of assessment form to collect this type of information?

Do you feel that knowing the level of social support available to women; can help you to refer patients to Sanad group in KHCC?

Do you feel that providing this Sanad group decreases the burden of breast cancer?

Do you feel that Sanad group is a social learning process? (Probe)

- How do women' religion and cultural beliefs affect their experience as a woman with breast cancer?

What are the factors that might affect women's decisions about taking part in Sanad or not?

How do you think taking part in Sanad affects women's recovery?

What difficulties women with breast cancer might encounter while in the Sanad meeting?

Why some women with breast cancer refuse the idea of Sanad group?

Do you feel that it is important to increase healthcare professional's awareness regarding Sanad group?

If you feel that it is important to increase professionals' awareness of psychosocial support needs of women? What do you feel be the best method(s) of achieving this?

What are the advantages or disadvantages of Sanad group?

Would you recommend breast cancer women to participate in self-help groups?

Is there anything else you would like to tell me, or think that I should know?

Appendix C: Invitation letters and information sheets

Patient Invitation Letter

Dear Madam,

I am writing to invite you to take part in a research study. My name is Deema Mahasneh; I am a Jordanian staff nurse currently studying for a PhD in the School of Nursing, Midwifery and Physiotherapy at the University of Nottingham in the United Kingdom.

I am studying ***‘the role of self-help group following treatment for breast cancer in King Hussein Cancer Centre (KHCC)’***. The aim of my study is to understand the Jordanian women’s breast cancer experiences that are involved in self-help groups or have chosen not to take part in self-help groups.

People who take part in the study will be interviewed. If you are happy to participate, please complete your contact details and post it to me using the stamped-addressed envelope enclosed.

Yours sincerely,

Researcher: Miss Deema Mahasneh

PhD student, University of Nottingham

Telephone Number: 00962788614787

Email: ntxdm10@nottingham.ac.uk



Patient Information Sheet

Study title: *“The role of self-help group in Jordan following treatment for breast cancer”*

Name of Investigator: *Miss Deema Mahasneh*

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Take time to consider whether or not you wish to take part. Please contact me to ask about anything that is not clear or if you would like more information.

What is the purpose of the study?

This study aims to gather information from women about their support needs following treatment for breast cancer with focus on the role of self-help group.

Why have I been chosen?

You are being invited to take part in this research because you have received or currently treated. I hope to recruit women who are either involved in self-help group or have chosen not to take part in self-help group.

Do I have to take part?

No. It is entirely up to you whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to change your mind and withdraw at any time, without giving a reason. A decision to withdraw at any time, or decision not to take part, will not affect the standard of care you receive.

What will happen if I take part?

If you are interested in taking part in the study, I will invite you to an interview. The interview will last around one to two hours. The interviews will take place at the King Hussein Cancer Centre (KHCC) at a suitable date and time agreed by both of us. I will be more than happy to answer any further questions about the study. With your permission, I will need to tape record the interview and keep notes during our conversation. This record will be listened to only by me (Deema Mahasneh) and none of your personal details will be included. The recording and diary notes will be transcribed. The tapes and the transcripts will be made anonymous and stored securely.

What are the possible disadvantages and risks of taking part?

There is very little risk involved in taking part in this study however I will be asking questions about your experiences of breast cancer which may find upsetting. If this happens and you want to stop the interview at any time, you can do so. If you decide to withdraw from the study after you have been interviewed, it will be possible to ensure back all the information collected will be destroyed.

In addition, I am a registered nurse, so when you feel that you need any medical or nursing care, doctors or nurses from the clinic will be called to assess you immediately.

What are the possible benefits of taking part?

It is not anticipated that you will experience any direct benefit as a result of taking part in this study. However, some people find it is helpful to talk about their experiences. By taking part in the research you will have the opportunity to increase my own and others' knowledge of the experience of attending or not attending a self-help group and its role in facilitating recovery after treatment.

What will happen to the results of the study?

The findings of the study will be summarized and then written up in the form of important issues. It is hoped that taking part in the research will be a rewarding experience for you. The findings will be translated by me (Deema Mahasneh) and written up in the final thesis. It will also be used to write academic articles for publication in journals, to help healthcare professionals understand developing support care strategies from your perspectives.

What if something goes wrong?

It is extremely unlikely that anything will go wrong as a result of taking part in this study. However, if you feel unhappy about continuing the interview the researcher will stop the interview immediately. If during the course of the interview, you say anything about your health that causes concern, with your permission I will let your doctors or nurses know.

Will my taking part in this study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept confidential. To protect the participant's anonymity, no names or personal details will be shown. Each participant will be given an identification code and a pseudonym. To assure confidentiality, I will keep all the records and the transcribed data on my personal computer, which is password-protected. In addition, all of the research diaries and notes, and the translated papers, were kept in a locked cupboard, to be destroyed at the end of the study.

Who has reviewed the study?

This study has been reviewed and approved by the research committee at the King Hussein Cancer Centre in Jordan. It has also been reviewed by the University of Nottingham Medical School Ethics Committee.

Who to complain to?

Louise Sabir

Secretarial Support for the Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor, South Block
QMC Campus
Nottingham University Hospitals
Nottingham
NG7 2UH
Tel: +44 (0) 115 82 31063

What if I have further questions?

Please, feel free to contact me if you require further information before or after the interview my details are below.

Miss Deema Mahasneh (the researcher)

PhD student, University of Nottingham
Mobile: 00962788164787
Email: ntxdm10@nottingham.ac.uk

Thank you for considering taking part in this study.

Yours sincerely

Deema Mahasneh

University of Nottingham

School of Health Sciences

Healthcare Professionals Invitation Letter



**The University of
Nottingham**

Dear.....,

I am writing to invite you to participate in a research study. My name is Deema Mahasneh; I am a Jordanian staff nurse currently studying for a PhD in the School of Nursing, Midwifery and Physiotherapy at the University of Nottingham in the United Kingdom.

I am studying ***‘the role of self-help group following treatment for breast cancer in King Hussein Cancer Center (KHCC)’***. The aim of my study is to understand the Jordanian women’s breast cancer experiences that are involved in self-help groups or have chosen not to take part in self-help groups.

I would like to know more about your views on self-help groups for this group of patients. People who take part in the study will be interviewed. If you are interested in taking part in the study, please complete your contact details and post it to me using the stamped-addressed.

Yours sincerely,

Researcher: Miss Deema Mahasneh

PhD student, University of Nottingham

Telephone Number: 00962788614787

Email: ntxdm10@nottingham.ac.uk

Healthcare Professionals Information Sheet

Study title: *“The role of self-help group in Jordan following treatment for breast cancer”*

Name of Investigator: *Miss Deema Mahasneh*

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Take time to consider whether or not you wish to take part. Please contact me to ask about anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to understand the women’s experiences of treatment for breast cancer in Jordan, with a particular focus in whether participating self-help groups make a difference. The information generated by this study will be used to help healthcare professionals understand the impact of self-help groups on women’s recovery after treatment for breast cancer.

Why have I been chosen?

You have been chosen as you are a healthcare professional working with women with breast cancer. Your thoughts and experiences will be helpful in informing the development of supportive care strategies to this client group.

Do I have to take part?

No. It is entirely up to you whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to change your mind and withdraw at any time, without giving a reason.

What will happen if I take part?

If you are interested in taking part in the study, I will invite you to an interview. The interview will last around one to two hours. The interviews will take place at the King Hussein Cancer Centre (KHCC) at a suitable date and time agreed by both of us. I will be more than happy to answer any further questions about the study. Then I will explain the project in more detail and answer any questions you may have. With your permission, I will need to tape record the interview and keep notes during our conversation. This recording will be listened to only by me (Deema Mahasneh) and none of your personal details will be included. The recording and diary notes will be transcribed. The tapes and the transcripts will be made anonymous and stored securely.

What are the possible disadvantages and risks of taking part?

Any disadvantage or risk related to this study is unlikely. However it is possible that you may become uncomfortable during the interview. If this happens and you want to stop the interview at any time, you can do so. If you decide to withdraw from the study after you have been interviewed, it will be possible to ensure back all the information collected will be destroyed.

What are the possible benefits of taking part?

It is not anticipated that you will experience any direct benefit as a result of taking part in this study. However, some people find it is helpful to talk about their experiences.

What will happen to the results of the study?

The findings of the study will be summarized and then written up in the form of important issues. It is hoped that taking part in the research will be a rewarding experience for you. The findings will be translated by me (Deema Mahasneh) and written up in the final thesis. It will also be used to write academic articles for publication in journals, to help healthcare professionals understand developing support care strategies from patients' perspectives.

What if something goes wrong?

It is extremely unlikely that anything will go wrong as a result of taking part in this study. However, if you feel unhappy about continuing the interview the researcher will stop the interview immediately.

Will my taking part in this study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept confidential. To protect the participant's anonymity, no names or personal details will be shown. Each participant will be given an identification code and a pseudonym. To assure confidentiality, I will keep all the records and the transcribed data on my personal computer, which is password-protected. In addition, all of the research diaries and notes, and the translated papers, were kept in a locked cupboard, to be destroyed at the end of the study.

Who has reviewed the study?

This study has been reviewed and approved by the research committee at the King Hussein Cancer Centre in Jordan. It has also been reviewed by the University of Nottingham Medical Ethics Committee.

Who to complain to?

Louise Sabir

Secretarial Support for the Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor, South Block

QMC Campus
Nottingham University Hospitals
Nottingham
NG7 2UH
Tel: +44 (0) 115 82 31063

What if I have further questions?

Please, feel free to contact me if you require further information before or after the interview my details are below.

Miss Deema Mahasneh, The researcher.

PhD student, University of Nottingham
Mobile: 00962788164787
Email: ntxdm10@nottingham.ac.uk

Thank you for considering taking part in this study.

Yours sincerely

Deema Mahasneh

University of Nottingham

School of Health Sciences



The University of
Nottingham

Study Title: The role of self-help groups in Jordan following treatment for breast cancer.

Investigator: Deema Mahasneh, BSc, MSc, PhD Nursing Studies

Supervisors:

Prof. Karen Cox

Prof. Mark Avis

Professor of Cancer & Palliative Care
University of Nottingham

Professor in Social Context of Health
University of Nottingham

Participant's Consent Form

Please read this form and sign it once the investigator has explained fully the aims and procedures of the study to you (Please tick box as necessary).

- I voluntarily agree to take part in this study. ☐
- I confirm that I have been given a full explanation by Deema Mahasneh and/or that I have read and understand the information sheet given to me which is attached. ☐
- I have been given the opportunity to ask questions and discuss the study with Deema Mahasneh. ☐
- I agree to Deema Mahasneh contacting me on the address I gave to her ☐
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Anonymised data will be kept for 7 years after the results of this study have been published. ☐
- I understand that I can ask for further instructions or explanations at any time. ☐
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing. ☐

Name of participant: _____

Participant's signature: _____ Date: _____

I confirm that I have fully explained the purpose of the study and what is involved to:

I have given the above named a copy of this form together with the information sheet.

Name of investigator: _____

Investigators' signature: _____ Date: _____

Study volunteer number: _____

Participant Reply Slip

I confirm that have read the information about the above research study.

I am interested in taking part in this research study.

I am happy for Deema Mahasneh to contact me to arrange the interview at a time and place convenient to me.

Name: _____

Contact Address: _____

Telephone number: _____

Email (If present): _____

Signature: _____

Thank you for your help. Please don't hesitate to contact me if you have any questions.

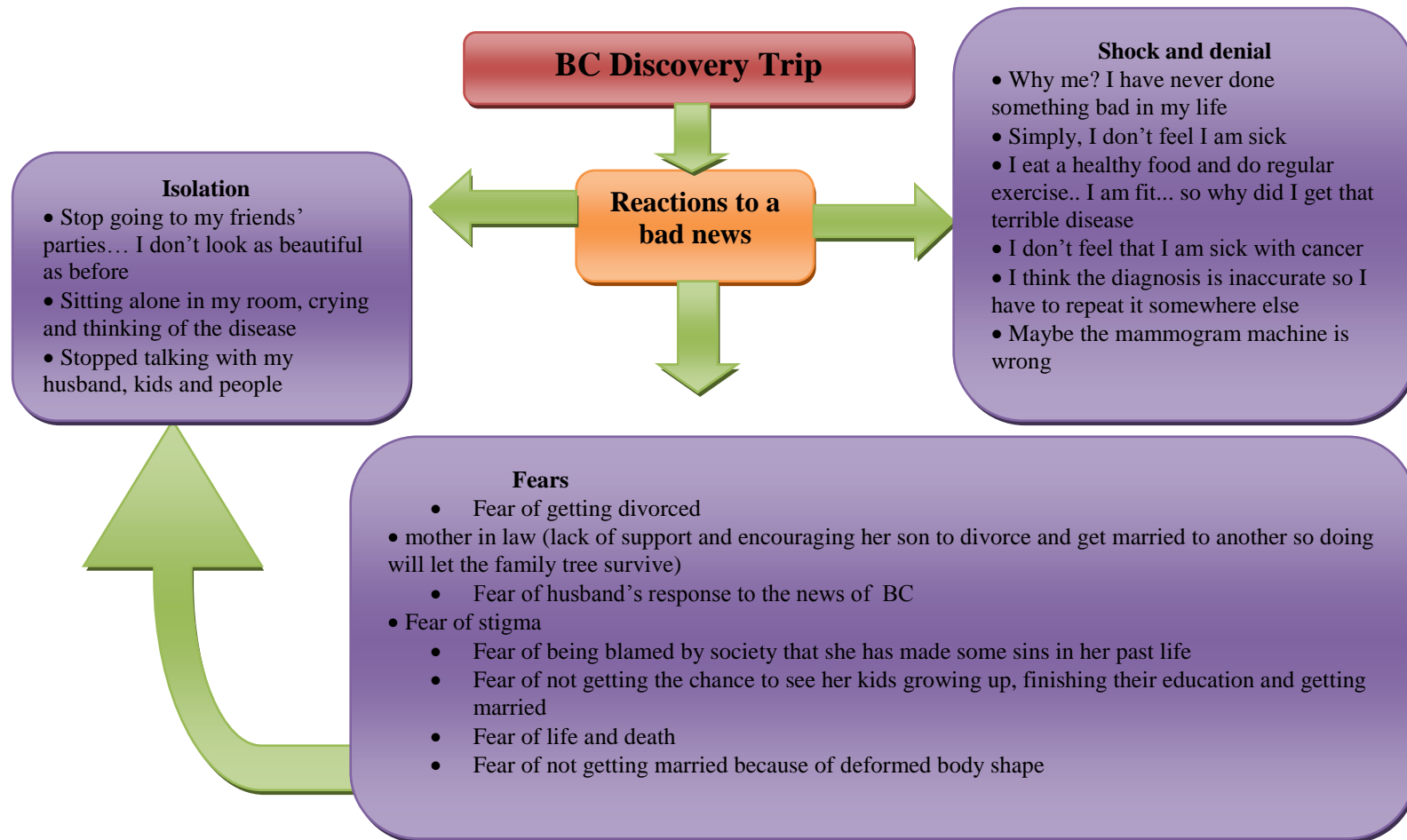
Deema Mahasneh, The researcher.

