Life journeys with advanced breast cancer in Mauritania: A mixed methods case study

David Mark Fearon

MBChB, MRCGP, DTMH

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere

Abstract

Background:

Breast cancer is the most common cancer for women, globally. Social, religious and healthcare contexts have been shown to influence women's experiences of advanced breast cancer; however, research has tended to focus on resource-rich nations. There is limited research from low-resource contexts, and little is known on the experiences of Arab, Muslim and African women with advanced breast cancer.

Aim:

To explore and understand the experiences of advanced breast cancer in the Islamic Republic of Mauritania, West Africa.

Methods:

Using a constructivist Stakian multi-case study approach, eight cases were constructed around women (n=8) with advanced breast cancer, family members (n=10) and health professionals (n=9). Data were collected longitudinally (up to nine months per case) and consisted of interviews, audio-journals, a patient reported outcome measurement scale and a performance status scale. Within-case and cross-case analysis was undertaken, with thematic analysis of qualitative data.

Findings:

Three key themes were identified: 1. Destiny, 2. Patience & Acceptance and 3. Journeying in search of a cure. Mauritanian women appreciate that Allah is all powerful and maintains control over their destinies and their breast cancer. A fear of causing offence to Allah influences how they express negative experiences of breast cancer and its treatments. The women's access to information and treatment is controlled by health professionals and families. Women are, therefore, required to use their own observations and interpretations to understand their breast cancer and empower their pursuit of treatment and a cure.

Conclusion:

Maure women's experiences of advanced breast cancer in Mauritania are influenced by power imbalances. Allah is all-powerful. Families and health professionals exert power over Maure women's access to information, healthcare decisions and how they express negative experiences. This thesis demonstrates that Maure women are cognisant of these challenges and, either, accept them as reality or attempt to work around them.

Acknowledgements

To the voiceless women in Mauritania:

May your intelligence be recognised and respected
May you care and speak out for one another
May those around you be willing to listen, respond with empathy and speak gently with you
May you continue to seek understanding

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Chapter 1: Introduction

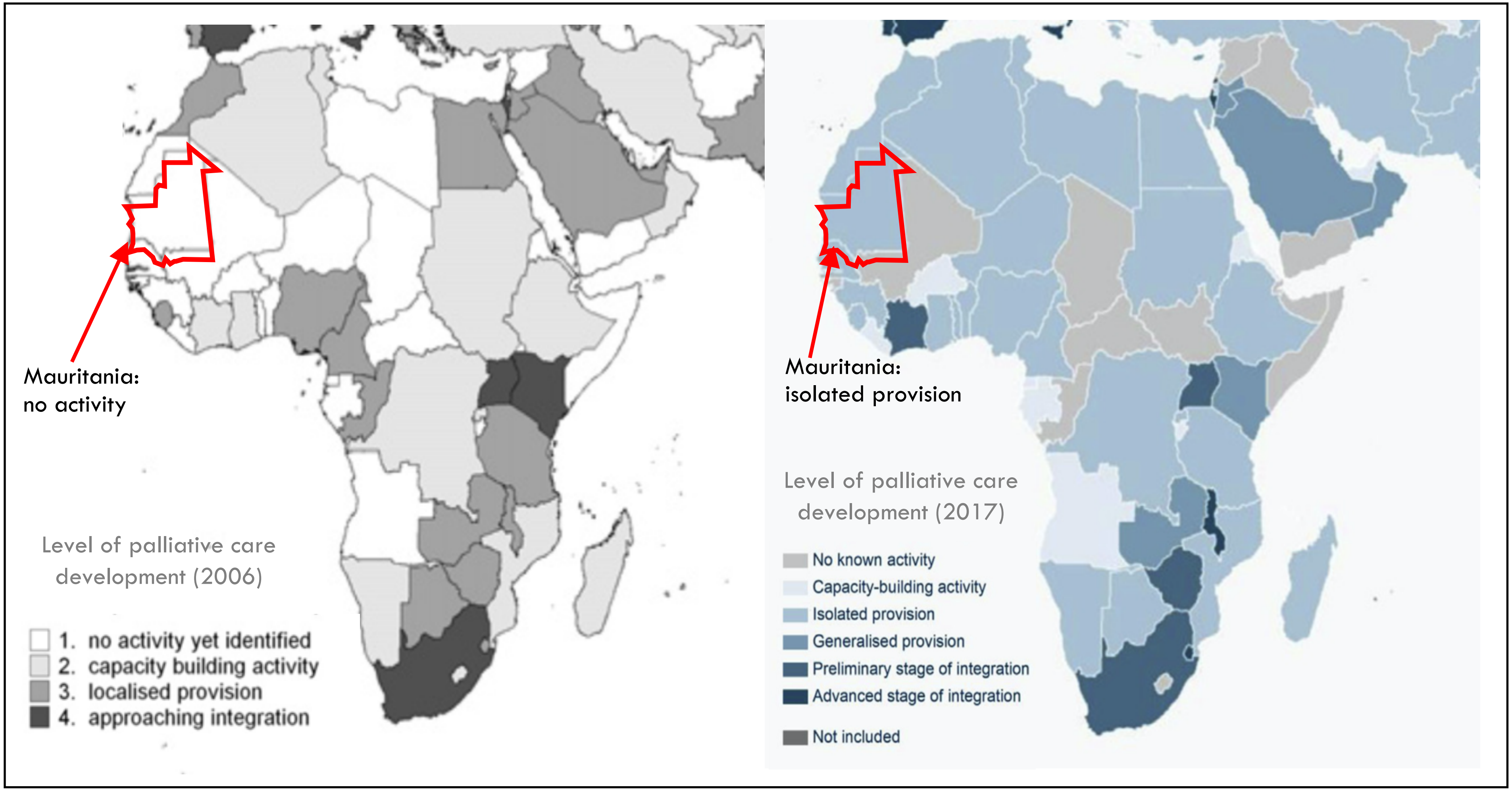
1.1 Introduction

This chapter introduces the study of experiences of advanced breast cancer in Mauritania. The first section will provide descriptions of palliative care and breast cancer. In the second section, the study context of Mauritania will be highlighted, with introduction to the social, medical and religious cultural contexts. In the third section, the motivations for this research will be summarised. The chapter will conclude with a summary of the thesis structure.

1.2 Palliative care

Palliative care is the holistic care destined for individuals and their families who face potentially life-limiting illnesses (World Health Organisation (WHO), 2019). Its aim, influenced by the mortality of the individual, is the enhancement of the quality rather than the duration of life. Palliative care has been implicit in care provided for centuries in many contexts; for example, the religious hospices in Ireland and the United Kingdom where nuns cared holistically for those with tuberculosis and in poverty (Payne and Lynch, 2015). The modern hospice movement started in the 1960's, with the founding of St Christopher's hospice in London (Payne and Lynch, 2015). In the following decades, the provision of palliative care expanded first across Europe and North America, and then globally.

In high-income contexts, palliative care became closely associated with cancer and, at times, was entrenched within cancer services to the disadvantage of those with non-cancerous life-limiting conditions (Dempers and Gott, 2017). This relationship was identified and challenged, and palliative care became more integrated into non cancer specialities; such as, cardiology, care of the eldery, renal and respiratory (Laird, 2015). In contrast, the development of palliative care in Africa has been slower, despite the continent's first hospice being founded in 1979 (Clark et al., 2007). Much of the available palliative care service provision in Africa has been focused on Anglophone regions with high rates of Human Immunodeficiency Virus (HIV) (Rhee, et al., 2017; Human Rights Watch, 2015; Gysels et al., 2011). The provision of palliative care is increasing across Africa. Over the last two decades, many African countries have transitioned from having no palliative care activity to having isolated services, while a few have integrated palliative care provision in the national healthcare system (figure 1.1) (Clark et al., 2019; Grant et al., 2017; Lynch et al., 2013; Wright et al., 2008). In Mauritania, West Africa, palliative care has transitioned from no activity in 2006 to isolated provision in 2017.



Taken from Wright et al. (2008) and Clark et al. (2019)

Figure 1.1 Mapping of palliative care development in Africa between 2006 and 2017

Research from Africa demonstrates that life-threatening illnesses are often associated with negative experiences, such as symptoms, financial worries and uncertainty of their diagnosis (Ajayi et al., 2014; Powell et al., 2014; Lewington et al., 2012; Gysels et al., 2011). Firstly, symptoms remain unrelieved due to a lack of access to appropriately trained health professionals, facilities and medications, such as strong analgesia for pain (Beterame et al., 2016; Cleary et al, 2013). Opioid consumption, a proxy measure for palliative care provision, remains very low in much of the African continent. Seventy-five percent of African countries use less than 1mg per capita per year, in contrast to the global average of 48mg (Rhee et al., 2017).

Secondly, families may experience catastrophic health spending, a reduction of their basic expenditure to cover health-related costs, which results in deeper poverty (Xu et al., 2003). In addition to the direct healthcare costs, serious illness can result in time off work for the patient and family members, and secondary costs such as travelling long distances to access appropriate care. Many prefer to travel abroad for healthcare, if resources permit, because of a lack of confidence in local facilities and personnel (Mostert et al., 2015).

Thirdly, healthcare encounters are associated with limited communication and the non-disclosure of serious diagnoses, which is at time protected by national legislation (Khalil, 2012; Mystakidou et al., 2004). This paternalistic approach reinforces the patient and families' uncertainty of events and lack of confidence in health professionals and can lead to prolonged anxiety and depression (Abazari et al., 2016).