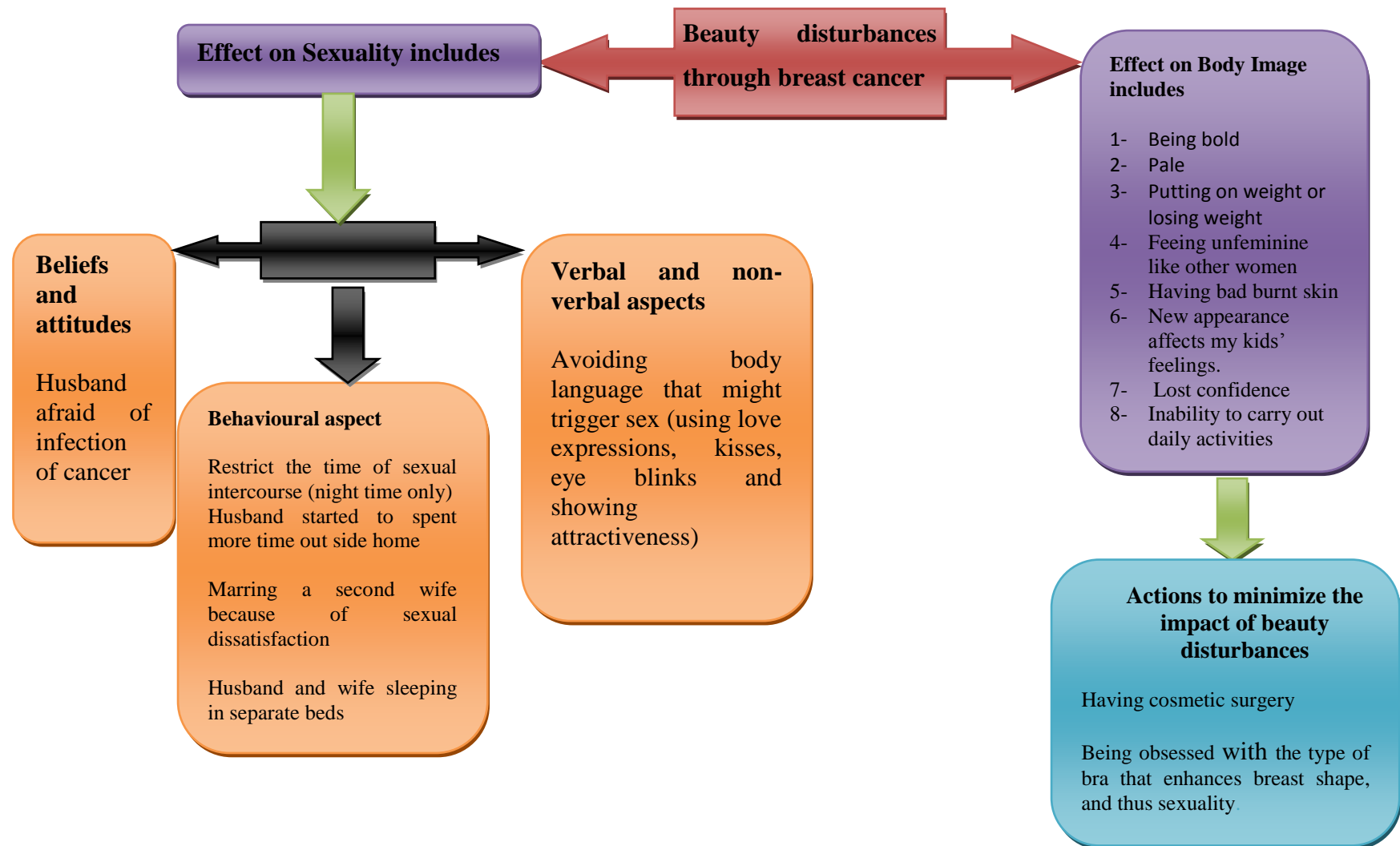
Address: Faculty of Nursing, Mutah University, Karak, Jordan, B.O 61710

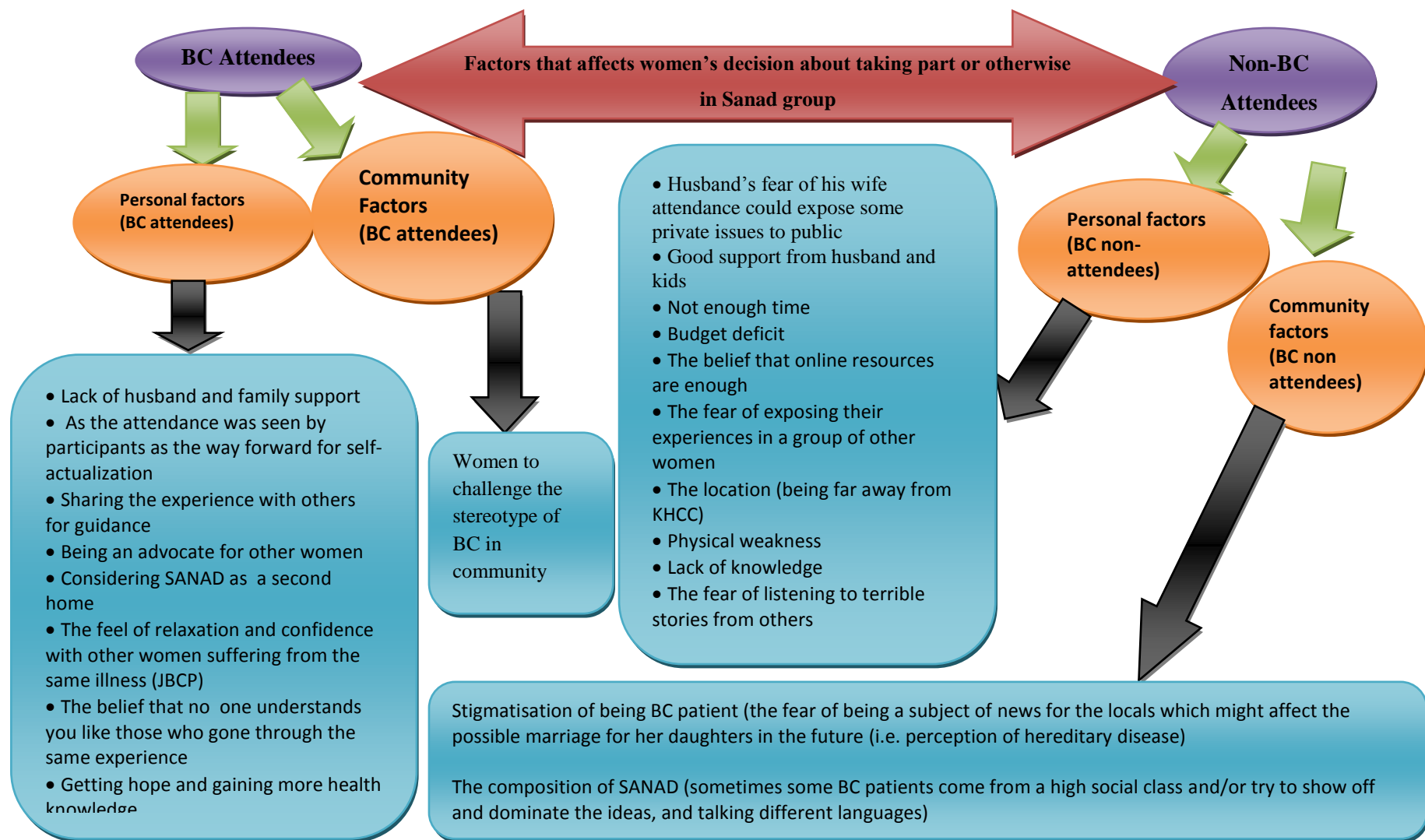
Mobile: 00962788164787

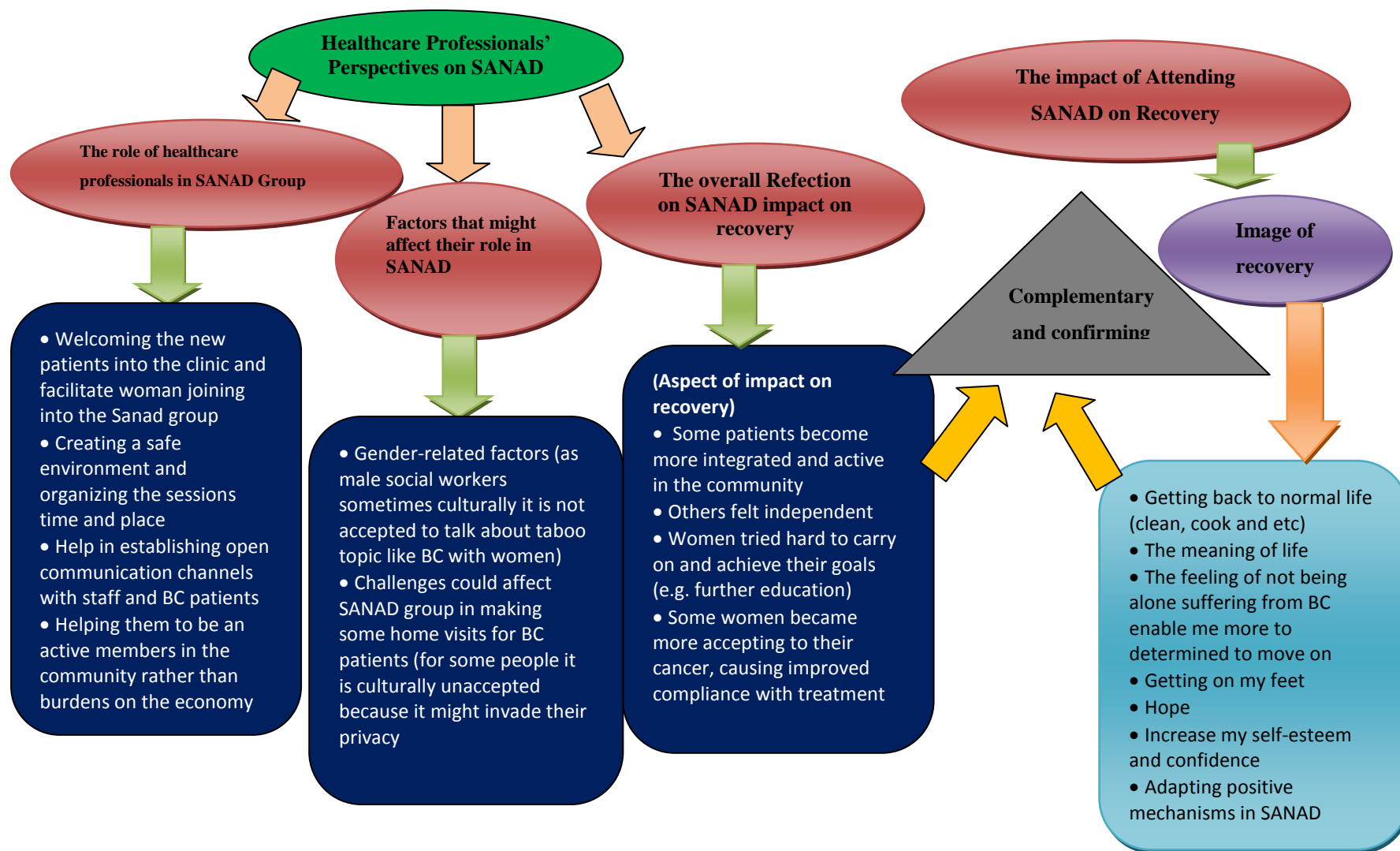
Email: ntxdm10@nottingham.ac.uk

Appendix D: Examples of the preliminary data analysis diagram









Appendix E: Sanad group leaflet

In addition to the weekly group meeting, social workers and nurses, who work in the psychosocial unit, hold a monthly meeting with the Sanad group. This is a formal meeting so that social workers and nurses can listen to women's feedback, regarding Sanad meetings, identify their goals, concerns and problems, so as to evaluate and enhance the Sanad group meetings.

The psychosocial unit in KHCC is trying to expand Sanad's reach, and contribute to a social movement of women with breast cancer throughout Jordan. Thus, by prior arrangement with nurses and social workers, some Sanad women volunteers make daily clinical visits to the chemotherapy clinics, and the waiting rooms to let other women know about Sanad and its role, and to encourage them to talk about, and share their breast cancer experiences (see the Sanad leaflet).

مركز الحسين للسرطان
KING HUSSEIN CANCER CENTER



مجموعة سند هي أول مجموعة دعم ومساندة لمرضى
السرطان في مركز الحسين للسرطان .

مؤسسة الحسين للسرطان
KING HUSSEIN CANCER FOUNDATION



أم أذينة، شارع سعد بن أبي وقاص
ص.ب ٣٥١٠٢، عمان ١١١٨٠ الأردن
هاتف: ٥٥٤٤٩٦٠ (٩٦٢٦)
فاكس: ٥٥٤٤٩٦٢ (٩٦٢٦)
الموقع الإلكتروني: www.khcf.jo

مركز الحسين للسرطان
KING HUSSEIN CANCER CENTER



شارع الملكة رانيا العبدالله
ص.ب ١٢٦٩، عمان ١١٩٤١ الأردن
هاتف: ٥٣٠٠٤٦٠ (٩٦٢٦)
فاكس: ٥٣٤٢٥٦٧ (٩٦٢٦)
الموقع الإلكتروني: www.khcc.jo

• الرقم المجاني: ٨٠٠٢٢٦٦٢

Sanad is the first cancer patient support group at the King Hussein Cancer Center.

It was established in 2003 by a group of women, who survived from breast cancer.

Objective:

The group seeks to provide psychological and social support to cancer patients in general and breast cancer patients in particular, with the aim of helping these patients cope with their condition and accept the medical treatment. This objective will be achieved through sharing past experiences with patients.

What do we do:

- We will be at the chemotherapy clinics to provide support and encouragement.
- We will share experiences at the weekly educational breast-cancer clinic.
- We will supply you with wigs in order to lift your morale and ease the impact of chemotherapy.
- We organize charity events in order to support programs and activities.
- We participate in international conferences in order to acquire new experiences that benefit our patients.
- We participate in community awareness campaigns promoting early detection of breast cancer.
- We will be at your side during recreational and educational programs, where we will seek to know you better and strengthen our relations with you.
- We meet monthly to develop work and make future plans.

We want to say, "You are not alone, because we are with you!"

"Do not hesitate to contact us."

For any information, please contact:

Raja Al-Salhi or Amaal Al-Hajjaj
Social Work Department
King Hussein Cancer Center
Tel.: 530 0460

مجموعة سند هي أول مجموعة دعم ومساندة لمرضى السرطان في مركز الحسين للسرطان .

تأسست عام ٢٠٠٣ من سيدات تعافين من سرطان الثدي .

الهدف من المجموعة:

تهدف المجموعة إلى دعم مرضى السرطان بشكل عام ومرضيات سرطان الثدي بشكل خاص ، دعماً نفسياً وإجتماعياً بهدف مساعدتهم على مواجهة السرطان وتقبل العلاج الطبي وتزويدهم بالخبرات السابقة التي مروا بها.

ماذا نقدم:

- نحن موجودين معكم يومياً في عيادات الكيماوي لتقديم الدعم والتشجيع.
- نشارككم في عيادة الثدي التعليمية الأسبوعية ونزودكم بالخبرات السابقة التي مررنا بها.
- نزودكم بباروكات للشعر لرفع روحكم المعنوية والتخفيف من أثر العلاج الكيماوي.
- نقيم بازارات خيرية لدعم البرامج والنشاطات .
- نشارك في مؤتمرات دولية لنكتسب خبرات جديدة نفيد بها المرضى .
- نشارك في نوعية المجتمع المحلي من خلال برنامج الكشف المبكر عن سرطان الثدي.
- نكون بجانبكم أثناء البرامج الترفيهية والتنشيطية للتعرف بكم ونوطيد العلاقة معكم .
- نجتمع شهرياً لتطوير العمل ووضع الخطط المستقبلية.

نريد أن نقول لك أنت لست وحدك نحن معك

فلا تتردد في الاتصال بنا.

نحن موجودين من خلال:

قسم العمل الاجتماعي
وحدة العمل المجتمعي
رجاء الصالحي / آمال الحاجج
هاتف : ٥٣٠٠٤٦٠

BIBLIOGRAPHY

- American Cancer Society 2007. *Breast Cancer Facts and Figures 2007-2008* [Online]. Available: <http://www.cancer.org/acs/groups/content/@nho/documents/document/bcffffinalpdf.pdf> [Accessed 28th May 2007].
- ABLON, J. 2002. The nature of stigma and medical conditions. *Epilepsy & Behavior*, 3, 2-9.
- ADAMS, C. & GLANVILLE, N. T. 2005. The meaning of food to breast cancer survivors. *Can J Diet Pract Res*, 66, 62-6.
- ADAMSEN, L. & RASMUSSEN, J. M. 2001. Sociological perspectives on self-help groups: reflections on conceptualization and social processes. *Journal of advanced nursing*, 35, 909-917.
- ADAMSEN, L., RASMUSSEN, J. M. & PEDERSEN, L. S. 2001. 'Brothers in arms': how men with cancer experience a sense of comradeship through group intervention which combines physical activity with information relay. *Journal of clinical nursing*, 10, 528-537.
- AGRAWAL, A., AYANTUNDE, A. A., RAMPAUL, R. & ROBERTSON, J. F. 2007. Male breast cancer: a review of clinical management. *Breast Cancer Res Treat*, 103, 11-21.
- AL-RIMAWI, H. S. 2012. Pediatric Oncology Situation Analysis (Jordan). *Journal of pediatric hematology/oncology*, 34, S15-S18.
- ALDRICH, T. & HACKLEY, B. 2010. The impact of obesity on gynecologic cancer screening: an integrative literature review. *J Midwifery Womens Health*, 55, 344-56.
- ALKHASAWNEH, I. M. 2007. Knowledge and practice of breast cancer screening among Jordanian nurses. *Oncol Nurs Forum*, 34, 1211-7.
- ALKHASAWNEH, I. M., AKHU-ZAHEYA, L. M. & SULEIMAN, S. M. 2009. Jordanian nurses' knowledge and practice of breast self-examination. *J Adv Nurs*, 65, 412-6.
- ALLARD, N. 2006. Day surgery and recovery in women with a suspicious breast lesion: evaluation of a psychoeducational nursing intervention. *Can Oncol Nurs J*, 16, 137-53.
- ALLEN, D. 2004. Ethnomethodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings. *Nursing Inquiry*, 11, 14-24.
- ALTHUIS, M. D., DOZIER, J. M., ANDERSON, W. F., DEVESA, S. S. & BRINTON, L. A. 2005. Global trends in breast cancer incidence and mortality 1973-1997. *International journal of epidemiology*, 34, 405-412.
- AMASHA, H. A.-R. 2013. Breast self-examination and risk factors of breast cancer: Awareness of Jordanian nurses. *Health Science Journal*, 7.
- ANDRESEN, R., OADES, L. & CAPUTI, P. 2003. The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37, 586-594.
- ARORA, N. K., FINNEY RUTTEN, L. J., GUSTAFSON, D. H., MOSER, R. & HAWKINS, R. P. 2007. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psycho-Oncology*, 16, 474-486.

- ASHING-GIWA, K. T., PADILLA, G. V., BOHORQUEZ, D. E., TEJERO, J. S. & GARCIA, M. 2006. Understanding the breast cancer experience of Latina women. *J Psychosoc Oncol*, 24, 19-52.
- ASHING-GIWA, K. T., PADILLA, G., TEJERO, J., KRAEMER, J., WRIGHT, K., COSCARELLI, A., CLAYTON, S., WILLIAMS, I. & HILLS, D. 2004. Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, 13, 408-428.
- AVIS, M., ELKAN, R., PATEL, S., WALKER, B. A., ANKTI, N. & BELL, C. 2008. Ethnicity and participation in cancer self-help groups. *Psycho-Oncology*, 17, 940-947.
- AVIS, N. E., CRAWFORD, S. & MANUEL, J. 2004. Psychosocial problems among younger women with breast cancer. *Psycho-Oncology*, 13, 295-308.
- AZAIZA, F. & COHEN, M. 2008. Between traditional and modern perceptions of breast and cervical cancer screenings: a qualitative study of Arab women in Israel. *Psychooncology*, 17, 34-41.
- BAIDER, L., ANDRITSCH, E., GOLDZWEIG, G., UZIELY, B., EVER-HADANI, P., HOFMAN, G., KRENN, G. & SAMONIGG, H. 2004. Changes in psychological distress of women with breast cancer in long-term remission and their husbands. *Psychosomatics*, 45, 58-68.
- BAKHT, S. & NAJAFI, S. 2010. Body image and sexual dysfunctions: comparison between breast cancer patients and healthy women. *Procedia-Social and Behavioral Sciences*, 5, 1493-1497.
- BANNING, M., HAFEEZ, H., FAISAL, S., HASSAN, M. & ZAFAR, A. 2009. The impact of culture and sociological and psychological issues on Muslim patients with breast cancer in Pakistan. *Cancer nursing*, 32, 317-324.
- BANNING, M., HASSAN, M., FAISAL, S. & HAFEEZ, H. 2010. Cultural interrelationships and the lived experience of Pakistani breast cancer patients. *European Journal of Oncology Nursing*, 14, 304.
- BARBERA, A. & PROSA, L. 2002. The Amazon Project: helping the patient to become an instrument of her own recovery. *Ann N Y Acad Sci*, 963, 1-5.
- BARON-EPEL, O. & KLIN, A. 2009. Cancer as perceived by a middle-aged Jewish urban population in Israel. *Oncol Nurs Forum*, 36, E326-34.
- BAUMAN, L. J., GERVEY, R. & SIEGEL, K. 1993. Factors associated with cancer patients' participation in support groups. *Journal of Psychosocial Oncology*, 10, 1-20.
- BEAVER, K. & WITHAM, G. 2007a. Information needs of the informal carers of women treated for breast cancer. *European Journal of Oncology Nursing*, 11, 16-25.
- BEAVER, K. & WITHAM, G. 2007b. Information needs of the informal carers of women treated for breast cancer. *European journal of oncology nursing: the official journal of European Oncology Nursing Society*, 11, 16.
- BENTON, D. 2000. *Ground theory in the research process in nursing* Oxford, Cormack-Blackwell science.
- BENTON, T. & CRAIB, I. 2001. *Philosophy of social science: The philosophical foundations of social thought*, Palgrave New York.
- BENZEIN, E. & SAVEMAN, B. I. 1998. One step towards the understanding of hope: a concept analysis. *International journal of nursing studies*, 35, 322-329.

- BERG, S. W. V. D., PETERS, E. J., KRAAIJEVELD, J. F., GIELISSEN, M. F. M., PRINS, J. B. & EYSENACH, G. 2013. Usage of a Generic Web-Based Self-Management Intervention for Breast Cancer Survivors: Substudy Analysis of the BREATH Trial. *Journal of Medical Internet Research*, 15, 1-1.
- BERGER, A. M., WIELGUS, K., HERTZOG, M., FISCHER, P. & FARR, L. 2010. Patterns of circadian activity rhythms and their relationships with fatigue and anxiety/depression in women treated with breast cancer adjuvant chemotherapy. *Support Care Cancer*, 18, 105-14.
- BERTERÖ, C. & WILMOTH, M. C. 2007. Breast cancer diagnosis and its treatment affecting the self: a meta-synthesis. *Cancer nursing*, 30, 194-202.
- BINNS-TURNER, P. G., WILSON, L. L., PRYOR, E. R., BOYD, G. L. & PRICKETT, C. A. 2011. Perioperative music and its effects on anxiety, hemodynamics, and pain in women undergoing mastectomy. *AANA J*, 79, S21-7.
- BLOOM, J. R., STEWART, S. L., JOHNSTON, M., BANKS, P. & FOBAIR, P. 2001. Sources of support and the physical and mental well-being of young women with breast cancer. *Social science & medicine*, 53, 1513-1524.
- BOESEN, E. H., KARLSEN, R., CHRISTENSEN, J., PAASCHBURG, B., NIELSEN, D., BLOCH, I. S., CHRISTIANSEN, B., JACOBSEN, K. & JOHANSEN, C. 2011. Psychosocial group intervention for patients with primary breast cancer: a randomised trial. *European Journal of Cancer*, 47, 1363-1372.
- BORKMAN, T. 1976. Experiential knowledge: A new concept for the analysis of self-help groups. *The Social Service Review*, 445-456.
- BORKMAN, T. 1999. *Understanding self-help/mutual aid: Experiential learning in the commons*, New Brunswick, Rutgers University Press.
- BORKMAN, T. & MUNN-GIDDINGS, C. 2001. Self-help groups challenge health care systems in the US and UK. *Advances in Medical Sociology*, 10, 127-150.
- BOWEN, D. J., BURKE, W., YASUI, Y., MCTIERNAN, A. & MCLERAN, D. 2002. Effects of risk counseling on interest in breast cancer genetic testing for lower risk women. *Genet Med*, 4, 359-65.
- BOWLBY, J. 2008. *Loss-Sadness and Depression: Attachment and Loss*, New York, Vintage Digital.
- BOWLING, A. 2009. *Research methods in health: investigating health and health services*, New York, McGraw-Hill International.
- BRADSHAW, M. & STRATFORD, E. 2010. *Qualitative research design and rigour*, Melbourne, Oxford University Press.
- BRAHAMS, D. 2011. Breast cancer: does universal screening do more harm than good? Discuss. *Med Leg J*, 79, 1-2.
- BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3, 77-101.
- BREZDEN, C. B., PHILLIPS, K.-A., ABDOLELL, M., BUNSTON, T. & TANNOCK, I. F. 2000. Cognitive function in breast cancer patients receiving adjuvant chemotherapy. *Journal of Clinical Oncology*, 18, 2695-2701.
- BROCKOW, T., DUDDECK, K., GEYH, S., SCHWARZKOPF, S., WEIGL, M., FRANKE, T. & BRACH, M. 2004. Identifying the concepts contained in outcome measures of clinical trials on breast cancer using the International Classification of Functioning, Disability and Health as a reference. *Journal of Rehabilitation Medicine*, 36, 43-48.