The limited access to palliative care in many low and middle-income countries (LMIC) is to the detriment of people's experiences of life limiting illnesses (De Lima and Pastrana, 2016; Lynch et al. 2013). In Arabic and French speaking North and West Africa there is inadequate palliative care provision or research, in part due to the relatively lower rates of HIV and their lingua francas (Human Rights Watch, 2015; Ajayi et al., 2014). There is, therefore, little understanding of the experiences of life limiting conditions, such as advanced breast cancer, in this region.

1.3 Life journeys and experiences

The exploration of life limiting conditions centres on two key concepts, journey and experience (Gibson et al., 2016; Willig, 2011). A life has a start and an end, whether this may be viewed as death or a transition to another realm. The diagnosis of a life limiting condition, such as advanced breast cancer, draws attention to the trajectory of life, changing the journey's finish from an abstract idea to an inescapable reality (Kenne Sarenmalm et al., 2009). Researchers exploring these transformative processes employ the concept of experiences to describe moments along a life's journey.

Approaches to understanding and exploring experiences differ according to the research's underlying paradigm. For example, the experience of pain is often viewed through a positivist lens by scientists and medical professionals who focus on its physiology, pathology and management, with many successes reported (Renqvist, 2015). Much of this genre of research is congruent with a biomedical definition of pain; such as, ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage’ (International association for the study of pain, 1994). This positivist approach has faced criticism for attempting to reduce the complex, multifaceted experience of pain into a series of numbers (Fearon et al., 2019). In contrast, research from other disciplines, such as phenomenology, qualitative research, sociology, anthropology and philosophy, tends to take a more subjective and interpretive approach. Experiences such as pain are viewed as personally and socially constructed phenomenon, influenced by the individual’s cultural context, and challenging to measure (Neilson, 2016; Morrissey, 2011; Best, 2007; Van der Geest, 2004).

It is important to consider how experience is defined and interpreted within this thesis. Experiences are defined as streams of private events, known only to the owner (Blackburn, 1996). They are closely associated with meaning because a person not only lives experiences, but they also interpret and give meaning to them (Daher, M. et al., 2017). These views have implications for this thesis. Firstly, experiences and their meanings are considered as unique to the life of the individual. The extraction and measurement of experiences is incomplete because they need to be interpreted in light of the whole person (Daher, M. et al., 2017). Secondly, experiences are temporal, and their nature is changed by the acts of recollection and reporting. Any reported experience is a construction based on factors such as the person's memories of past events, their current situation and their anticipation of future events (Luft and Overgaard, 2012). In addition, this process of an individual re-entering an experience is influenced by the presence of a researcher (Davies and Shackleton, 1975).

This thesis incorporates qualitative and quantitative data in the literature review and the collected empirical data. Much of the qualitative data is congruent with the adopted definition of experience. There is more heterogeneity in the approach to experience in the quantitative data. A looser definition of experience is at times employed within this thesis; for example, the inclusion of measurement studies of psychological distress or quality of life in the literature review. Such an approach allowed the inclusion of relevant data, despite it being implicitly founded on a more positivist defintion of experience. The implications of these challenges, including the incorporation of mixed-methods of data collection and the cross-cultural and cross-language issues, are further explored in chapters four: *Methodology and methods*, and six: *Discussion and conclusion.*

1.4 Breast cancer

1.4.1 Background

Breast cancer is the most common cancer diagnosed in women, globally (Ferlay et al., 2015). It is staged according to tumour size, the number and location of affected lymph nodes and the presence of cancer-spread to other organs, metastases (Edge and Compton, 2010). The presence of metastases or involvement of distant lymph nodes is termed advanced breast cancer (Rivera-Franco and Leon-Rodriguez, 2018). Breast cancer can be further subtyped on whether the cancer expresses oestrogen, progesterone, and human epidermal growth factor 2 (HER2) receptors. Triple negative breast cancer, in which none of these receptors are expressed, is associated with a poorer prognosis (Corbex et al., 2014).

The incidence of breast cancer is highest in high-income regions such as North America and Europe (Ferlay et al., 2015). Inversely, breast cancer mortality is highest in LMICs which have lower rates of disease (Adeloye et al., 2018; Frie et al., 2018). Reasons for these variations are multifactorial, with higher incidences relating to genetic differences, improved screening, and lifestyle factors (Corbex et al., 2014). The higher mortality rates in LMICS are partly explained by the increased rates of more aggressive cancer subtypes, delayed presentations and diagnoses, and limited cancer care services (Espina et al., 2017; Corbex et al., 2014). In LMICs, 20 to 30% of new breast cancer diagnoses are metastatic, compared with less than 8% in high-income regions (Cardoso et al., 2018).

The incidence of breast cancer in the Arab region is higher than in other African regions but lower than that found in Europe and North America (Ferlay et al., 2015). In North Africa and the Middle East, breast cancer is the most frequently diagnosed cancer overall, representing an estimated 17.7 to 19% of all new cancers in 2018 (Globocan, 2018a, 2018b). Mortality rates vary across the Arab region, with worse outcomes for women in LMICs. For example, the five-year survival rates for breast cancer ranges from 85.3% in Qatar to 43.1% in Jordan, a LMIC (Allemani et al., 2015).

LMIC healthcare systems are poorly prepared for dealing with cancer. They have been focused on infectious illnesses, such as HIV and Tuberculosis because they are the major local causes of death (WHO, 2018). These causes of morbidity and mortality will soon be overtaken by non-communicable diseases, such as cancer, in LMICs if current global patterns continue (WHO, 2018). These emerging challenges require different approaches which LMIC health systems have been slow to adopt. For example, there is limited availabily and quality of screening, diagnostic facilities, and curative and palliative care for breast cancer in many LMICs.

1.4.2 Experiences of breast cancer

There has been much interest in understanding the experiences of women with breast cancer, and that of their families (Reed and Corner, 2013; Tighe et al., 2011; Montazeri, 2008; Burgess et al., 2005; Mols et al., 2005). Key events along a cancer journey include undertaking tests, learning of the diagnosis, undergoing treatments, symptoms, changing roles, and adapting to survivorship and, or end-of-life. Some of these events are associated with certain experiences. Those undergoing anti-cancer treatments, such as chemotherapy, hormone treatment, radiotherapy and surgery, typically experience lower health-related quality of life (HRQOL) (Lewis et al., 2017; Tiezzi, et al., 2017; Abazari et al., 2016). Chemotherapy is associated with physical side effects such as nausea, diarrhoea, hair loss, and neuropathy (Bergkvist and Wengström, 2006). Women undergoing radiotherapy experience skin changes and fatigue, and those undergoing surgery face changes to their body image and sexuality (Hadou Rahou et al., 2016; Schnur et al., 2009). Some of these experiences are temporary whereas others are permanent.

The psychological impact of breast cancer on women starts before any official diagnosis and continues to be present throughout many journeys. There is often a peak of psychological distress on receiving a diagnosis of breast cancer, which can be more severe and prolonged when the news is poorly communicated (Silva et al., 2012; Hanratty et al., 2011). Throughout a cancer journey, women observe and interpret their symptoms and experiences trying to understand whether they or the cancer are winning the battle, with a resulting fluctuation of psychological well-being (Willig, 2011; Davis, 2006).

Symptomatology and survival are strongly influenced by the cancer staging and sub-type. Advanced breast cancer is associated with increased symptom burden and decreased HRQOL (Jedy-Agba et al., 2016; Mols et al., 2005) and has a lower survival rate than early breast cancer and tends to render disease-modifying treatments non-curative (Rivera-Franco and Leon-Rodriguez, 2018). However, at least in high-income regions, it is not uncommon for women with metastatic HER2 positive breast cancer to live with cancer for many years

(Cardoso et al., 2018; Rivera-Franco and Leon-Rodriguez, 2018; Turner et al., 2018). Such women, similiar to a proportion of breast cancer survivors, often report reduced physical and social functioning, and increased pain and financial difficulties beyond the conventional five-year milestone (Koch et al., 2012).

There is no typical woman's journey with breast cancer. Every woman's particular experiences of breast cancer are shaped by a complex interplay of their personal, cultural and societal values. For example, women who face stigmatisation because of their breast cancer, or societal expectations of stoicism in the face of adversity, have different experiences to those women without these pressures (Gibson et al., 2016; So et al., 2014; Yoo et al., 2014; Goldblatt et al., 2013; Tighe et al., 2011; Mols et al., 2005). In line with the imagery of a cancer battle, most women tend to be labeled as either heroes or victims (Davis, 2006). Much of the evidence for cultural differences in breast cancer experiences and journeys comes from research among different ethnic groups in higher-income contexts. The relatively limited research from LMICs and the Arab region suggests that breast cancer in these regions is associated with a lower HRQOL than in more developed contexts (Hashemi et al., 2019; Haddou Rahou et al., 2016, Al-Azri et al., 2009; Mols et al., 2005). This is likely related to the more advanced and aggressive cancers, and limited access to curative treatment, symptomatic relief, information, and palliative care.

1.5 Research context

1.5.1 Mauritania

The Islamic Republic of Mauritania is positioned as a bridge between North and West Africa, bordered by the Sahara Desert on the east and the Atlantic Ocean on the west (figure 1.2). Much of the country is desert and one million, a quarter of the population, live in the coastal capital, Nouakchott (Central Intelligence Agency, 2019). Official languages are Hassaniya, a dialect of Arabic, Pulaar and Soninke, with French widely used. There are five major ethnic groups; Bedhane, Haratine, Pulaar, Soninke and Wolof. The Bedhane and Haratine are collectively known as Maures and speak Hassaniya. They are referred to as white and black Maures, respectively, on account of a generalisation of their phenotype which is no longer reliable (Wiley, 2014). The Bedhane are from a Northern Arab-Berber descent. They have governed the country since its independence in 1960, from French colonial rule, and control the majority of the private sector (Esseissah, 2018; Traoré, 1979). This power stretched to being slave masters over the Haratine, who are thought to have been either indigenous to the area or came from Sub-Saharan Africa, when the Bedhane arrived and began to oppress them. Although slavery was made illegal in 1980, it continues to impact upon society and its hierarchal structures, and reinforces the imbalance of power between the ethnic groups (Rütti, 2017; Ciré, 2014). According to the government, all Mauritanians are Muslim (Central Intelligence Agency, 2019).

Google maps, 2018

Figure 1.2. Map of Africa

1.5.2 Religion in Mauritania

Sunni Islam has been the major religion in Mauritania since it first arrived through trans-Saharan commerce in the 11th century (Fortier, 2005). This is illustrated in the country's official title of Islamic Republic, which was adopted in the 1950's prior to it becoming independent from French colonial rule (Freire, 2018). Islam remains a strong influencer on experiences of health and illness (Silbermann and Hassan, 2011). Islamic belief and practices are based on the Quran, believed to have been transmitted to and written down by the prophet Mohammed, and hadiths which are records of the words and actions of

Mohammed passed down by his followers. The fundamentals of Islam include a series of beliefs and actions; belief in angels, the holy books, prophets, of whom Mohammed was the last, judgement day and destiny. The five obliged actions are referred to as the five pillars of Islam (Al-Shahri, 2016);

1. Repetition of the creed: belief in the oneness of Allah and acceptance that Mohammed is His prophet
2. Daily prayers
3. Almsgiving
4. Fasting during the month of Ramadan
5. Pilgrimage to Mecca at least once in a lifetime

There are four major schools of Islamic law, Maliki, Hanafi, Hanbali, and Shafi'i (Moors, 2018). These four schools came to be considered as the only valid interpretations of Islamic law by the ninth century and continue to be regarded as such by many Muslims. Mauritania, which follows the Maliki school of law, has been described as a bastion of traditional Islamic teaching because of the limited influences of secularism associated with colonialisation, perhaps due to its harsh, inaccessible physical climate (Hunwick, 1996; Harrison, 1988). Islam has changed very little in Mauritania over centuries, and it continues to be influential in public and personal life. At the political level, the image of an Islamic country has been emphasised for various gains, such as strengthening relationships with the gulf states, unifying different ethnic groups, consolidating power for the Bedhane, justifying slavery, and maintaining traditional societal values such as prescriptive gender roles (Freire, 2018; Esseissah, 2016).

1.5.3 Cancer care in Mauritania

Mauritania is a lower middle-income country (World Bank, 2019a). Much of its healthcare provision lacks resources, both physical and personnel. Access to the available services is inequitable, with the majority of structures centralised in the capital, Nouakchott (Taleb et al., 2006). National cancer services are provided at the Centre National d'Oncologie (CNO) in Nouakchott, where chemotherapy, hormone therapy and radiotherapy are provided free of charge (Yusuf, 2015). Prior to the opening of the CNO in 2008, all patients were required to travel abroad for cancer care, mainly to Tunisia and Senegal. Today, many Mauritanians continue to prefer to travel abroad for cancer treatment, because they perceive it as better and more reliable, consistent with experiences in other Arab countries (Kronfol, 2012). On returning to Mauritania, these medical tourists often reintegrate into the CNO care and follow up.

There is no national cancer registry in Mauritania and any cancer estimates are based on anecdotal evidence and data from neighbouring countries. These data suggest that breast cancer is the most common cancer amongst women in Mauritania, estimated at between 25 to 30 percent of all cancers in women (Corbex et al., 2014). Many of the women presenting to the CNO with breast cancer have advanced cancer and palliative care needs, consistent with experiences in other African and Arab LMICs (Grosse Frie et al., 2018; Espina et al., 2017). There is no published research on the experiences of women with breast cancer in Mauritania. Research on non-specific life-limiting conditions in Mauritania suggests that breast cancer is likely to be associated with experiences of challenging symptoms, a financial burden for the family, difficulties in travelling to the capital for treatment, and limited access to information on the condition and treatment (Fearon et al., 2018b; Kane and Fearon, 2018; Kane, 2016b).

In Mauritania, there is limited access to palliative care, with it inequitably found at the CNO and through a small not-for-profit home-based palliative care service (Rhee et al., 2017). There are signs of increasing palliative care capacity; for example, opioids are being increasingly prescribed at the CNO, and in March 2019, a short-acting morphine tablet was added to the already available intravenous and long-acting oral formulations.

1.6 Motivation for the research

The first Mauritanian palliative care service was started in 2015. This home-based service, Cairdeas Sahara, is affiliated with the Scotland based Cairdeas International Palliative Care Trust (CIPCT) (CIPCT, 2018). My involvement with Cairdeas Sahara has brought me into contact with Mauritanians with palliative care needs, most of whom have had advanced breast cancer. In seeking to understand the experiences of these women and their families, I oversaw the translation and partial validation of a patient reported outcome measurement scale (PROM) to better understand and measure experiences in palliative care (Fearon et al., 2015). Subsequent research collaborations explored the perceptions and experiences of the family, community leaders and health professionals as related to palliative and end-of-life care (Kane and Fearon, in press; Fearon et al., 2018b). We found that patients were well supported by their families and that physical symptoms were common and difficult experiences; but our research failed to capture the voices of patients. The aim of this thesis was to build on this research and to understand how women in Mauritania experience advanced breast cancer, a life-threatening illness.

1.7 Contribution to knowledge

Experiences of breast cancer are shaped within a web of personal, family, religious and cultural factors, as discussed above. There are no published data on the role these play in experiences of the phenomenon of advanced breast cancer in Mauritania. A phenomenon is defined as ‘a particular (kind of) fact, occurrence, or change as perceived through the senses or known intellectually, ...the cause or explanation of which is in question’ (Oxford English Dictionary, 2005). Stake (2006) suggests phenomenon is too narrow a term to capture the complexities and multiple manifestations of certain events, such as that of advanced breast cancer as experienced by multiple parties. His comparison of a phenomenon to a bull eye’s target contrasts with his proposed alternative, a quintain, which refers to a larger target area (see chapter three: *Methodology and methods*). This study seeks to understand and describe the quintain of advanced breast cancer in Mauritania, by exploring the experiences and perceptions of Mauritanian women with advanced breast cancer, their family members and health professionals.

1.8 Outline of thesis

The thesis comprises six chapters, described as follows:

In chapter two, a review of the literature on the experiences of Arab women with breast cancer is presented. A thematic synthesis of the literature was undertaken in order to incorporate a wide range of the available data, both quantitative and qualitative (Thomas et al., 2012). This was carried out in 2016, revisited in 2017 and again in 2019.

In chapter three, the research question and methodology are presented. The philosophical paradigm of the thesis, constructivism, and the research design, Stakian multi-case study research, are shown to be congruent with the research aims and the cross-cultural, cross-language context of the research. The chapter concludes with a presentation of the working methods, describing how the experiences of Mauritanian women were explored through the use of interviews, audio journals, patient reported outcome measurements and a performance scale.

In chapter four, the findings from the eight within-case analyses are presented. These include rich descriptions of the individual journeys with advanced breast cancer, with an emphasis on the particularity, or uniqueness, of each case rather than generalisations of experiences.

In chapter five, the findings of the cross-case analysis are presented. A synthesis of the longitudinal, quantitative and qualitative data helps construct a broader picture of the quintain of advanced breast cancer in Mauritania.

In chapter six, the findings from chapter four and five are discussed within the context of social, cultural and religious influences and the existing literature on the experiences of breast cancer. The chapter concludes with reflections on the research process, contribution to knowledge, limitations and strengths of the study, opportunities for further research and implications for practice and policy.

Chapter 2: Literature review

2.1 Introduction

The previous chapter has outlined how breast cancer is the most common cancer amongst women globally (Ferlay et al., 2015). This chapter presents a systematic review of the literature undertaken to better understand the experiences of women with breast cancer in Arab countries and to identify gaps in knowledge. The ways in which women experience the quintain of breast cancer is complex, influenced by cultural, societal, religious and personal values in addition to the staging and progression of cancer (Tiezzi, et al., 2017; So et al., 2014; Tighe et al., 2011; Mols et al., 2005). Receiving a diagnosis of breast cancer and undergoing aggressive treatments are associated with periods of lower HRQOL (Silva et al., 2012; Burgess et al., 2005). Certain experiences appear to be sensitive to ethnicity and culture; for example, the importance of religious and spiritual coping strategies are emphasised by American women of colour more than Caucasian Americans (Yoo et al., 2014), and women of Pakistani origin with breast cancer experienced stigmatisation in Pakistan more than in the United Kingdom (UK) (Banning et al., 2010). Previous reviews of the experiences of breast cancer have tended to synthesise research from high income regions (Yoo et al., 2014; Al-Azri et al., 2009; Mols et al., 2005; Payne et al., 2003). Such research may not apply to Arab women in Arab countries, because of the cultural differences. Reviews on breast cancer in Arab countries have focused on attitudes towards screening (Donnelly et al., 2013), reasons for delayed diagnosis (Alhurishi et al., 2011), or HRQOL measurements (Hashemi et al., 2019; Haddou Rahou et al., 2016). The meta-analysis by Hashemi et al. (2019) found that 21% of Eastern Mediterranean women with breast cancer graded their HRQOL as good. This finding may not reflect the situation for Arab women due to the broader geographical inclusion of Iran and Pakistan, neither of which are Arab countries. Haddou Rahou et al. (2016) limited their review to Arab countries and HRQOL. They found much heterogeneity in their results and insufficient data to perform meta-analyses, which may have been related to their narrow search terms related to HRQOL. Content from this chapter was accepted for publication in the journal Quality of Life Research (included in appendix 1).