- BROECKEL, J. A., THORS, C. L., JACOBSEN, P. B., SMALL, M. & COX, C. E. 2002. Sexual functioning in long-term breast cancer survivors treated with adjuvant chemotherapy. *Breast cancer research and treatment*, 75, 241-248.
- BROWALL, M., GASTON-JOHANSSON, F. & DANIELSON, E. 2006. Postmenopausal women with breast cancer: their experiences of the chemotherapy treatment period. *Cancer nursing*, 29, 34-42.
- BRYMAN, A. 2012. *Social research methods*, New York Oxford university press.
- BUDIN, W. C., CARTWRIGHT-ALCARESE, F. & HOSKINS, C. N. 2008. The breast cancer treatment response inventory: development, psychometric testing, and refinement for use in practice. *Oncol Nurs Forum*, 35, 209-15.
- BUSSING, A., ABU-HASSAN, W. M., MATTHIESSEN, P. F. & OSTERMANN, T. 2007. Spirituality, religiosity, and dealing with illness in Arabic and German patients. *Saudi medical journal*, 28, 933.
- CARELLE, N., PIOTTO, E., BELLANGER, A., GERMANAUD, J., THUILLIER, A. & KHAYAT, D. 2002. Changing patient perceptions of the side effects of cancer chemotherapy. *Cancer*, 95, 155-163.
- CARROLL, J. C., GRAY, R. E., ORR, V. J., CHART, P., FITCH, M. & GREENBERG, M. 2000. Changing physicians' attitudes toward self-help groups: An educational intervention. *Journal of Cancer Education*, 15, 14-18.
- CEBECI, F., YANGIN, H. B. & TEKELI, A. 2010. Determination of changes in the sexual lives of young women receiving breast cancer treatment: a qualitative study. *Sexuality and Disability*, 28, 255-264.
- CEBECI, F., YANGIN, H. B. & TEKELI, A. 2011. Life experiences of women with breast cancer in south western Turkey: A qualitative study. *European Journal of Oncology Nursing*.
- CHAMBERLAIN WILMOTH, M., TULMAN, L., COLEMAN, E. A., STEWART, C. B. & SAMAREL, N. 2006. Women's perceptions of the effectiveness of telephone support and education on their adjustment to breast cancer. *Oncol Nurs Forum*, 33, 138-44.
- CHANTLER, M., PODBILEWICZ-SCHULLER, Y. & MORTIMER, J. 2006. Change in need for psychosocial support for women with early stage breast cancer. *Journal of Psychosocial Oncology*, 23, 65-77.
- CHATMAN, M. C. & GREEN, R. D. 2011. Addressing the unique psychosocial barriers to breast cancer treatment experienced by African-American women through integrative navigation. *J Natl Black Nurses Assoc*, 22, 20-8.
- CHAUDHARY, S., AVIS, M. & MUNN-GIDDINGS, C. 2013. Beyond the therapeutic: A Habermasian view of self-help groups' place in the public sphere. *Social Theory & Health*, 11, 59-80.
- CHEVILLE, A. L. & TCHOU, J. 2007. Barriers to rehabilitation following surgery for primary breast cancer. *Journal of surgical oncology*, 95, 409-418.
- CHIDA, Y., STEPTOE, A. & POWELL, L. H. 2009. Religiosity/spirituality and mortality. *Psychotherapy and psychosomatics*, 78, 81-90.
- CHINMAN, M., KLOOS, B., O'CONNELL, M. & DAVIDSON, L. 2002. Service providers' views of psychiatric mutual support groups. *Journal of Community Psychology*, 30, 349-366.
- CHO, H. S., DAVIS, G. C., PAEK, J. E., RAO, R., ZHAO, H., XIE, X. J., YOUSEF, M. G., FEDRIC, T., EUHUS, D. H. & LEITCH, M. 2012. A randomised trial of nursing interventions supporting recovery of the postmastectomy patient. *J Clin Nurs*.

- CHO, O. H., YOO, Y. S. & KIM, N. C. 2006. Efficacy of comprehensive group rehabilitation for women with early breast cancer in South Korea. *Nurs Health Sci*, 8, 140-6.
- CHOUMANOVA, I., WANAT, S., BARRETT, R. & KOOPMAN, C. 2006. Religion and spirituality in coping with breast cancer: perspectives of Chilean women. *The breast journal*, 12, 349-352.
- CHRISTENSEN, S., ZACHARIAE, R., JENSEN, A. B., VÆTH, M., MØLLER, S., RAVNSBÆK, J. & VON DER MAASE, H. 2009. Prevalence and risk of depressive symptoms 3–4 months post-surgery in a nationwide cohort study of Danish women treated for early stage breast-cancer. *Breast cancer research and treatment*, 113, 339-355.
- CIA. 2014. *The World Fact Book* [Online]. Available: <https://www.cia.gov/library/publications/the-world-factbook/geos/jo.html> [Accessed 25th July 2014].
- COLLINS, L. G., NASH, R., ROUND, T. & NEWMAN, B. 2004. Perceptions of upper-body problems during recovery from breast cancer treatment. *Supportive care in cancer*, 12, 106-113.
- CONNELL, S., PATTERSON, C. & NEWMAN, B. 2006. Issues and concerns of young Australian women with breast cancer. *Supportive care in cancer*, 14, 419-426.
- COOK, J. A. & JONIKAS, J. A. 2002. Self-Determination Among Mental Health Consumers/Survivors Using Lessons From the Past to Guide the Future. *Journal of Disability Policy Studies*, 13, 88-96.
- COOK, J. A., TERRELL, S. & JONIKAS, J. A. 2004. Promoting self-determination for individuals with psychiatric disabilities through self-directed services: A look at federal, state and public systems as sources of cash-outs and other fiscal expansion opportunities. *Substance Abuse and Mental Health Services Administration*.
- COREIL, J., CORVIN, J. A., NUPP, R., DYER, K. & NOBLE, C. 2012a. Ethnicity and cultural models of recovery from breast cancer. *Ethnicity & Health*, 17, 291-307.
- COREIL, J., CORVIN, J. A., NUPP, R., DYER, K. & NOBLE, C. 2012b. Ethnicity and cultural models of recovery from breast cancer. *Ethn Health*, 17, 291-307.
- COREIL, J., WILKE, J. & PINTADO, I. 2004. Cultural models of illness and recovery in breast cancer support groups. *Qual Health Res*, 14, 905-23.
- COUNTY, E. E. I. N. & CHEPCHIRCHIR, S. C. 2013. INTERDISCIPLINARY JOURNAL OF CONTEMPORARY RESEARCH IN BUSINESS.
- COYNE, E. & BORBASI, S. 2009. Living the experience of breast cancer treatment: The younger women's perspective. *Australian Journal of Advanced Nursing*, 26, 6-13.
- COYNE, E., WOLLIN, J. & CREEDY, D. K. 2012. Exploration of the family's role and strengths after a young woman is diagnosed with breast cancer: Views of women and their families. *European Journal of Oncology Nursing*, 16, 124-130.
- COYNE, J. C., LEPORE, S. J. & PALMER, S. C. 2006. Efficacy of psychosocial interventions in cancer care: Evidence is weaker than it first looks. *Annals of Behavioral Medicine*, 32, 104-110.
- CRESWELL, J. W. & CLARK, V. L. P. 2007. Designing and conducting mixed methods research.

- CRUZ, F. A. D., PADILLA, G. V. & AGUSTIN, E. O. 2000. Adapting a measure of acculturation for cross-cultural research. *Journal of Transcultural Nursing*, 11, 191-198.
- CURTIS, S., GESLER, W., SMITH, G. & WASHBURN, S. 2000. Approaches to sampling and case selection in qualitative research: examples in the geography of health. *Social science & medicine*, 50, 1001-1014.
- DA COSTA VARGENS, O. M. & BERTERÖ, C. M. 2007. Living with breast cancer: its effect on the life situation and the close relationship of women in Brazil. *Cancer nursing*, 30, 471-478.
- DAMEN, S., MORTELMANS, D. & VAN HOVE, E. 2000. Self-help groups in Belgium: their place in the care network. *Sociology of Health & Illness*, 22, 331-348.
- DAVIDSON, L., O'CONNELL, M. J., TONDORA, J., LAWLESS, M. & EVANS, A. C. 2005. Recovery in serious mental illness: A new wine or just a new bottle? *Professional psychology, research and practice*, 36, 480-487.
- DAVIDSON, L. & STRAUSS, J. S. 1992. Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, 65, 131-145.
- DAVISON, K. P., PENNEBAKER, J. W. & DICKERSON, S. S. 2000. Who talks? The social psychology of illness support groups. *American Psychologist*, 55, 205.
- DE BRABANDER, B., GERITS, P., SACRE, R. & LAMOTE, J. 1998. What determines primary breast cancer patients' hope to recover. *Psychol Rep*, 82, 835-40.
- DE VER DYE, T., BOGALE, S., HOB DEN, C., TILAHUN, Y., HECHTER, V., DERESSA, T., BIZE, M. & REELER, A. 2011. A mixed-method assessment of beliefs and practice around breast cancer in Ethiopia: implications for public health programming and cancer control. *Glob Public Health*, 6, 719-31.
- DELANTY, G. & STRYDOM, P. 2003. *Philosophies of social science: The classic and contemporary readings*, Philadelphia, Open University Press.
- DELL, D. D., WEAVER, C., KOZEMPEL, J. & BARSEVICK, A. 2008. Recovery after transverse rectus abdominis myocutaneous flap breast reconstruction surgery. *Oncol Nurs Forum*, 35, 189-96.
- DEN HEIJER, M., SEYNAEVE, C., VANHEUSDEN, K., DUIVENVOORDEN, H. J., VOS, J., BARTELS, C. C., MENKE-PLUYMERS, M. B. & TIBBEN, A. 2011. The contribution of self-esteem and self-concept in psychological distress in women at risk of hereditary breast cancer. *Psychooncology*, 20, 1170-5.
- DENIEFFE, S. & GOONEY, M. 2011. A meta-synthesis of women's symptoms experience and breast cancer. *Eur J Cancer Care (Engl)*, 20, 424-35.
- DENZIN, N. K. & LINCOLN, Y. S. 1994. *Handbook of qualitative research*, Sage Publications, Inc.
- DENZIN, N. K. & LINCOLN, Y. S. 2000. *The discipline and practice of qualitative research*.
- DOUMIT, M. A., HUIJER, H. A., KELLEY, J. H., EL SAGHIR, N. & NASSAR, N. 2010a. Coping with breast cancer: a phenomenological study. *Cancer Nurs*, 33, E33-9.
- DOUMIT, M. A. A., ABU-SAAD HUIJER, H. & KELLEY, J. H. 2007. The lived experience of Lebanese oncology patients receiving palliative care. *European Journal of Oncology Nursing*, 11, 309-319.