2.2 Review question

The aim of this review was to identify and synthesise qualitative and quantitative data to construct an understanding of Arab women's experiences of breast cancer, in Arab countries. It was guided by the review question, what is the experience of Arab women with breast cancer?

2.3 Thematic synthesis

There is a choice of approaches which are suitable for integrating qualitative and quantitative research in a single review (Whittemore and Knafl, 2005). These include qualitative metasummary (Sandelowski et al., 2007), critical interpretive synthesis (Dixon-Woods et al., 2006), meta-narrative (Greenhalgh et al., 2005), and thematic synthesis (Thomas et al., 2012). These have different epistemological foundations and aims. Qualitative metasummary is a quantitatively orientated approach to the mapping of data, rather than data transformation or synthesis (Sandelowski et al., 2007). Critical interpretive synthesis draws explicitly from grounded theory with an emphasis on the generaton of theories (Dixon-Woods et al., 2006). The meta-narrative approach, congruent with a constructivist paradigm, creates and compares multiple storylines from different research disciplines which have explored a common issue (Barnett-Page and Thomas, 2009; Greenhalgh et al., 2005). Thematic synthesis incorporates aspects of meta-ethnography, grounded theory and thematic analysis (Thomas et al., 2012; Thomas and Harden, 2008; Braun and Clarke, 2006). It employs an inductive analysis of data, in which descriptive themes are initially identified and later synthesised to a higher level of analytic themes, in some ways translating the concept of thematic analysis of primary data to the level of secondary data (Braun and Clarke, 2006). Each of these approaches are useful in the synthesis of literature from different research methodologies and would hold utility for this literature review. An initial scoping of the literature revealed a high level of heterogeneity, consistent with the two regional reviews described above; Hashemi et al. (2019) and Haddou Rahou et al. (2016).

Thematic synthesis was considered to be a suitable design for answering the review question. The developing authors, Thomas et al. (2004), proposed it as a model to integrate syntheseses of qualitative data with findings from statistical meta-analyses in a single integrative review; for example, exploring the barriers and facilitators of healthy eating in children (Thomas et al., 2003; 2004). They provide limited instructions on the synthesis of quantitative data, referring to well-established approaches of meta-analysis. In contrast, they provide a step-by-step guide for the synthesis of qualitative data. These two syntheses are then combined, in part through the use of matrices to help visualise the process of comparative analysis (Thomas et al., 2004).

Researchers have adapted thematic synthesis to their own purposes. It has referred to systematic reviews limited to qualitative research (Bradley et al., 2016; Tong et al., 2012) or the analysis of only the qualitative data in integrative reviews (García-Rueda et al., 2016; Joseph-Williams et al., 2014). This fluidity of purpose and meaning was useful for this review because it provided the framework for the in-depth synthesis of the qualitative data, which were proposed to be most useful for answering the review question, while guiding its synthesis with quantitative data (Thomas et al., 2012).

2.4 Methods

2.4.1 Search strategy

The electronic databases of PubMED, Embase, Web of Science, SCOPUS, PsychInfo, CINAHL, Allied and Complementary Medicine Database, and Index Medicus for the Eastern Mediterranean Region, were searched for articles with no restriction of date. Relevant journals published in Arab countries were hand searched, the Middle East Journal of Family Medicine, Oman Medical Journal, Journal Medical Libanais, la Tunisie Médicale, the Arab Journal of Psychiatry and the Pan African Journal of Oncology. Citation-tracking of included articles and identified measurement scales was completed using Google Scholar. Included studies' reference lists were reviewed for relevant articles. Finally, oncologists in Mauritania, Sudan and Lebanon were contacted for suggestions on eligible articles. Searches were conducted in 2016 and updated in 2017 and in March 2019.

2.4.2 Search terms

The literature review employed MESH/keyword terms in the search of electronic databases, developed in collaboration with a subject librarian at the University of Lancaster. The PubMED search is shown in table 2.1. Headings and key words were modified as appropriate for subsequent databases.

Table 2.1: Search terms employed in the electronic search of PubMED

	Term
1	Breast OR Mammary [ALL FIELDS]
2	Cancer OR Tumour OR Tumor OR Malignan* [ALL FIELDS]
3	Breast Neoplasms [MeSH Terms]
4	Arab OR Algeria* OR Bahrain* OR Comoros OR Comori* OR Djibouti* OR Egypt* OR Iraq* OR Jordan* OR Kuwait* OR Leban* OR Libya* OR Mauritania* OR Morocc* OR Oman* OR Palestin* OR Qatar* OR Saudi Arabia* OR Somalia* OR Sudan* OR Syria OR Tunisia* OR United Arab Emirates, OR Emirat* OR Yemen* [ALL FIELDS]
5	Adaptation OR Coping OR Enduring OR Lived experience OR Perception* OR Experience* OR Perspective* OR View* OR Idea* OR Expectation* OR Belief* OR Believe* OR Motivat* OR barrier* OR Narrative [ALL FIELDS]
6	Depression OR Psychological OR Quality of life OR Perception OR Social support OR Risk assessment OR Cultural characteristics OR Health knowledge OR attitudes OR Survivors/Psychology OR Anxiety OR practice [MeSH Terms]
7	1 AND 2
8	3 OR 7
9	5 OR 6
10	4 AND 8 AND 9

2.4.3 Eligibility criteria

Inclusion criteria are outlined in table 2.2.

Table 2.2: Inclusion criteria

Inclusion	Exclusion
English or French language (1)	Non-English, non-French language
Empirical studies published in peer-reviewed journals, with no restriction to study methodology	Review articles, books, conference articles, posters, letters to editor and opinion pieces
Inclusion of data on the experiences of women	Experiences of relatives or healthcare professionals
Data available directly relating to breast cancer	No data on breast cancer, or impossible to disaggregate this data from that relating to other cancers
Data collected in Arab country (2)	Immigrant Arab women, in a non-Arab country
	Full text is unavailable

(1) The majority of bio-medical journals in the Middle East and North Africa region are published in either English or French (Appendix 2), while Arabic remains the main political and spoken language of Arab countries.

(2) Defined as a member country of the Arab League (League of Arab States, 2019)

2.4.4 Quality assessment

Quality assessment of included studies was not performed. Many quality-assessment tools have limited utility in research coming from non-Anglophone countries with less developed research platforms, because they measure how well a report is written rather than identifying findings of interest and novelty (Thorne, 2017). In addition, there is no accepted level of quality at which the exclusion of papers is justified or beneficial (Thomas and Harden, 2008).

2.4.5 Data extraction

For the identified literature, data were extracted in three phases. Firstly, study characteristics were extracted using a standardised form. Secondly, findings were summarised for each article and entered into two tables, one for data originating from qualitative methods, such as focus groups or semi-structured interviews (appendix 3); and one from quantitative methods such as PROMs (appendix 4). Finally, data were extracted in preparation for analysis. For qualitative articles, the sections ‘findings’ or ‘results’ were exported verbatim into N-Vivo for Mac version 10.2.2 (Thomas and Harden, 2008). For quantitative articles, PROM scores and participant demographics were exported into SPSS for Mac version 25.

2.4.6 Data analysis

There are three analytical steps in thematic synthesis; analysis of the qualitative data, analysis of the quantitative data, and a synthesis of the two (see figure 2.1). In the first step, qualitative data were thematically analysed (Thomas et al., 2012; Braun and Clark, 2006). The extracted data were read and re-read, and then coded line by line. nVivo’s annotation function was used to highlight and record pertinent reflections on the data (Saldana, 2012). Preliminary themes were identified inductively from the data. These themes were then examined for interconnectedness across the sample with the development and refinement of superordinate themes.

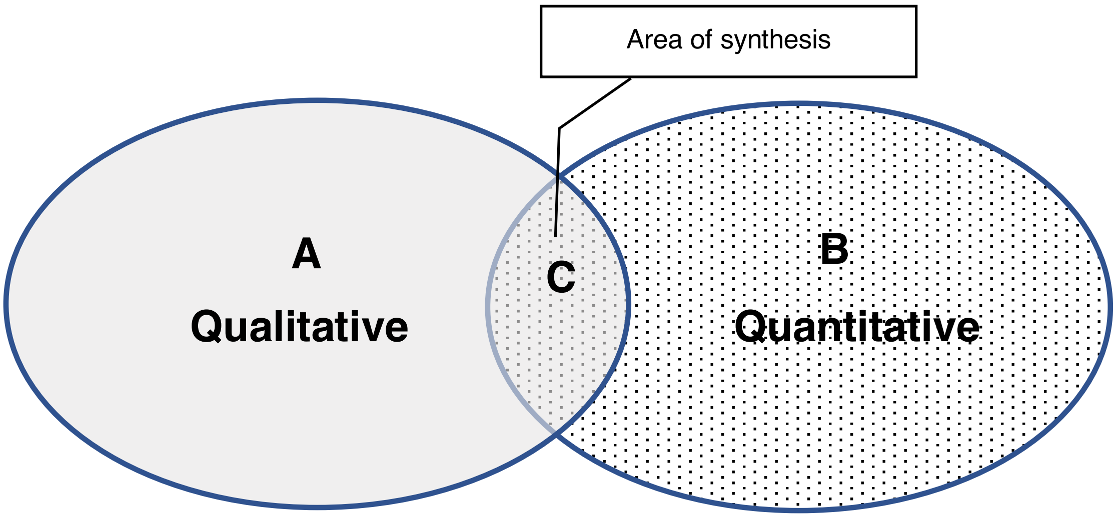


Figure 2.1: Venn diagram illustrating the area of synthesis

Secondly, quantitative data were analysed. Meta-regression was carried out on standardised means using the MetaReg.sps macro (random effects model) on SPSS version 25 for Mac (Wilson, 2006). A regression coefficient with a p-value of <0.05 was considered as statistically significant.

Thirdly, the findings of the preceding steps were synthesised. Women's views and experiences described in the qualitative data were compared and contrasted with the findings from the measurement studies, looking for common experiences (Harden at al., 2009). This area of synthesis is illustrated in area of overlap, C, in figure 2.1.

2.5 Findings

Identification and selection of studies were carried out in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al., 2009). A total of 5,228 citations were identified, and screening of titles and abstracts resulted in the full text review of 262 papers (see figure 2.2). Of these, 88 papers fulfilled the inclusion criteria and were included in the review (table 2.3). 18 papers exclusively used qualitative methods, 69 exclusively quantitative, and one paper used both. The included papers represented 13,185 women with breast cancer from 17 countries; Bahrain (n=3), Egypt (23), Iraq (n=2), Jordan (n=8), Kuwait (n=2), Lebanon (n=8), Libya (n=1), Morocco (n=9), Oman (n=3), Palestine (n=2), Qatar (n=3), Saudi Arabia (n=9), Sudan (n=4), Syria (n=1), Tunisia (n=5), United Arab Emirates (n=3) and Yemen (n=2).

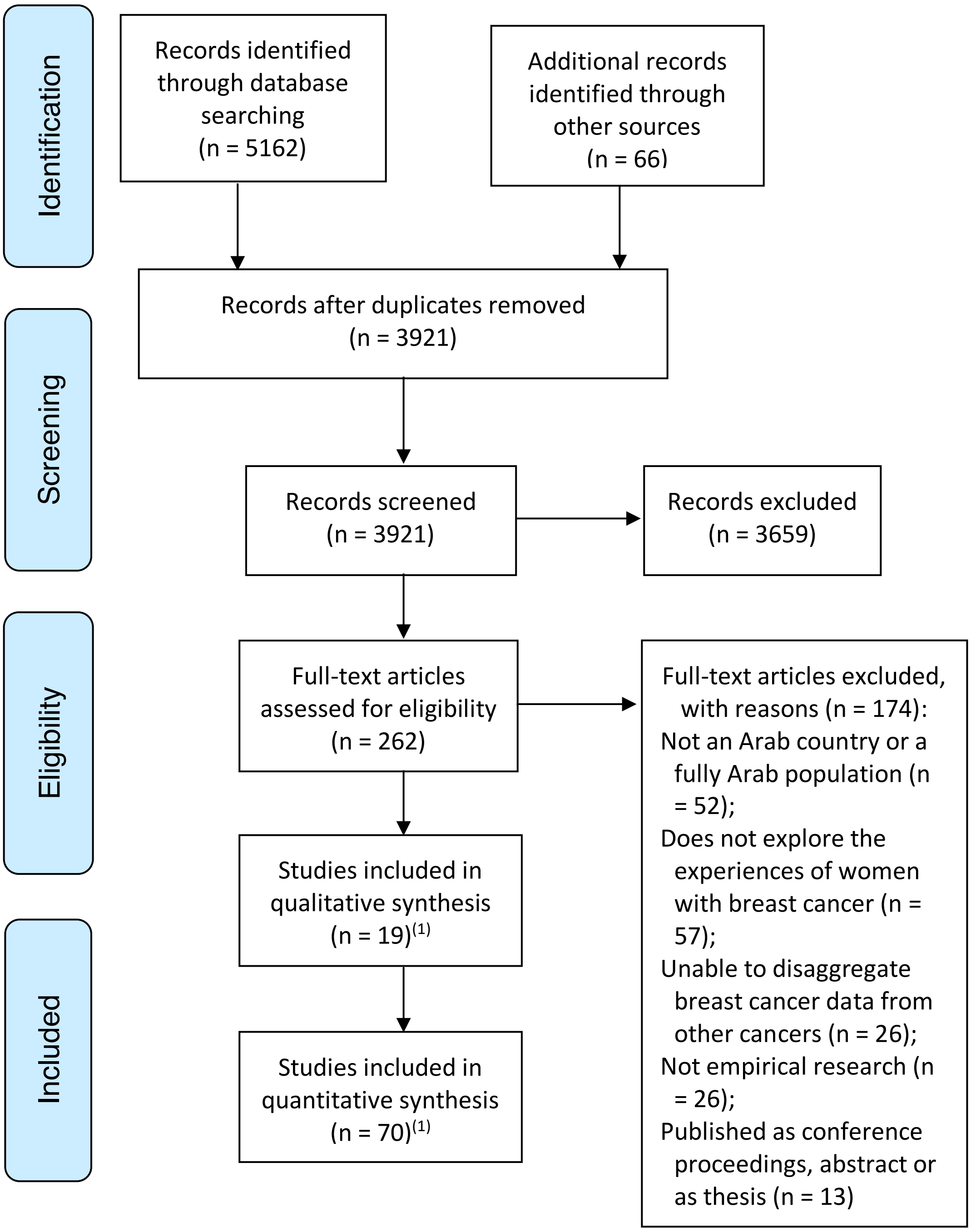


Figure 2.2: Flow diagram to show literature search process

(1) One article, Kobeissi et al. 2014, was included in both the qualitative and quantitative synthesis

Table 2.3. Characteristics of included studies

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
Abasher	2009	Sudan	Case-control	WSFQ	100	<50: 84% ≥50: 16%	NR	NR
Abasher	2014	Sudan	RCT	WSFQ, HADS	89	<50: 76% ≥50: 24%	II: 29%, III: 29%, IV: 23%, NR: 19%	≤ 6 months 18% 7-11 months 40% ≥12 months 42%
Abdel Aziz	1986	Egypt	Cross-sectional	NSSQ, TPRS, WEDS	40	30 to 64	NR	NR
Abou Kassm	2017	Lebanon	Cross-sectional	BDI, unidentified religiosity questionnaire	102	54 ± 10.4	0/I: 7.9%, II: 29.4%, III: 20.6%, IV: 41.1%, NR: 1%	3.5 years (SD NR)
Abu-Helalah	2014	Jordan	Cross-sectional	EORTC QLQ-C30, EORTC QLQ-BR23, HADS	236	50.7 ± 10.7	I: 12.8%, II: 45.5%, III: 34.6%, IV: 7.1%	1.9 ± 1.3 years
Abu Farha	2017	Palestine	Cross-sectional	BPI, EQ-5D	170	51.7 ± 11.1	I: 34.1%, II: 14.1%, III: 23.5%, IV: 27.6%	NR
Ahmed	2005	Sudan	Cross-sectional	Unidentified QOL scale	90	47 ± 13	IV: 100%	NR
Ahmed	2017	Saudi Arabia	Cross-sectional	SF-36	145	50.3 ± 13.5	I/II: 61.2%, III/IV: 38.8% (Mets: 30.3%)	<1 year 52.4% ≥1 year 47.6
Ahmed	2018	Saudi Arabia	Cross-sectional	DASS-21	125	NR*	NR*	NR*
Akel	2017	Lebanon	Cross-sectional	HADS, FACT-B	150	53.5 ± 10.4 [median]	0/I 29.3%, II 38.7%, III 23.3%, IV 8.7%	< 2 years 13.3% 2 to 5 years 68.7% >5 years 18%

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
Al-Azri	2014a	Oman	Qualitative	Semi-structured interviews	19	40	NR	12.2 months
Al-Azri	2014b	Oman	Qualitative	Semi-structured interviews	19	40	NR	12.2 months
Al-Bahri	2019	Oman	Cross-sectional	CanCORS (modified)	79	45 ± 10	I-II: 44.3%, III: 38.0%, IV: 17.7%	5.5 ± 5.7 months
Al-Maskati	2003	Bahrain	Cross-sectional	HADS	11	NR*	NR	NR
Al-Naggar	2011	Yemen	Cross-sectional	FACT-B	106	<55: 67.9% ≥55: 32.1%	III 35.8% Mets: excluded	<2 years 34% ≥2 years 66%
Al-Natour	2017	Jordan	Cross-sectional	FACIT-Sp	150	47.9 ± 9.7	I: 25.5%, II: 48.9%, III: 19.0%, IV: 6.6%	NR
Al-Sulaiman	2018	Qatar	RCT	DASS-21 EORTC QLQ-C30	201	<50: 67.5% ≥50: 32.5%	I-III 100% Mets: excluded	NR
Alawadhi	2009	Kuwait	Validation study	EORTC QLQ-C30 EORTC QLQ-BR23	348	48.3 ± 10.3	I: 7.0%, II: 34.3%, III: 36.0%, IV: 22.7%	<1 month: 92.4% ≥1 month: 7.6%
Albabtain	2018	Saudi Arabia	Cross-sectional	EORTC QLQ-C30 EORTC QLQ-BR23	95	≤39: 26.3% >40: 73.7%	NR	NR
Algamdi	2019	Saudi Arabia	Cross-sectional	FACT-B, CBI-BA	167	NR*	NR	NR
Ali	1991	Egypt	Cross-sectional	MCEQ	64	51.3 ± 7.7	NR	NR
Alkhyatt	2012	Iraq	Cross-sectional	BSI, IES, SIE, THQ	100	NR	I/II	4 to 12 months
Almegewly	2019	Saudi Arabia	IPA	Semi-structured interviews	18	30 to 50	I/II	6 to 47 months