- DOUMIT, M. A. A., EL SAGHIR, N., ABU-SAAD HUIJER, H., KELLEY, J. H. & NASSAR, N. 2010b. Living with breast cancer, a Lebanese experience. *European Journal of Oncology Nursing*, 14, 42-48.
- DOWLING, M. 2006. Approaches to reflexivity in qualitative research. *Nurse Researcher*, 13, 7.
- DUNN, J. & STEGINGA, S. K. 2000. Young women's experience of breast cancer: defining young and identifying concerns. *Psycho-Oncology*, 9, 137-146.
- EHRENREICH, B. 2010. *Bright-sided: how positive thinking is undermining America*, New York, Metropolitan Books.
- EISINGER, F., BLAY, J. Y., MORERE, J. F., COSCAS, Y., CALAZEL-BENQUE, A., ROUSSEL, C. & PIVOT, X. 2011. Impact of awareness of cancer among acquaintances on cancer screening attendance. *Eur J Cancer Prev*, 20 Suppl 1, S36-8.
- ELL, K., SANCHEZ, K., VOURLEKIS, B., LEE, P. J., DWIGHT-JOHNSON, M., LAGOMASINO, I., MUDERSPACH, L. & RUSSELL, C. 2005. Depression, correlates of depression, and receipt of depression care among low-income women with breast or gynecologic cancer. *Journal of Clinical Oncology*, 23, 3052-3060.
- ELLIOTT, T. R., USWATTE, G., LEWIS, L. & PALMATIER, A. 2000. Goal instability and adjustment to physical disability. *Journal of Counseling Psychology*, 47, 251.
- ELMIR, R., JACKSON, D., BEALE, B. & SCHMIED, V. 2010. Against all odds: Australian women's experiences of recovery from breast cancer. *J Clin Nurs*, 19, 2531-8.
- ELSE-QUEST, N. M., LOCONTE, N. K., SCHILLER, J. H. & HYDE, J. S. 2009. Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychol Health*, 24, 949-64.
- ENGLISH, J., WILSON, K. & KELLER-OLAMAN, S. 2008. Health, healing and recovery: Therapeutic landscapes and the everyday lives of breast cancer survivors. *Social science & medicine*, 67, 68-78.
- ERCI, B. & KARABULUT, N. 2007. Appraising the self-assessed support needs of Turkish women with breast cancer. *European journal of cancer care*, 16, 137-143.
- ERLANDSON, D. A. 1993. *Doing naturalistic inquiry: A guide to methods*, London, Sage.
- EYSENBACH, G., POWELL, J., ENGLESAKIS, M., RIZO, C. & STERN, A. 2004. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *Bmj*, 328, 1166.
- FALLBJORK, U., FREJEUS, E. & RASMUSSEN, B. H. 2012. A preliminary study into women's experiences of undergoing reconstructive surgery after breast cancer. *Eur J Oncol Nurs*, 16, 220-6.
- FANG, S. Y., SHU, B. C. & CHANG, Y. J. 2013. The effect of breast reconstruction surgery on body image among women after mastectomy: a meta-analysis. *Breast Cancer Res Treat*, 137, 13-21.
- FANG, S. Y., SHU, B. C. & FETZER, S. J. 2011. Deliberating over mastectomy: survival and social roles. *Cancer Nurs*, 34, E21-8.
- FEATHER, B. L., WAINSTOCK, J. M., REMINGTON, A. & RINGENBERG, Q. S. 1988. Postmastectomy educational needs and social support. *J Cancer Educ*, 3, 135-44.

- FESTINGER, L. 1954. A theory of social comparison processes. *Human relations*, 7, 117-140.
- FIGUEIREDO, M. I., FRIES, E. & INGRAM, K. M. 2004. The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. *Psycho-Oncology*, 13, 96-105.
- FINFGELD, D. L. 2003. Metasynthesis: The state of the art—so far. *Qualitative Health Research*, 13, 893-904.
- FOBAIR, P. 1998. Cancer support groups and group therapies: Part II. Process, organizational, leadership, and patient issues. *Journal of Psychosocial Oncology*, 15, 123-147.
- FOBAIR, P., STEWART, S. L., CHANG, S., D'ONOFRIO, C., BANKS, P. J. & BLOOM, J. R. 2005. Body image and sexual problems in young women with breast cancer. *Psycho-Oncology*, 15, 579-594.
- FOSS, C. & ELLEFSEN, B. 2002. The value of combining qualitative and quantitative approaches in nursing research by means of method triangulation. *Journal of advanced nursing*, 40, 242-248.
- FOX, B.-L. 2007. Behind the Scenes of Breast Cancer: A News Anchor Tells Her Story of Body and Soul Recovery. *Library Journal*, 132, 160-160.
- FOX, B.-L. 2012. Surviving Triple Negative Breast Cancer: Hope, Treatment, and Recovery. *Library Journal*, 137, 121-124.
- FOX, B.-L. 2013. Breast Cancer Journey: The Essential Guide to Treatment and Recovery/American Cancer Soc. *Library Journal*, 138, 135.
- FRANKFORT-NACHMIAS, C. & NACHMIAS, D. 2007. *Research methods in the social sciences*, New York, Macmillan.
- FUJIMORI, M. & UCHITOMI, Y. 2009. Preferences of cancer patients regarding communication of bad news: a systematic literature review. *Japanese journal of clinical oncology*, 39, 201-216.
- GALLAGHER, P., BUCKMASTER, A., O'CARROLL, S., KIERNAN, G. & GERAGHTY, J. 2009. Experiences in the provision, fitting and supply of external breast prostheses: findings from a national survey. *Eur J Cancer Care (Engl)*, 18, 556-68.
- GANZ, P. A., DESMOND, K. A., LEEDHAM, B., ROWLAND, J. H., MEYEROWITZ, B. E. & BELIN, T. R. 2002. Quality of life in long-term, disease-free survivors of breast cancer: a follow-up study. *Journal of the National Cancer Institute*, 94, 39-49.
- GARSSEN, B., VOS, P., DE JAGER MEEZENBROEK, E., DE KLERK, C. & VISSER, A. 2011. Analyzing differences between psychotherapy groups and social support groups for breast cancer patients: Development of an assessment method using video recordings. *Patient education and counseling*, 82, 377-383.
- GARTNER, R., CALLESEN, T., KROMAN, N. & KEHLET, H. 2010. Recovery at the post anaesthetic care unit after breast cancer surgery. *Dan Med Bull*, 57, A4137.
- GASSON, S. 2004. Rigor in grounded theory research: An interpretive perspective on generating theory from qualitative field studies. In: M. E. WHITMAN & A. B. WOSZCZYNSKI (EDS.), T. (ed.) *The handbook of information systems research* Hershey: PA: Idea Group.
- GIDDENS, A. 1991. *Modernity and self-identity: Self and society in the late modern age*, Cambridge, Stanford University Press.

- GILLIS, A. & JACKSON, W. Research for nurses: Methods and interpretation, 2002. Philadelphia: FA Davis Company.
- GILLIS, A. & JACKSON, W. 2002. Research for nurses: Methods and interpretation, 2002. Philadelphia: FA Davis Company.
- GIORGI, A. 2002. The question of validity in qualitative research. *Journal of Phenomenological Psychology*, 33, 1-18.
- GLASER, B. G. 2001. *The Grounded Theory Perspective: Conceptualization Contrasted with Description*. . , Mill Valley, CA, Sociology Pres.
- GOFFMAN, E. 1963. *Stigma: Notes on the Management of Spoiled Identity*, Prentice-Hall.
- GOLAFSHANI, N. 2003. Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8, 597-607.
- GOLDBLATT, H., COHEN, M., AZAIZA, F. & MANASSA, R. 2012. Being within or being between? The cultural context of Arab women's experience of coping with breast cancer in Israel. *Psychooncology*.
- GOLDBLATT, H., COHEN, M., AZAIZA, F. & MANASSA, R. 2013. Being within or being between? The cultural context of Arab women's experience of coping with breast cancer in Israel. *Psycho-Oncology*, 22, 869-875.
- GOODWIN, P. J. 2005. Support groups in advanced breast cancer. *Cancer*, 104, 2596-2601.
- GRASSI, L., ROSSI, E., SABATO, S., CRUCIANI, G. & ZAMBELLI, M. 2004. Diagnostic criteria for psychosomatic research and psychosocial variables in breast cancer patients. *Psychosomatics*, 45, 483-491.
- GRAVES, K. D. 2003. Social cognitive theory and cancer patients' quality of life: a meta-analysis of psychosocial intervention components. *Health Psychology*, 22, 210.
- GRAVES, K. D., JENSEN, R. E., CANAR, J., PERRET-GENTIL, M., LEVENTHAL, K. G., GONZALEZ, F., CAICEDO, L., JANDORF, L., KELLY, S. & MANDELBLATT, J. 2012. Through the lens of culture: quality of life among Latina breast cancer survivors. *Breast Cancer Res Treat*, 136, 603-13.
- GRBICH, C. 1999. *Qualitative research in health: An introduction*, Sage, Thousand Oaks.
- GREEN, J. & THOROGOOD, N. 2004. *Qualitative methods for health research*, London, Sage.
- GREENSTEIN, T. N. & DAVIS, S. N. 2012. *Methods of family research*, london, Sage Publications, Incorporated.
- GRIFFITHS, K. M., CALEAR, A. L. & BANFIELD, M. 2009. Systematic Review on Internet Support Groups (ISGs) and Depression (1): Do ISGs Reduce Depressive Symptoms? *Journal of Medical Internet Research*, 11, 17-17.
- GRIMSBO, G. H., RULAND, C. M. & FINSET, A. 2012. Cancer patients' expressions of emotional cues and concerns and oncology nurses' responses, in an online patient-nurse communication service. *Patient Educ Couns*, 88, 36-43.
- GROVE, S. K., BURNS, N. & GRAY, J. 2012. *The practice of nursing research: appraisal, synthesis, and generation of evidence*, Elsevier Health Sciences.
- GUBA, E. G. & LINCOLN, Y. S. 1985. *Naturalistic inquiry*, Newbury Park, Sage Publications.

- GUBA, E. G. & LINCOLN, Y. S. 1994. Competing paradigms in qualitative research. *Handbook of qualitative research*, 2, 163-194.
- GURM, B. K., STEPHEN, J., MACKENZIE, G., DOLL, R., BARROETAVENA, M. C. & CADELL, S. 2008a. Understanding Canadian Punjabi-speaking South Asian women's experience of breast cancer: A qualitative study. *International journal of nursing studies*, 45, 266-276.
- GURM, B. K., STEPHEN, J., MACKENZIE, G., DOLL, R., CRISTINA BARROETAVENA, M. & CADELL, S. 2008b. Understanding Canadian Punjabi-speaking South Asian women's experience of breast cancer: A qualitative study. *International journal of nursing studies*, 45, 266-276.
- GURUGE, S., MAHEU, C., ZANCHETTA, M. S., FERNANDEZ, F. & BAKU, L. 2011. Social support for breast cancer management among Portuguese-speaking immigrant women. *Can J Nurs Res*, 43, 48-66.
- HANN, D., BAKER, F., DENNISTON, M. & ENTREKIN, N. 2005. Long-term breast cancer survivors' use of complementary therapies: perceived impact on recovery and prevention of recurrence. *Integr Cancer Ther*, 4, 14-20.
- HANN, D., BAKER, F., DENNISTON, M., GESME, D., REDING, D., FLYNN, T., KENNEDY, J. & KIELTYKA, R. L. 2002. The influence of social support on depressive symptoms in cancer patients: age and gender differences. *Journal of psychosomatic research*, 52, 279-283.
- HARANDY, T. F., GHOFRAFIPOUR, F., MONTAZERI, A., ANOOSHEH, M., BAZARGAN, M., MOHAMMADI, E., AHMADI, F. & NIKNAMI, S. 2009. Muslim breast cancer survivor spirituality: coping strategy or health seeking behavior hindrance? *Health care for women international*, 31, 88-98.
- HASSON-OHAYON, I., BRAUN, M., GALINSKY, D. & BAIDER, L. 2009. Religiosity and hope: A path for women coping with a diagnosis of breast cancer. *Psychosomatics*, 50, 525-533.
- HATFIELD, A. B. & LEFLEY, H. P. 1993. *Surviving mental illness: Stress, coping, and adaptation*, Guilford Press.
- HEIDARI GORJI, M. A., BOUZAR, Z., HAGHSHEENAS, M., KASAEYAN, A. A., SADEGHI, M. R. & ARDEBIL, M. D. 2012. Quality of life and depression in caregivers of patients with breast cancer. *BMC Res Notes*, 5, 310.
- HEINEY, S. P., HAZLETT, L. J., WEINRICH, S. P., WELLS, L. M., ADAMS, S. A., UNDERWOOD, S. M. & PARRISH, R. S. 2011. Antecedents and mediators of community connection in African American women with breast cancer. *Res Theory Nurs Pract*, 25, 252-70.
- HELGESON, V. S., COHEN, S., SCHULZ, R. & YASKO, J. 2000. Group support interventions for women with breast cancer: Who benefits from what? *Health Psychology*, 19, 107.
- HERSCH, J., JURASKOVA, I., PRICE, M. & MULLAN, B. 2008. Psychosocial interventions and quality of life in gynaecological cancer patients: a systematic review. *Psycho-Oncology*, 18, 795-810.
- HIGGINBOTTOM, G. 2004. Sampling issues in qualitative research. *Nurse Researcher*, 12, 7.
- HOWARD, A. F., BALNEAVES, L. G. & BOTTORFF, J. L. 2007. Ethnocultural women's experiences of breast cancer: a qualitative meta-study. *Cancer nursing*, 30, E27-E35.
- HSU, H. T., HUANG, C. S., LIU, Y., DODD, M. J., JUAN, C. H., LAI, Y. H. & GUO, S. E. 2012. Exercise behaviors in breast cancer survivors in Taiwan. *Cancer Nurs*, 35, E48-56.