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
Almutairi	2016	Saudi Arabia	Cross-sectional	EORTC QLQ-C30, EORTC QLQ-BR23	145	<45: 43.4% ≥45: 56.6%	I: 21.4%, II: 57.9%, III/IV: 20.0%	NR
Aloulou	2015	Morocco	Cross-sectional	Unidentified QOL scale	130	46 [median] 20 to 78	II: 56%, III: 28%, Mets: 13.84%	NR
Alqaissi	2010	Jordan	Heideggerian qualitative study	Semi-structured interviews	20	24 to 72	II: 60%, III: 40%	12.7 months
Assaf	2017	UAE	Qualitative	Semi-structured interviews	20	50	IIB: 55%, III: 45%	8 to 24 months
Awad	2008	United Arab Emirates	Validation study	EORTC QLQ-C30, EORTC QLQ-BR23, HADS	87	48.6 ± 9.9	I: 9%, II: 46%, III: 44%, IV: 1%	NR
Awadalla	2007	Sudan	Cross-sectional	WHOQOL-Bref	117	43.0 ± 10.0	NR	3.2 ± 2.3 years
Awan	2015	Saudi Arabia	Cross-sectional	Unidentified QOL scale	91	51 [median] 27 to 80	I-III: 100% IV: excluded	NR
Ba-Khubaira	2012	Yemen	Cross-sectional	FACT-B	58	43.8 ± 10.5	I/II 100% III/IV: excluded	NR
Bani Mohammad	2019	Jordan	RCT	VAS-Pain, State Anxiety Inventory	80	51.99 ± 10.34	I: 11.2%, II: 40%, III: 36.3%, IV: 12.5% Mets: excluded	NR
Bener	2017a	Qatar	Cross-sectional	EORTC QLQ-C30	678	47.7 ± 10.2	I: 13.9%, II: 42.1%, III: 36%, IV: 8%	1-2 years: 24.8% 3-4 years: 41.5% ≥5 years 33.7%
Bener	2017b	Qatar	Cross-sectional	BDI, BHS, MSPSS	678	47.7 ± 10.2	I: 13.9%, II: 42.1%, III: 36%, IV: 8%	1-2 years: 24.8% 3-4 years: 41.5% ≥5 years 33.7%
Berhili	2017	Morocco	Cross-sectional	DT, HADS	446	50 ± 8	NR Mets: 8.3%	NR

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
Berhili	2019	Morocco	Cross-sectional	HADS	122	38.5 ± 5.6	I-III: 100% Mets: excluded	NR
Daher, A. M.	2017	Iraq	Cross-sectional	BCIS	247	<50: 19.7% ≥50: 80.3%	NR	>1 year: 100%
Daldoul	2018	Tunisia	Cross-sectional	HADS, SF-36	70	NR	I: 24.3%, II: 27.1%, III: 24.3%, IV: 24.3%	NR
Denewar	2011	Egypt	Cross-sectional	HMQ, SSMQ	301	45.8 ± 13.3 [median]	NR	NR
Denewer	2007	Egypt	Case-control	Unidentified QOL scale	41	41.5 (no SD) 30 to 52	I-III 100% Mets: excluded	NR
Denewer	2012	Egypt	Cross-sectional	BITS, BSS	200	45.7 ± 11.6	0/I: 5.5%, II: 47%, III: 47.5% Mets: excluded	NR
Doumit	2007	Lebanon	Phenomenological	Semi-structured interviews	3	NR*	IV: 100%	NR*
Doumit	2010a	Lebanon	Qualitative	Secondary analysis of Doumit et al., 2010b	10	51.3	I-III:100%	4 months to 9 years
Doumit	2010b	Lebanon	Phenomenological	Semi-structured interviews	10	51.3	I-III:100%	4 months to 9 years
El Fakir	2014	Morocco	Validation study	EORTC QLQ-BR23	105	48 ± 16	NR	NR
El Fakir	2016	Morocco	Cross-sectional	EORTC QLQ-C30 EORTC QLQ-BR23	1463	55.6 ± 11.2	II: 45.9%, IV: 12.9%	<3 months
El-Hadidy	2012	Egypt	Cross-sectional	BDI, HAM-A, RSES	54	48.3 ± 5.2	NR Mets: excluded	<6 months

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
El Missiry	2011	Egypt	Cross-sectional	BDI, DICI, MOS-SSS, MTAS,	100	47.75 ± 9.5	I/II: 75% Local recurrence: 25% Mets: excluded	3.8 ± 1.17 years (for the 25% with recurrence)
El-Sayed	2011	Egypt	Quasi experimental design	EORTC QLQ-C30 (modified), EORTC QLQ-BR23 (modified)	42	47.4 ± 13.6	NR Mets: excluded	NR
El-Sharkawi	1997	Egypt	Cross-sectional	Unidentified QOL scale	272	44.4 ± 9.7	I: 19.1%, II: 80.9%	NR
El-Shinawi	2013	Egypt	Cross-sectional	Unidentified QOL scale	45	47 ± 10.2 [median]	NR	<6 months
Ellouz	2019	Tunisia	Cross-sectional	HADS, BIS, FSFI	100	42.6 ± 6.9	T2: 44%, N1: 73%	6 to 12 months
Elmoez	2016	Egypt	Case-control	BDI, HAM-A	37	43.0 ± 6.1	Mets: excluded	NR
Elobaid	2016	UAE	Qualitative	Semi-structured interviews	19	48.2 ± 11.6	IIB, III, IV	<2 years
Elsheshtawy	2014	Egypt	Cross-sectional	Brief COPE scale, HADS	56	52 ± 13.3	I: 8.9%, II: 66.1%, III: 25% (Mets 12.5%)	NR
Elsheshtawy	2015	Egypt	Cross-sectional	HADS, MOS-SSS, MOS-SRRS, RLC	104	51 ± 14.8	II: 66.3%, III: 25%, Mets: 11.5%	NR
Enien	2018	Egypt	Cross-sectional	EORTC QLQ-C30 EORTC QLQ-BR23	172	<50: 70.9% ≥50: 29.1%	I: 14.5%, II: 47.1%, III: 38.4% Mets: excluded	NR
Ermiah	2012	Libya	Cross-sectional	Undefined QOL scale	200	45.4 (no SD) 22 to 75	I: 9%, II: 25.5%, III: 54%, IV: 11.5%	NR
Fido	1992	Kuwait	Cross-sectional	GHQ-28	40	44.2 ± 7.3	NR	NR

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
Hammoudeh	2016	Palestine	Qualitative	Focus groups, Semi-structured interviews	35	<50:51% ≥50: 49%	NR	<1 year: 37% 1-2 years: 29% ≥3 years: 34%
Huijer	2012	Lebanon	Cross-sectional	Barthel Index, EORTC-QLQ-C30, MSAS, NEST	89	49.2 ± 11.0	NR Mets: 37.1%	30.6 ± 39.1 months
Jassim	2014	Bahrain	Qualitative	Semi-structured interviews	12	50.3 ± 8.16	I: 8%, II: 33%, III: 59%	2.6 ± 2.42 years
Jassim	2013	Bahrain	Cross-sectional	EORTC QLQ-C30, EORTC QLQ-BR23	239	≤50: 57.3% >50: 42.7%	0/I: 29.9%, II: 44.8%, III/IV: 25.3% (Mets: 7.2%)	<1 year: 14.6% 1 to 5 years: 53.6% >5: 31.8%
Kobeissi	2014	Lebanon	Validation study	FACT-B & interviews	33	47.2 ± 11.8	I: 21.2%, II: 30.3%, III: 18.3%, IV: 15.2%, NR: 15.2%	NR
			Qualitative	Focus group	8	NR	NR	NR
Lazenby	2012	Jordan	Cross-sectional	FACIT-Sp, FACT-G	59	NR*	NR*	NR
Leila	2016	Tunisia	Cross-sectional	EORTC QLQ-BR23, HADS	50	52.1 ± 10.1	NR Mets: excluded	NR
McEwan	2014	Egypt	Qualitative	Semi-structured interviews	15	29 to 60	NR	NR
Masmoudi	2016	Tunisia	Qualitative	NR	2	44 & 48	NR	NR
Masmoudi	2009	Tunisia	Cross-sectional	EORTC QLQ-C30	23	48 (no SD) 35 to 65	II/III: 100% Mets: excluded	NR
Melam	2016	Saudi Arabia	RCT	EORTC QLQ-C30, EORTC QLQ-BR23, VAS-Pain	60	56.2 ± 3.4	I/II: 100%	NR

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
Mortada	2018	Egypt	Cross-sectional	EORTC QLQ-C30, EORTC QLQ-BR23	142	≤50: 55% >50: 45%	0: 8.5%, I: 33.8%, II: 47.8%, III: 9.9% Mets: excluded	≤1 yr: 36.6% 1-2 yrs: 39.4% >2 years: 24.0%
Mostafa	2010	Egypt	Non-randomised trial	EORTC QLQ-C30, EORTC QLQ-BR23	180	45.9 ± 10.6	III: 36.7% Mets: 19.4%	≤2 years: 68.3%
Naja	2015	Lebanon	Cross-sectional	FACT-B, unidentified QOL scale	180	53.8 ± 9.9	I/II: 55%, III: 24.4%, Mets: 20.6%	<1 year: 39.4% 1-5 years: 36.7% >5 years: 23.9%
Nejmi	2010	Morocco	Validation study	MDASI, ECOG PS	32	NR*	NR*	NR*
Nizamli	2011	Syria	Qualitative	Semi-structured interviews	17	37 (no SD) 30 to 45	II: 29%, III: 59%, IV: 12%	NR
Obeidat	2014	Jordan	Cross-sectional	INQ	156	50.2 ± 10.5	0/I: 19.3%, II: 35.3%, III: 34%, IV: 9.6%, NR: 1.8%	<18 months
Obeidat & Lally	2014	Jordan	Qualitative	Secondary analysis of Obeidat et al., 2013	28	48.5 ± 9.7	0/I: 36%, II: 64%	NR
Obeidat	2013	Jordan	Interpretative Phenomenological Analysis	Semi-structured interviews	28	48.5 ± 9.7	0/I: 36%, II: 64%	NR
Rostom	2012	Egypt	RCT	EORTC QLQ-C30, EORTC QLQ-BR23	120	<50: 56% >50: 44%	II/III: 100%	NR
Saati	2013	Saudi Arabia	Grounded theory	Semi-structured interviews and focus groups	60	46 (no SD or range)	NR	NR
Sbitti	2011	Morocco	Cross-sectional	BIS, FSFI	120	45.3 ± 5.2	II/III: 91.6% Mets: 8.4%	NR