- HUGHES, S., EDWARD, K. L. & HYETT, B. 2011. Enhancing nursing practice potential: breast free flap reconstruction following mastectomy. *Aust Nurs J*, 19, 30-3.
- HUMPHREYS, K. & RAPPAPORT, J. 1994. Researching self-help/mutual aid groups and organizations: Many roads, one journey. *Applied and Preventive Psychology*, 3, 217-231.
- IM, E. O., LEE, E. O., PARK, Y. S. & SALAZAR, M. K. 2002. Korean women's breast cancer experience. *Western Journal of Nursing Research*, 24, 751-771.
- IWAMITSU, Y., SHIMODA, K., ABE, H. & OKAWA, M. 2005. Anxiety, emotional suppression, and psychological distress before and after breast cancer diagnosis. *Psychosomatics*, 46, 19-24.
- JACKSON, A. M., MCKINSTRY, B., GREGORY, S. & AMOS, A. 2011. A qualitative study exploring why people do not participate in cardiac rehabilitation and coronary heart disease self-help groups, and their rehabilitation experience without these resources. *Primary Health Care Research & Development*, 1, 1-12.
- JACKSON, D., DALY, J. & DAVIDSON, P. 2008. Interviews. In: WATSON, R., MCKENNA, H., COWMAN, J. & KEADY, J. (eds.) *Nursing Research: Designs and methods* London: Churchill Livingstone.
- JACOBSEN, P. B., MEADE, C. D., STEIN, K. D., CHIRIKOS, T. N., SMALL, B. J. & RUCKDESCHEL, J. C. 2002. Efficacy and costs of two forms of stress management training for cancer patients undergoing chemotherapy. *Journal of Clinical Oncology*, 20, 2851-2862.
- JACOBSON, N. & CURTIS, L. 2000. Recovery as policy in mental health services: Strategies emerging from the states. *Psychosocial Rehabilitation Journal*, 23, 333-341.
- JACOBSON, N. & GREENLEY, D. 2001. What is recovery? A conceptual model and explication. *Psychiatric services*, 52, 482-485.
- JBCP. 2009a. *Jordan Breast Cancer Program* [Online]. Available: <http://www.jbcp.jo> [Accessed 6th October 2009].
- JBCP. 2009b. *Jordan Breast Cancer Program* [Online]. Available: <http://www.jbcp.jo> [Accessed 6th October 2009 2009].
- JDOS. 2007. *Department of Statistics* [Online]. Available: http://www.dos.gov.jo/dos_home_e/main/ [Accessed 15th May 2007].
- JONES, A. & BUGGE, C. 2006. Improving understanding and rigour through triangulation: an exemplar based on patient participation in interaction. *Journal of advanced nursing*, 55, 612-621.
- JONES, M., JOLLY, K., RAFTERY, J., LIP, G. Y. H. & GREENFIELD, S. 2007. 'DNA' may not mean 'did not participate': a qualitative study of reasons for non-adherence at home-and centre-based cardiac rehabilitation. *Family practice*, 24, 343-357.
- JONES, S. L., HADJISTAVROPOULOS, H. D. & SHERRY, S. B. 2012. Health anxiety in women with early-stage breast cancer: What is the relationship to social support? *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, 44, 108.
- JORDAN, J. R. & NEIMEYER, R. A. 2003. Does grief counseling work? *Death Studies*, 27, 765-786.

- JULKUNEN, J., GUSTAVSSON-LILIUS, M. & HIETANEN, P. 2009. Anger expression, partner support, and quality of life in cancer patients. *Journal of psychosomatic research*, 66, 235-244.
- KARBANI, G., LIM, J. N., HEWISON, J., ATKIN, K., HORGAN, K., LANSDOWN, M. & CHU, C. E. 2011. Culture, attitude and knowledge about breast cancer and preventive measures: a qualitative study of South Asian breast cancer patients in the UK. *Asian Pac J Cancer Prev*, 12, 1619-26.
- KAWAR, L. N. 2009. Jordanian and Palestinian immigrant women's knowledge, affect, cultural attitudes, health habits, and participation in breast cancer screening. *Health Care Women Int*, 30, 768-82.
- KELLER, M. E. & PRENDERGAST, B. 2009. The potential of survivorship care plans in primary care follow-up of minority breast cancer patients. *Journal of general internal medicine*, 24, 467-471.
- KHCC. 2009a. *King Hussein Cancer Centre* [Online]. Available: <http://www.khcc.jo> [Accessed 6th October 2009].
- KHCC, K. H. C. C. 2009b. Available: <http://www.khcc.jo> [Accessed 6th October 2009].
- KIKUCHI, S., KATADA, N., SAKURAMOTO, S., KOBAYASHI, N., SHIMAO, H., WATANABE, M. & HIKI, Y. 2004. Survival after surgical treatment of early gastric cancer: surgical techniques and long-term survival. *Langenbeck's Archives of Surgery*, 389, 69-74.
- KILGOUR, R. D., JONES, D. H. & KEYSERLINGK, J. R. 2008. Effectiveness of a self-administered, home-based exercise rehabilitation program for women following a modified radical mastectomy and axillary node dissection: a preliminary study. *Breast Cancer Res Treat*, 109, 285-95.
- KIM, S., KO, Y. H. & JUN, E. Y. 2012. The impact of breast cancer on mother-child relationships in Korea. *Psychooncology*, 21, 640-6.
- KITZINGER, J. & BARBOUR, R. S. 1999. *Developing focus group research: politics, theory and practice*, London, Sage Publications Ltd.
- KLEIN, H. K. 2004. Seeking the new and the critical in critical realism: déjà vu? *Information and organization*, 14, 123-144.
- KRIZEK, C., ROBERTS, C., RAGAN, R., FERRARA, J. J. & LORD, B. 1999. Gender and cancer support group participation. *Cancer Practice*, 7, 86-92.
- KROENKE, C. H., KUBZANSKY, L. D., SCHERNHAMMER, E. S., HOLMES, M. D. & KAWACHI, I. 2006. Social networks, social support, and survival after breast cancer diagnosis. *Journal of Clinical Oncology*, 24, 1105-1111.
- KROMM, E. E., SMITH, K. C. & SINGER, R. F. 2007. Survivors on Cancer: the portrayal of survivors in print news. *J Cancer Surviv*, 1, 298-305.
- KUMAR, S. & PHROMMATHED, P. 2005. *Research methodology*, Springer.
- KUNKEL, E. J. & CHEN, E. I. 2003. Psychiatric aspects of women with breast cancer. *The Psychiatric clinics of North America*, 26, 713.
- KWOK, C. & SULLIVAN, G. 2006. Chinese-Australian women's beliefs about cancer: implications for health promotion. *Cancer Nurs*, 29, E14-21.
- KWOK, C. & WHITE, K. 2011. Cultural and linguistic isolation: The breast cancer experience of Chinese-Australian women-A qualitative study. *Contemporary nurse*, 39, 85-94.
- LAM, W. W. & FIELDING, R. 2003. The evolving experience of illness for Chinese women with breast cancer: a qualitative study. *Psycho-Oncology*, 12, 127-140.
- LAM, W. W., LI, W. W., BONANNO, G. A., MANCINI, A. D., CHAN, M., OR, A. & FIELDING, R. 2012a. Trajectories of body image and sexuality during the

- first year following diagnosis of breast cancer and their relationship to 6 years psychosocial outcomes. *Breast Cancer Res Treat*, 131, 957-67.
- LAM, W. W., SHING, Y. T., BONANNO, G. A., MANCINI, A. D. & FIELDING, R. 2012b. Distress trajectories at the first year diagnosis of breast cancer in relation to 6 years survivorship. *Psychooncology*, 21, 90-9.
- LAMB, G. S. & HUTTLINGER, K. 1989. Reflexivity in nursing research. *Western Journal of Nursing Research*, 11, 765-772.
- LAMBERT, H. & MCKEVITT, C. 2002. Anthropology in health research: from qualitative methods to multidisciplinary. *BMJ: British Medical Journal*, 325, 210.
- LANDMARK, B., STRANDMARK, M. & WAHL, A. 2002. Breast cancer and experiences of social support. *Scandinavian Journal of Caring Sciences*, 16, 216-223.
- LAPSLEY, H., NIKORA, L. W. & BLACK, R. M. 2002. "Kia Mauri Tau!" *Narratives of recovery from disabling mental health problems*, Wellington, New Zealand Mental Health Commission.
- LAZARUS, R. S. & FOLKMAN, S. 1984. *Stress, appraisal, and coping*, New York, Springer Publishing Company.
- LAZENBY, M. & KHATIB, J. 2012. Associations among Patient Characteristics, Health-Related Quality of Life, and Spiritual Well-Being among Arab Muslim Cancer Patients. *J Palliat Med*, 15, 1321-4.
- LEE, E.-H., YAE CHUNG, B., BOOG PARK, H. & HONG CHUN, K. 2004. Relationships of mood disturbance and social support to symptom experience in Korean women with breast cancer. *Journal of pain and symptom management*, 27, 425-433.
- LENGACHER, C. A., KIP, K. E., POST-WHITE, J., FITZGERALD, S., NEWTON, C., BARTA, M., JACOBSEN, P. B., SHELTON, M. M., MOSCOSO, M., JOHNSON-MALLARD, V., HARRIS, E., LOFTUS, L., COX, C., LE, N., GOODMAN, M., DJEU, J., WIDEN, R. H., BERCU, B. B. & KLEIN, T. W. 2013. Lymphocyte Recovery After Breast Cancer Treatment and Mindfulness-Based Stress Reduction (MBSR) Therapy. *Biol Res Nurs*, 15, 37-47.
- LEVENTHAL, H., NERENZ, D. R. & PURSE, J. 1984. *Illness representations and coping with health threats*, New Jersey, Lawrence Erlbaum Associates.
- LEZOCHÉ, E., BALDARELLI, M., DE SANCTIS, A., LEZOCHÉ, G. & GUERRIERI, M. 2007. Early rectal cancer: definition and management. *Digestive Diseases*, 25, 76-79.
- LIEBERMAN, M. A. & GOLDSTEIN, B. A. 2006. Not all negative emotions are equal: the role of emotional expression in online support groups for women with breast cancer. *Psycho-Oncology*, 15, 160-168.
- LINCOLN, Y. S. 1985. *Naturalistic inquiry*, Beverly Hills, CA, Sage.
- LIU, C. J., HSIUNG, P. C., CHANG, K. J., LIU, Y. F., WANG, K. C., HSIAO, F. H., NG, S. M. & CHAN, C. L. W. 2008. A study on the efficacy of body-mind-spirit group therapy for patients with breast cancer. *Journal of clinical nursing*, 17, 2539-2549.
- LOCONTE, N. K., ELSE-QUEST, N. M., EICKHOFF, J., HYDE, J. & SCHILLER, J. H. 2008. Assessment of guilt and shame in patients with non-small-cell lung cancer compared with patients with breast and prostate cancer. *Clin Lung Cancer*, 9, 171-8.

- LOPEZ, K. A. & WILLIS, D. G. 2004. Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, 14, 726-735.
- LOZI, B. 2013. The Effect of Refugees on Host Country Economy Evidence from Jordan *INTERDISCIPLINARY JOURNAL OF CONTEMPORARY RESEARCH IN BUSINESS* [Online]. Available: <http://journal-archieves34.webs.com/114-126.pdf> [Accessed 09/04/2014].
- LUTGENDORF, S. K., SOOD, A. K., ANDERSON, B., MCGINN, S., MAISERI, H., DAO, M., SOROSKY, J. I., DE GEEST, K., RITCHIE, J. & LUBAROFF, D. M. 2005. Social support, psychological distress, and natural killer cell activity in ovarian cancer. *Journal of Clinical Oncology*, 23, 7105-7113.
- LYNN GALL, T. & CORNBLAT, M. W. 2002. Breast cancer survivors give voice: a qualitative analysis of spiritual factors in long-term adjustment. *Psycho-Oncology*, 11, 524-535.
- LYONS, K. D. 2006. Occupation as a vehicle to surmount the psychosocial challenges of cancer. *Occupational Therapy in Health Care*, 20, 1-16.
- MANEESRIWONGUL, W. & DIXON, J. K. 2004. Instrument translation process: a methods review. *Journal of advanced nursing*, 48, 175-186.
- MANNE, S. L., OSTROFF, J. S., NORTON, T. R., FOX, K., GOLDSTEIN, L. & GRANA, G. 2005. Cancer-related relationship communication in couples coping with early stage breast cancer. *Psycho-Oncology*, 15, 234-247.
- MANNE, S. L., RUBIN, S., EDELSON, M., ROSENBLUM, N., BERGMAN, C., HERNANDEZ, E., CARLSON, J., ROCERETO, T. & WINKEL, G. 2007. Coping and communication-enhancing intervention versus supportive counseling for women diagnosed with gynecological cancers. *Journal of consulting and clinical psychology*, 75, 615.
- MARIJNEN, C., KAPITEIJN, E., VAN DE VELDE, C., MARTIJN, H., STEUP, W., WIGGERS, T., KRANENBARG, E. K. & LEER, J. 2002. Acute side effects and complications after short-term preoperative radiotherapy combined with total mesorectal excision in primary rectal cancer: report of a multicenter randomized trial. *Journal of Clinical Oncology*, 20, 817-825.
- MARSHALL, M. N. 1996. Sampling for qualitative research. *Family practice*, 13, 522-526.
- MASON, J. 2002. *Qualitative researching*, London, Sage.
- MAXWELL, J. A. 2012. *Qualitative research design: An interactive approach*, Thousand Oaks, Sage.
- MCKENZIE, H. & CROUCH, M. 2004. Discordant feelings in the lifeworld of cancer survivors. *Health*, 8, 139-157.
- MEIER, A., LYONS, E. J., RIMER, B. K., FRYDMAN, G. & FORLENZA, M. 2007. How Cancer Survivors Provide Support on Cancer-Related Internet Mailing Lists. *Journal of Medical Internet Research*, 9, 58-84.
- METCALFE, K. A., SEMPLER, J., QUAN, M. L., VADAPARAMPIL, S. T., HOLLOWAY, C., BROWN, M., BOWER, B., SUN, P. & NAROD, S. A. 2012. Changes in psychosocial functioning 1 year after mastectomy alone, delayed breast reconstruction, or immediate breast reconstruction. *Ann Surg Oncol*, 19, 233-41.
- MILES, M. B. & HUBERMAN, A. M. 1994. *Qualitative data analysis: An expanded sourcebook*, Sage Publications, Incorporated.

- MOH. 2008. *MOH* [Online]. Available: <http://www.moh.gov.jo/AR/Pages/default.aspx> [Accessed 4th December 2008].
- MOORE, R. J. 2001. African American women and breast cancer: notes from a study of narrative. *Cancer nursing*, 24, 35-42.
- MORGAN, P. D., FOGEL, J., ROSE, L., BARNETT, K., MOCK, V., LANE, B., GASKINS, M. & BROWN-DAVIS, C. Year. African American couples merging strengths to successfully cope with breast cancer. *In: Oncology nursing forum*, 2005. Onc Nurs Society, 979-987.
- MUNHALL, P. L. 2011. *Nursing research*, Sudbury, MA, Jones & Bartlett Publishers.
- MUNN-GIDDINGS, C. & MCVICAR, A. 2007. Self-help groups as mutual support: What do carers value? *Health & social care in the community*, 15, 26-34.
- NAUSHEEN, B., GIDRON, Y., PEVELER, R. & MOSS-MORRIS, R. 2009. Social support and cancer progression: a systematic review. *Journal of psychosomatic research*, 67, 403-415.
- NETTLETON, S., BURROWS, R. & O'MALLEY, L. 2005. The mundane realities of the everyday lay use of the internet for health, and their consequences for media convergence. *Sociology of Health & Illness*, 27, 972-992.
- NEWELL, S. A., SANSON-FISHER, R. W. & SAVOLAINEN, N. J. 2002. Systematic review of psychological therapies for cancer patients: overview and recommendations for future research. *Journal of the National Cancer Institute*, 94, 558-584.
- NEWMAN, K., MAYLOR, U. & CHANSARKAR, B. 2002. "The nurse satisfaction, service quality and nurse retention chain": Implications for management of recruitment and retention. *Journal of Management in Medicine*, 16, 271-291.
- NGOMA, T. 2006. World Health Organization cancer priorities in developing countries. *Annals of oncology*, 17, viii9-viii14.
- NHMRC. National Health and Medical Research Council 2003. Available: <http://www.nhmrc.gov.au> [Accessed 20th April 2013].
- NÖRES, D., VON GARMISSSEN, A., NEISES, M. & GEYER, S. 2011. Differences in illness-related knowledge of breast cancer patients according to their involvement in self-help groups. *Journal of Psychosomatic Obstetrics & Gynecology*, 32, 147-153.
- NORTHOUSE, L. L., ROSSET, T., PHILLIPS, L., MOOD, D., SCHAFENACKER, A. & KERSHAW, T. 2006. Research with families facing cancer: the challenges of accrual and retention. *Research in nursing & health*, 29, 199-211.
- NORTON, E. A. 1999. The philosophical bases of grounded theory and the implications for research practice. *Nurse Researcher*, 7, 31-44.
- OBEIDAT, R. F., DICKERSON, S. S., HOMISH, G. G., ALQAISSI, N. M. & LALLY, R. M. 2012a. Controlling Fear: Jordanian Women's Perceptions of the Diagnosis and Surgical Treatment of Early-Stage Breast Cancer. *Cancer Nurs.*
- OBEIDAT, R. F., LALLY, R. M. & DICKERSON, S. S. 2012b. Arab American women's lived experience with early-stage breast cancer diagnosis and surgical treatment. *Cancer nursing*, 35, 302-311.
- OHAERI, B. M., OFI, A. B. & CAMPBELL, O. B. 2012. Relationship of knowledge of psychosocial issues about cancer with psychic distress and adjustment

- among breast cancer clinic attendees in a Nigerian teaching hospital. *Psychooncology*, 21, 419-26.
- OKA, T. 2011. Self-Help Groups, Self-Help Supporters, and Social Work: A Theoretical Discussion with Some Case Illustrations of Family Survivors of Suicide in Japan. *Studies on Social Work*, 37, 168-183.
- OKA, T. 2013. Self-Help Groups in Japan: Historical Development and Current Issues. *International Journal of Self Help and Self Care*, 7, 217-232.
- OMRAN, S., SAEED, A. M. & SIMPSON, J. 2012. Symptom distress of Jordanian patients with cancer receiving chemotherapy. *Int J Nurs Pract*, 18, 125-32.
- ONKEN, S. J., CRAIG, C. M., RIDGWAY, P., RALPH, R. O. & COOK, J. A. 2007a. An analysis of the definitions and elements of recovery: a review of the literature. *Psychiatric Rehabilitation Journal*, 31, 9.
- ONKEN, S. J., CRAIG, C. M., RIDGWAY, P., RALPH, R. O. & COOK, J. A. 2007b. An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatric Rehabilitation Journal*, 31, 9-22.
- OWEN, J. E., GOLDSTEIN, M. S., LEE, J. H., BREEN, N. & ROWLAND, J. H. 2007. Use of health-related and cancer-specific support groups among adult cancer survivors. *Cancer*, 109, 2580-2589.
- PALMADOTTIR, G. 2009. The road to recovery: Experiences and occupational lives of Icelandic women with breast cancer. *Occupational Therapy in Health Care*, 23, 319-335.
- PARDINI, D. A., PLANTE, T. G., SHERMAN, A. & STUMP, J. E. 2000. Religious faith and spirituality in substance abuse recovery: Determining the mental health benefits. *Journal of substance abuse treatment*, 19, 347-354.
- PATTON, M. Q. 2002. *Qualitative Research & Evaluation Methods* London, Sage Publication.
- PEETERS, K., VAN DE VELDE, C., LEER, J., MARTIJN, H., JUNGGEURT, J., KRANENBARG, E. K., STEUP, W., WIGGERS, T., RUTTEN, H. & MARIJNEN, C. 2005. Late side effects of short-course preoperative radiotherapy combined with total mesorectal excision for rectal cancer: increased bowel dysfunction in irradiated patients—a Dutch colorectal cancer group study. *Journal of Clinical Oncology*, 23, 6199-6206.
- PETRO-NUSTAS, W. I. 2001. Factors associated with mammography utilization among Jordanian women. *J Transcult Nurs*, 12, 284-91.
- PHILLIPS, K. D. & SOWELL, R. L. 2000. Hope and coping in HIV-infected African-American women of reproductive age. *J Natl Black Nurses Assoc*, 11, 18-24.
- PHILLIPS, K. D., SOWELL, R. L., MISENER, T. R. & TAVAKOLI, A. 2000. Levels of hope in HIV-infected African-American women of reproductive age. *Clin Excell Nurse Pract*, 4, 90-7.
- PICCART-GEHART, M. J., PROCTER, M., LEYLAND-JONES, B., GOLDBIRSCH, A., UNTCH, M., SMITH, I., GIANNI, L., BASELGA, J., BELL, R. & JACKISCH, C. 2005. Trastuzumab after adjuvant chemotherapy in HER2-positive breast cancer. *New England Journal of Medicine*, 353, 1659-1672.
- PINQUART, M., SILBEREISEN, R. K. & FRÖHLICH, C. 2009. Life goals and purpose in life in cancer patients. *Supportive care in cancer*, 17, 253-259.
- PISTRANG, N., BARKER, C. & HUMPHREYS, K. 2008. Mutual help groups for mental health problems: a review of effectiveness studies. *American Journal of Community Psychology*, 42, 110-121.

- PISTRANG, N., JAY, Z., GESSLER, S. & BARKER, C. 2012. Telephone peer support for women with gynaecological cancer: recipients' perspectives. *Psychooncology*, 21, 1082-90.
- PLASS, A. & KOCH, U. 2001. Participation of oncological outpatients in psychosocial support. *Psycho-Oncology*, 10, 511-520.
- POLIT, D., BECK, C. & HUNGLER, B. 2006. Essentials of Nursing Research: Methods, Appraisal and Utilization. 2006. *Lippincott Williams & Wilkins, Philadelphia*, 2, 11-23.
- POLIT, D. B. & HUNGLER, C. C (2006) Essentials of nursing research: Methods, Appraisal, and Utilization. Philadelphia: Lippincott Williams & Wilkins.
- POLIT, D. F., BECK, C. T. & HUNGLER, B. P. 2001. *Essentials of nursing research : Methods, appraisal, and utilization*, Philadelphia: Lippincott-Raven.
- PORTER, S. 2007. Validity, trustworthiness and rigour: Reasserting realism in qualitative research. *Journal of advanced nursing*, 60, 79-86.
- RALPH, R. O., CORRIGAN, P. W. & NELSON, G. 2009. Recovery in Mental Illness: Broadening Our Understanding of Wellness. *Canadian Journal of Community Mental Health (Revue canadienne de santé mentale communautaire)*, 28, 99-101.
- RASHID, M. U., ZAIDI, A., TORRES, D., SULTAN, F., BENNER, A., NAQVI, B., SHAKOORI, A. R., SEIDEL-RENKERT, A., FAROOQ, H. & NAROD, S. 2006. Prevalence of BRCA1 and BRCA2 mutations in Pakistani breast and ovarian cancer patients. *International journal of cancer*, 119, 2832-2839.
- RAUPACH, J. C. & HILLER, J. E. 2002. Information and support for women following the primary treatment of breast cancer. *Health Expectations*, 5, 289-301.
- RAWABDEH, A. A. A. 2005. Health care cost containment strategies: the Jordanian experience. *The International journal of health planning and management*, 20, 53-66.
- REED, E., SIMMONDS, P., HAVILAND, J. & CORNER, J. 2011. Quality of Life and Experience of Care in Women With Metastatic Breast Cancer: A Cross-Sectional Survey. *Journal of pain and symptom management*.
- REED, E., SIMMONDS, P., HAVILAND, J. & CORNER, J. 2012. Quality of life and experience of care in women with Metastatic breast cancer: a cross-sectional survey. *Journal of pain and symptom management*, 43, 747-758.
- REMMERS, H., HOLTGRÄWE, M. & PINKERT, C. 2010. Stress and nursing care needs of women with breast cancer during primary treatment: A qualitative study. *European Journal of Oncology Nursing*, 14, 11-16.
- REYNOLDS, D. 2006. Examining spirituality among women with breast cancer. *Holistic Nursing Practice*, 20, 118-121.
- REYNOLDS, F. & PRIOR, S. 2006. The role of art-making in identity maintenance: case studies of people living with cancer. *European journal of cancer care*, 15, 333-341.
- RICHARDSON, L. 2000. Writing: A method of inquiry. In: Y., D. & S, L. (eds.) *Handbook of qualitative research* (2nd) ed. Thousand Oaks: CA: Sage.
- RICOEUR, P. 1976. *Interpretation theory: Discourse and the surplus of meaning*, Texas, Texas Christian University Press.
- RUBIN, I. S. & RUBIN, H. J. 2011. *Qualitative interviewing: The art of hearing data*, California, Sage Publications.

- RUSSELL, G. M. & KELLY, N. H. Year. Research as interacting dialogic processes: Implications for reflexivity. In: Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 2002.
- SAEGROV, S. & HALDING, A. G. 2004. What is it like living with the diagnosis of cancer? *European journal of cancer care*, 13, 145-153.
- SALKOVSKIS, P. M. & WARWICK, H. M. 2001. Meaning, misinterpretations, and medicine: a cognitive-behavioral approach to understanding health anxiety and hypochondriasis. *Hypochondriasis: Modern perspectives on an ancient malady*, 202-222.
- SAMMARCO, A. 2003. Quality of life among older survivors of breast cancer. *Cancer nursing*, 26, 431-438.
- SANDAUNET, A. G. 2008. The challenge of fitting in: non-participation and withdrawal from an online self-help group for breast cancer patients. *Sociology of Health & Illness*, 30, 131-144.
- SANDELOWSKI, M. 2000. Focus on Research Methods-Whatever Happened to Qualitative Description? *Research in nursing and health*, 23, 334-340.
- SCHMID-BUCHI, S., HALFENS, R. J., DASSEN, T. & VAN DEN BORNE, B. 2008. A review of psychosocial needs of breast-cancer patients and their relatives. *J Clin Nurs*, 17, 2895-909.
- SCHROEVERS, M. J., RANCHOR, A. V. & SANDERMAN, R. 2003. The role of social support and self-esteem in the presence and course of depressive symptoms: a comparison of cancer patients and individuals from the general population. *Social science & medicine*, 57, 375-385.
- SEEBOHM, P., CHAUDHARY, S., BOYCE, M., ELKAN, R., AVIS, M. & MUNN-GIDDINGS, C. 2013. The contribution of self-help/mutual aid groups to mental well-being. *Health & social care in the community*, 21, 391-401.
- SEEGERS, C., WALKER, B. L., NAIL, L. M., SCHWARTZ, A., MUDGETT, L. L. & STEPHEN, S. 1998. Self-care and breast cancer recovery. *Cancer Pract*, 6, 339-45.
- SELDEN, L. 2005. On Grounded Theory-with some malice. *Journal of Documentation*, 61, 114-129.
- SHANNON, C. & BOURQUE, D. 2005. Overlooked and underutilized: the critical role of leisure interventions in facilitating social support throughout breast cancer treatment and recovery. *Social work in health care*, 42, 73.
- SHENTON, A. K. 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22, 63-75.
- SHERMAN, D. W., ROSEDALE, M. & HABER, J. 2012. Reclaiming life on one's own terms: a grounded theory study of the process of breast cancer survivorship. *Oncol Nurs Forum*, 39, E258-68.
- SHIELDS, C. G. & ROUSSEAU, S. J. 2004. A pilot study of an intervention for breast cancer survivors and their spouses. *Family process*, 43, 95-107.
- SILVA, M. B. D., MIRANDA, F. A. N. D., PESSOA JÚNIOR, J. M. & COUTINHO, F. S. V. 2013. WOMEN WITH BREAST CANCER UNDERWENT CHEMOTHERAPY: NURSING ASSISTANCE THROUGH A CONTEXTUAL ANALYSIS. *Revista de Pesquisa: Cuidado é Fundamental Online*, 5, 264-272.
- SILVA, M. C. S. A. & LAUTERT, L. 2010. The sense of self-efficacy in maintaining health promoting behaviors in older adults. *Revista da Escola de Enfermagem da USP*, 44, 61-67.