First author	Year	Country	Design	Data collection	Size	Age (mean ± SD years or distribution)	Stage of disease	Time since diagnosis (mean ± SD or distribution)
Shoma	2009	Egypt	RCT	BITS, BSS, IES, SDS	100	54.3 ± 8.8	I/II: 100%	NR
Shouman	2016	Egypt	Cross-sectional	FACT-B, FACT-G, unidentified QOL scale	64	51.1 ± 9.2	NR	NR
Soliman	2018	Morocco	Grounded theory	Semi-structured interviews	25	NR	II: 8%, III/IV: 92%	NR
Soltan	2012	Egypt	Cross-sectional	BDI, DICI, MOS-SRRQ, MTAS	100	30 to 65	I/II: 100% Mets: excluded	NR
Stapleton	2011	Egypt	Cross-sectional	Unidentified QOL scale	343	49.6 ± 10.9	I/II: 53.9%, III/IV: 46.1%	NR
Thabet	2007	Egypt	Case-control	BDI, Symptoms Distress Scale	50	≤55: 80% >55: 20%	NR	1-6 months: 46% 6-12 months: 54%
Traore	2018	Morocco	Cross-sectional	EORTC QLQ-C30, EORTC QLQ-BR23	1463	50.5 ± 10.9	I: 14.9%, II: 42.9%, III: 28.9%, IV: 13.3%	NR

* Unable to disaggregate data from all cancer data

Notes: BC, Breast Cancer; BDI, Beck Depression Inventory; BHS, Beck Hopelessness Scale; BIS, Body Image Scale; BITS, Breast Impact of Treatment Scale; BPI, Brief Pain Inventory; BSI, Brief Symptom Inventory; BSS, Body Satisfaction Scale; CAM, Complementary and Alternative Medicine; CanCORS, Cancer Care Outcomes Research and Surveillance questionnaire; CBI-BA, Cancer Behaviour Inventory – Brief; CI, Confidence Intervals; DICL, Dealing with Illness Coping Inventory; DSM, Diagnostic and Statistical Manual of Mental Disorders; DT, Distress Thermometer; ECOG PS, Eastern Cooperative Oncology Group Performance Status; EORTC QLQ C-30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Cancer Specific; EORTC QLQ Br23, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Breast Cancer Specific; EQ-5D, EuroQol five-dimensional instrument; FACT-B, Functional Assessment in Cancer Therapy–Breast; FACT-G, Functional Assessment in Cancer Therapy–General; FACIT-Sp, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being; FSFI, Female Sexual Function Index; GHQ, General Health Questionnaire; HAM-A, Hamilton Anxiety Scale; HADS, Hospital anxiety and depression scale; HMQ, Hope Measurement Questionnaire; IES, Impact of Event Scale; INQ, Information Needs Questionnaire; MCEQ, McNett's Coping Effectiveness Questionnaire; Mets: metastasis; MDASI, M. D. Anderson Symptom Inventory; MSAS, Memorial Symptom Assessment Scale; MSPSS, Multidimensional Scale of Perceived Social Support; MTAS, Taylor Manifest Anxiety Scale; MOS-

SRRQ, Medical Outcome Study Social Readjustment Rating Questionnaire; MOS-SSS, Medical Outcome Study Social Support Scale; NEST, Needs at End of life Screening Tool; NNSQ, Norbeck Social Support Questionnaire; PTSD, Post Traumatic Stress Disorder; QOL, Quality of life; RLC, Rotter's Locus of Control scale; RSES, Rosenberg Self-Esteem Scale; SD, Standard Deviation; SIE, Stressful Illness Experiences; SDS, Situational Discomfort Scale; SSMQ, Social Support Measurement Questionnaire; THQ, Trauma History Questionnaire; TPRS, Thomas Psychological Reaction Scale; VAS-Pain, Visual Analogue Scale for Pain; WEPRS, Woods and Earp Depression scale; WHOQOL, World Health Organisation Quality of Life; WSFQ, Watts Sexual Function Questionnaire

2.5.1 Qualitative findings

The 19 included papers using qualitative methods of data collection represented 401 women with breast cancer from 11 Arab countries. A summary of the papers and their findings is included in appendix 3. Thematic synthesis of the extracted data identified three major themes and seven sub-themes (table 2.4).

Table 2.1: Themes and sub-themes

Theme	Sub-theme
Perceptions of breast cancer and its treatments	*Reactions to the diagnosis*
	Perceptions of treatment
	Changing perceptions
Coping with breast cancer	*Challenges to coping*
	Strategies for coping
Breast cancer and roles	*Care-provider versus care-receiver*
	Positive new roles

2.5.1.1 Theme 1. Perceptions of breast cancer and its treatments

Reactions to the diagnosis

Women's reactions to the diagnosis of breast cancer were strongly negative and characterised by fear (Almegewly et al., 2019; Soliman et al., 2018; Hammoudeh et al., 2017; Al-Azri et al., 2014a; Al-Azri et al., 2014b; Obeidat et al., 2013; Alqaissi and Dickerson, 2010). These reactions were influenced by the place of care. Those treated in specialist centres, typically felt well informed of their diagnosis and empowered to make choices regarding their treatment

(Obeidat and Lally, 2013; Alqaissi and Dickerson, 2010). In contrast, women who received care in their local non-specialist hospital felt powerless and tended to catastrophise their diagnosis, considering it as a death sentence, especially at the time of diagnosis and shortly afterwards (Soliman et al., 2018; Hammoudeh et al., 2017; Al-Azri et al., 2014b; Jassim and Whitford, 2014; Obeidat et al., 2013; Nizamli et al., 2011; Alqaissi and Dickerson, 2010). It was found that such women considered that their healthcare professionals had a controlling power over them, which was reinforced by lies and the provision of incorrect management and advice (Elobaid et al., 2016; McEwan et al., 2014; Obeidat and Lally, 2013; Alqaissi and Dickerson, 2010). These experiences increased the women's fear and mistrust, leading, at times, to a persisting uncertainty of their diagnosis (Obeidat and Lally, 2013; Alqaissi and Dickerson, 2010).

Although Arab women with breast cancer were afraid at the time of diagnosis, many felt unable to express concerns or doubts with their healthcare professionals. They either underwent the prescribed tests and treatments without posing any questions, or they disengaged from care; for example, seeking a second opinion and treatment abroad (Al-Azri et al., 2014b; McEwan et al., 2014; Obeidat et al., 2013; Saati, 2013; Alqaissi and Dickerson, 2010). There were examples in the data where this seeking care included consideration of traditional treatments, such as branding with hot wire, although most rejected this option (Soliman et al. 2018; Elobaid et al., 2016; Al-Azri et al., 2014b; Saati, 2013).

Perceptions of treatment

Arab women experienced limited control over their healthcare choices, with decisions often being made by doctors and/or family members, especially husbands (Jassim and Whitford, 2014; McEwan et al., 2014; Obeidat and Lally et al., 2013; Obeidat et al., 2013; Doumit et al. 2007). Women did not question this position and perceived that these decisions were made in their best interests; for example, latterly accepting when a mastectomy was performed against their expressed wishes (Jassim and Whitford, 2014).

Breast cancer treatments were associated with many distressing experiences, often referred to as losses in the identified literature. These included the loss of hair, a breast, a normal life, independence and autonomy, physical attractiveness, fertility, and arm function (Almegewly et al., 2019; Hammoudeh et al., 2017; Elobaid et al., 2016; Al-Azri et al., 2014b; Jassim and Whitford, 2014; Obeidat and Lally, 2013; Obeidat et al., 2013; Nizamli et al., 2011; Alqaissi and Dickerson, 2010; Doumit et al., 2010a; Doumit et al., 2010b). Women considered that these losses, especially hair loss and mastectomy, negatively influenced their body image, and their psycho-social, sexual, and physical well-being (Doumit et al., 2010a; Jassim and Whitford, 2014). The loss of a breast elicited the most emotive reactions, with some considering the loss to be as shocking as when they first received the diagnosis of cancer (Obeidat et al., 2013; Nizamli et al., 2011). Over time, most came to accept their loss of a breast because they considered it as necessary when framed within the existential context of their diagnosis (Jassim and Whitford, 2014; Obeidat et al., 2013).