- SILVERMAN, D. 2003. *Qualitative Research Theory, Method and Practice*, London., SAGE Publications Ltd.
- SIM, J. 1998. Collecting and analysing qualitative data: issues raised by the focus group. *Journal of advanced nursing*, 28, 345-352.
- SKINNER, D. & MFECANE, S. 2004. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 1, 157-164.
- SMYTH, M. & WILLIAMSON, E. 2004. *Researchers and Their" subjects": Ethics, Power, Knowledge and Consent*, Policy Press.
- SOMLO, G., CHOW, W., HAMASAKI, V., LEONG, L., MARGOLIN, K., MORGAN, R., JR., SNIECINSKI, I., FRANKEL, P., REARDON, D., LONGMATE, E., RASCHKO, J., SHIBATA, S., O'DONNELL, M., SMITH, E., TETEF, M., FORMAN, S., YEN, Y., MOLINA, A. & DOROSHOW, H. 2001. Tandem-cycle high-dose melphalan and cisplatin with peripheral blood progenitor cell support in patients with breast cancer and other malignancies. *Biol Blood Marrow Transplant*, 7, 284-93.
- SOMLO, G., SNIECINSKI, I., ODOM-MARYON, T., NOWICKI, B., CHOW, W., HAMASAKI, V., LEONG, L., MARGOLIN, K., MORGAN, R., JR., RASCHKO, J., SHIBATA, S., TETEF, M., MOLINA, A., BERENSON, R. J., FORMAN, S. J. & DOROSHOW, J. H. 1997. Effect of CD34+ selection and various schedules of stem cell reinfusion and granulocyte colony-stimulating factor priming on hematopoietic recovery after high-dose chemotherapy for breast cancer. *Blood*, 89, 1521-8.
- SPIILKA, B., SHAVER, P. & KIRKPATRICK, L. A. 1985. A general attribution theory for the psychology of religion. *Journal for the Scientific Study of Religion*, 1-20.
- STANG, I. & MITTELMARK, M. B. 2009. Learning as an empowerment process in breast cancer self-help groups. *J Clin Nurs*, 18, 2049-57.
- STEFANEK, M., MCDONALD, P. G. & HESS, S. A. 2004. Religion, spirituality and cancer: current status and methodological challenges. *Psycho-Oncology*, 14, 450-463.
- STEFANEK, M., MCDONALD, P. G. & HESS, S. A. 2005. Religion, spirituality and cancer: current status and methodological challenges. *Psycho-Oncology*, 14, 450-463.
- STOLBERG, H. O., NORMAN, G. & TROP, I. 2004. Randomized controlled trials. *American Journal of Roentgenology*, 183, 1539-1544.
- SUSSNER, K. M., EDWARDS, T. A., THOMPSON, H. S., JANDORF, L., KWATE, N. O., FORMAN, A., BROWN, K., KAPIL-PAIR, N., BOVBJERG, D. H., SCHWARTZ, M. D. & VALDIMARSDOTTIR, H. B. 2011. Ethnic, racial and cultural identity and perceived benefits and barriers related to genetic testing for breast cancer among at-risk women of African descent in New York City. *Public Health Genomics*, 14, 356-70.
- SUSSNER, K. M., THOMPSON, H. S., JANDORF, L., EDWARDS, T. A., FORMAN, A., BROWN, K., KAPIL-PAIR, N., BOVBJERG, D. H., SCHWARTZ, M. D. & VALDIMARSDOTTIR, H. B. 2009. The influence of acculturation and breast cancer-specific distress on perceived barriers to genetic testing for breast cancer among women of African descent. *Psychooncology*, 18, 945-55.

- TAHA, H., AL-QUTOB, R., NYSTRÖM, L., WAHLSTRÖM, R. & BERGGREN, V. 2012. "Voices of Fear and Safety" Women's ambivalence towards breast cancer and breast health: a qualitative study from Jordan. *BMC women's health*, 12, 21.
- TAKAHASHI, M. & KAI, I. 2005. Sexuality after breast cancer treatment: changes and coping strategies among Japanese survivors. *Soc Sci Med*, 61, 1278-90.
- TALEGHANI, F., YEKTA, Z. P. & NASRABADI, A. N. 2006. Coping with breast cancer in newly diagnosed Iranian women. *Journal of Advanced nursing*, 54, 265-272.
- TARAWNEH, M. & NIMRI, O. 2007. *Cancer incidence in Jordan* [Online]. Available: http://www.emro.who.int/ncd/pdf/jor_cancer_2007.pdf [Accessed 10th November 2007].
- TAYLOR, C. 2012. Reach for recovery: Evaluating a pilot study of a colorectal cancer survivorship programme. *European Journal of Oncology Nursing*.
- TEPPER, J., KRASNA, M. J., NIEDZWIECKI, D., HOLLIS, D., REED, C. E., GOLDBERG, R., KIEL, K., WILLETT, C., SUGARBAKER, D. & MAYER, R. 2008. Phase III trial of trimodality therapy with cisplatin, fluorouracil, radiotherapy, and surgery compared with surgery alone for esophageal cancer: CALGB 9781. *Journal of Clinical Oncology*, 26, 1086-1092.
- TERCYAK, K. P., MAYS, D., DEMARCO, T. A., SHARFF, M. E. & FRIEDMAN, S. 2012. Results of an Online Community Needs Assessment for Psychoeducational Interventions Among Partners of Hereditary Breast Cancer Prevalors and Survivors. *Journal of Medical Internet Research*, 14, 24-24.
- THEWES, B., BUTOW, P., GIRGIS, A. & PENDLEBURY, S. 2004. The psychosocial needs of breast cancer survivors; a qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncology*, 13, 177-189.
- THORESEN, C. E., HARRIS, A. H. S. & OMAN, D. 2001. Spirituality, religion, and health. *Faith and health, TG Plante, & AC Sherman (Eds)*, 15-52.
- THORN, B. E. & KUHAJDA, M. C. 2006. Group cognitive therapy for chronic pain. *Journal of clinical psychology*, 62, 1355-1366.
- THORNE, S. 2008. *Interpretive Description*, Walnut, Creek, CA., Left Coast Press.
- THUNÉ-BOYLE, I., STYGALL, J., KESHTGAR, M., DAVIDSON, T. & NEWMAN, S. 2011. The impact of a breast cancer diagnosis on religious/spiritual beliefs and practices in the UK. *Journal of religion and health*, 50, 203-218.
- UK, C. R. 2008. *UK breast cancer incidence statistics*. [Online]. Available: <http://info.cancerresearchuk.org/cancerstats/types/breast/> [Accessed 15th October 2009].
- USSHER, J., KIRSTEN, L., BUTOW, P. & SANDOVAL, M. 2006. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social science & medicine*.
- USSHER, J. M., PERZ, J. & GILBERT, E. 2012. Changes to sexual well-being and intimacy after breast cancer. *Cancer Nurs*, 35, 456-65.
- VAN MANEN, M. 1990. *Researching lived experience: Human science for an action sensitive pedagogy*, Suny Press.
- VARGENS, O. M. & BERTERÖ, C. M. 2007. Living with breast cancer: its effect on the life situation and the close relationship of women in Brazil. *Cancer nursing*, 30, 471-478.

- VINCENT-SALOMON, A. & THIERY, J. P. 2003. Epithelial-mesenchymal transition in breast cancer development. *Breast Cancer Research*, 5, 101-106.
- VINH-HUNG, V. & VERSCHRAEGEN, C. 2004. Breast-conserving surgery with or without radiotherapy: pooled-analysis for risks of ipsilateral breast tumor recurrence and mortality. *Journal of the National Cancer Institute*, 96, 115-121.
- VOS, J., VAN ASPEREN, C. J., OOSTERWIJK, J. C., MENKO, F. H., COLLEE, M. J., GARCIA, E. G. & TIBBEN, A. 2012. The counselees' self-reported request for psychological help in genetic counseling for hereditary breast/ovarian cancer: not only psychopathology matters. *Psychooncology*.
- WALKER, S. 2005. *Prostate cancer support groups: an evaluation*. Department of Psychology, Swinburne University of Technology.
- WASSERSUG, R. J. & OLIFFE, J. L. 2009. The social context for psychological distress from iatrogenic gynecomastia with suggestions for its management. *J Sex Med*, 6, 989-1000.
- WEBB, C. & KEVERN, J. 2001. Focus groups as a research method: a critique of some aspects of their use in nursing research. *Journal of advanced nursing*, 33, 798-805.
- WENGRAF, T. 2001. *Qualitative research interviewing: Biographic narrative and semi-structured methods*, London, Sage Publications Limited.
- WENGSTROM, Y., HAGGMARK, C. & FORSBERG, C. 2001. Coping with radiation therapy: strategies used by women with breast cancer. *Cancer Nurs*, 24, 264-71.
- WHITE, B. J. & MADARA, E. J. 2002. *The self-help group sourcebook: Your guide to community and online support groups*, Cedar Knolls, Amer Self-Help Group Clearing house.
- WHO 2003. *World cancer report*, Lyon, IARC Press.
- WHO. 2008. *Are the numbers of cancer cases increasing or decreasing in the world?*. [Online]. Available: Retrieved June 11, 2010. From. <http://www.who.int/features/qa/15/en/index.html>. [Accessed].
- WHO. 2009. *World Health Organisation Retrieved* [Online]. <http://www.who.int/en/>. Available: <http://www.who.int/en/>. [Accessed].
- WILES, R., COTT, C. & GIBSON, B. E. 2008. Hope, expectations and recovery from illness: a narrative synthesis of qualitative research. *Journal of advanced nursing*, 64, 564-573.
- WILLIAMSON, J. M., JONES, I. H. & HOCKEN, D. B. 2011. How does the media profile of cancer compare with prevalence? *Ann R Coll Surg Engl*, 93, 9-12.
- WILMOTH, M. & SANDERS, L. D. Year. Accept me for myself: African American women's issues after breast cancer. In: *Oncology nursing forum*, 2001. 875.
- WINCHESTER, H. P. M. 2000. *Qualitative research and its place in human geography*, Melbourne, Oxford University Press Oxford.
- WONG-KIM, E., SUN, A., MERIGHI, J. R. & CHOW, E. A. 2005. Understanding quality-of-life issues in Chinese women with breast cancer: a qualitative investigation. *Cancer Control*, 12 Suppl 2, 6-12.
- WONG, L. Y., LEUNG, P. C., TANG, J. L. & MERCER, S. W. 2010. Use of dietary supplements by breast cancer patients undergoing conventional cancer treatment. *Patient Prefer Adherence*, 4, 407-14.
- WONG, R. & MALTHANER, R. 2006. Combined chemotherapy and radiotherapy (without surgery) compared with radiotherapy alone in localized carcinoma of the esophagus. *Cochrane Database Syst Rev*, 1, CD002092.

- WRIGHT, L. M. & BELL, J. M. 2009. *Beliefs and illness: A model for healing*, 4th Floor Press.
- WYATT, G. K., DONZE, L. F. & BECKROW, K. C. 2004. Efficacy of an in-home nursing intervention following short-stay breast cancer surgery. *Res Nurs Health*, 27, 322-31.
- YAMAKAWA, M., NITTA, N., SHIINA, T., MATSUMURA, T., TAMANO, S., MITAKE, T. & UENO, E. 2003. High-speed freehand tissue elasticity imaging for breast diagnosis. *Japanese journal of applied physics*, 42, 3265.
- YOSHIOKA, M. R. & SCHUSTACK, A. 2001. Disclosure of HIV status: cultural issues of Asian patients. *AIDS Patient Care and STDs*, 15, 77-82.
- YOUNG, S. L. & ENSING, D. S. 1999. Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 22, 219.
- ZORRILLA, C. D., SANTIAGO, L. E., HILERIO, C., ESTRONZA, G. & FALK, T. 2005. An empowerment intervention for women living with HIV and its adaptation for women with a diagnosis of breast cancer. *Ethn Dis*, 15, S5-128-32.
- ZUIDGEEST, M., HENDRIKS, M., KOOPMAN, L., SPREEUWENBERG, P. & RADEMAKERS, J. 2011. A Comparison of a Postal Survey and Mixed-Mode Survey Using a Questionnaire on Patients' Experiences With Breast Care. *Journal of Medical Internet Research*, 13, 23-23.