Changing perceptions

Women's views of breast cancer changed over their journey from initial diagnosis, through treatment and into survivorship. The initial identification of breast cancer as a death sentence was latterly rejected by many, who reframed it as a potentially curable illness or a chronic condition (Hammoudeh et al., 2017; Jassim and Whitford, 2014; Doumit et al., 2010a; Doumit et al., 2010b). This change in perception was seen most often in those several years post diagnosis, who had been given treatment options, and who had accessed information from the internet or from other breast cancer survivors (Hammoudeh et al., 2017; Al-Azri et al., 2014b; Jassim and Whitford, 2014; McEwan et al., 2014; Obeidat and Lally, 2013; Obeidat et al., 2013; Alqaissi and Dickerson, 2010; Doumit et al., 2010a; Doumit et al., 2010b). This reformulation of breast cancer was not experienced by all participants. It remained as a death sentence for those who were unsure of their diagnosis, had received limited or incorrect information, were afraid of recurrence, or were afraid of passing the disease on to others (Al-Azri et al., 2014b; Jassim and Whitford, 2014; Kobeissi et al., 2014; Obeidat and Lally, 2013; Obeidat et al., 2013; Alqaissi and Dickerson, 2010; Doumit et al., 2010a; Doumit et al., 2010b).

2.5.1.2 Theme 2. Coping with breast cancer

Arab women considered that coping with breast cancer was a continuous battle (Hammoudeh et al., 2017; Doumit et al., 2010a). A battle not just against their cancer, but also against social and familial prejudices.

Challenges to coping

Arab women described several challenges which they felt impeded their ability to cope with breast cancer. These related directly to their cancer and to society's perception of breast cancer. Cancer-related challenges included the costs of treatment and multiple fears; cancer recurrence, infertility, pain, losing their independence, and dying alone (Soliman et al., 2018; Elobaid et al, 2016; Al-Azri et al., 2014b; Kobeissi et al., 2014; Obeidat et al., 2013; Doumit et al., 2010b; Doumit et al., 2007).

The main social-related challenges related to relationships with husbands, family and friends. Married Arab women were afraid that their diagnosis would result in their husbands being no longer attracted to them sexually, and that they might divorce them or take a second, fertile and cancer-free, wife (Almegewly et al., 2019; Assaf et al., 2017; Elobaid et al., 2016; Jassim and Whitford, 2014; Nizamli et al., 2011). There were occasions in the literature where these fears were realised, with the rupture of sexual relationships, separation, divorce, and physical or emotional spousal abuse being experienced (Assaf et al., 2017; Elobaid et al., 2016; Masmoudi et al., 2016; Jassim and Whitford, 2014; Nizamli et al., 2011; Alqaissi and Dickerson, 2010).

Arab women with breast cancer found it difficult to cope with others' negative reactions to their illness, including being pitied for having a death sentence (Almegewly et al., 2019; Assaf et al., 2017; Hammoudeh et al., 2017; Kobeissi et al., 2014; Obeidat et al., 2013; Nizamli et al., 2011; Doumit et al., 2010a).

Women were shunned and blamed for having breast cancer. People were afraid of the women because they feared breast cancer to be contagious. Others blamed them, considering that it was a punishment for undisclosed past sins or because of the women's previous uncontrolled anger or stress (Elobaid et al., 2016; Jassim and Whitford, 2014; McEwan et al., 2014). Women described social humiliation and ridicule and developed a distrust of those around them (Assaf et al., 2017; Elobaid et al., 2016; Al-Azri et al., 2014b; Jassim and Whitford, 2014; Nizamli et al., 2011). These reactions from others were distressing and so women employed strategies to cope with, or avoid, such experiences.

Strategies for coping

Many Arab women attempted to maintain their pre-diagnosis persona because they found it difficult to be viewed as a sick person (Almegewly et al., 2019; Hammoudeh et al., 2017; Kobeissi et al., 2014; Obeidat et al., 2013; Doumit et al., 2010a; Doumit et al., 2010b). Women employed different strategies to help them achieve this or to cope when this portrayal became no longer feasible. Main strategies were the non-disclosure of diagnosis, faith in God, receiving support from friends and family, and relationships with others with breast cancer.

Non-disclosure of diagnosis

Arab women attempted to limit the number of persons aware of their diagnosis. They controlled such information through the non-disclosure of the diagnosis, concealment of signs of illness, and the explicit denial of any problems (Soliman el., 2018; Al-Azri et al., 2014a; Jassim and Whitford, 2014; Kobeissi et al, 2014; Obeidat et al., 2013; Nizamli et al., 2011; Alqaissi and Dickerson, 2010; Doumit et al. 2010a). Concealment techniques included wearing a wig or a traditional head covering (hijab) to hide their hair loss. When these attempts failed to sufficiently conceal their breast cancer, they often isolated themselves from others (Almegewly et al., 2019; Elobaid et al., 2016; Al-Azri et al., 2014a; Al-Azri et al., 2014b; Obeidat et al., 2013; Nizamli et al., 2011). This isolation was commonly temporary, for example during chemotherapy when the physical signs of illness were more visible and difficult to conceal. Periods of prolonged isolation were associated with low mood and depression (Al-Azri et al., 2014a; Obeidat et al., 2013; Nizamli et al., 2011).

Faith in God

Most Arab women considered their faith in God as a positive factor in how they coped with breast cancer. The participants expressed comfort that life and death were predestined (Almegewly et al., 2019; Hammoudeh et al., 2017; Obeidat et al., 2013; Doumit et al., 2007). Cancer, its treatment and its cure were perceived as coming from, and controlled by God (Assaf et al., 2017; Hammoudeh et al., 2017; Al-Azri et al., 2014a; Jassim and Whitford, 2014; Doumit et al., 2010a). Women's acceptance of their destiny did not equate to a fatalistic attitude to death; rather they argued it obliged them to seek medical advice and follow the prescribed treatment (Hammoudeh et al., 2017).

Women understood and accepted that their breast cancer came from God, and often described it as test of their faith (Almegewly et al., 2019; Hammoudeh et al., 2017; Al-Azri et al., 2014a; Saati, 2013). They expected that if they responded to the diagnosis with patience, endurance and acceptance they would likely earn eternal rewards from God, for example the pardoning of sins (Hammoudeh et al., 2017; Obeidat et al., 2013; Saati, 2013; Alqaissi and Dickerson, 2010). Several older participants considered that their diagnosis was a gift, because it had stimulated a healthy re-evaluation of their priorities (Obeidat et al., 2013). Finally, faith was perceived to help maintain hope for a cure and strengthen their resolve to endure the side effects of treatment (Hammoudeh et al., 2017; Al-Azri et al., 2014a; Al-Azri et al., 2014b; Obeidat et al., 2013; Saati, 2013).

Receiving support from friends and family

Arab women with breast cancer valued the presence of their friends and families and appreciated the support they provided. Participants considered it helpful to receive visitors, especially if the visitors did not mention the cancer (Al-Azri et al., 2014a; Alqaissi and Dickerson, 2010; Doumit et al., 2010a). In situations where their cancer arose as a topic, participants were encouraged by assurances that they would be cured (Alqaissi and Dickerson, 2010). Several of those who travelled abroad for treatment chose to return home early because they missed the support from friends and family (Al-Azri et al., 2014b). The type of support provided varied according to the relationship. A husbands' role was perceived as being the main provider of emotional and material support

(Hammoudeh et al., 2017; Al-Azri et al., 2014a; McEwan et al., 2014; Obeidat et al., 2013; Saati, 2013; Alqaissi and Dickerson, 2010; Doumit et al., 2010a). Practical support and help were expected and valued from female members of their immediate family, such as help with the household chores and childcare (Hammoudeh et al., 2017; Obeidat et al., 2013; Alqaissi and Dickerson, 2010; Doumit et al., 2010a). Financial aid was often offered by the wider family. It was usually gratefully received, even if the participant was not in need (McEwan et al., 2014; Alqaissi and Dickerson, 2010). Other familial assistance included help with transport or accommodation for the frequent hospital visits (Soliman et al., 2018)

Relationships with other women with breast cancer

Participants found that contact with other women with breast cancer helped them cope with their own diagnosis. Firstly, they found it helpful to know that they were not alone in their experiences (Assaf et al., 2017; Al-Azri et al., 2014a; Jassim and Whitford, 2014). Secondly, some participants found it reassuring to compare themselves with others perceived as less fortunate than themselves, specifically those with more advanced disease or those who were younger and unmarried (Alqaissi and Dickerson, 2010). Favourable comparisons were also made with patients with other types of cancers or illnesses, such as the chronic, incurable diabetes (McEwan et al., 2014; Obeidat et al., 2013; Doumit et al., 2010a). Thirdly, participants found it empowering and encouraging to be a support to others with breast cancer, especially those more recently diagnosed (Al-Azri et al., 2014a; Jassim and Whitford, 2014; Doumit et al., 2010a; Doumit et al., 2010b). For some women, this activity evolved into a new post-diagnosis role.

2.5.1.3 Theme 3. Breast cancer and roles

Women's roles in Arab societies were perceived to be founded on their relationships to others, as a daughter, a wife or a mother (Almegewly et al., 2019; Soliman et al., 2018; Hammoudeh et al., 2017; Jassim and Whitford, 2014; Obeidat et al., 2013; Nizamli et al., 2011). Their traditional identities and roles in society were threatened by the diagnosis of breast cancer.

Care-provider versus care-receiver

The participants considered that their primary role was to protect the well-being of their family. Their initial concealment of the diagnosis was, in part, to protect others from experiencing distress, especially their children (Jassim and Whitford, 2014; Obeidat et al., 2013). It was therefore frustrating for these Arab women when their breast cancer limited their ability to meet their own and others' expectations to be self-sufficient care-providers. Instead breast cancer had rendered them as care-receivers. This was most evident during active treatments or with an increasing disease burden (Hammoudeh et al., 2017; Obeidat et al., 2013; Nizamli et al., 2011).

The care-provider role was not limited to practical tasks. The women also felt responsible for the social and spiritual well-being of their families. At times, the women perceived that they had failed in this role because they had introduced breast cancer into the family (Elobaid et al., 2016; McEwan et al., 2014; Doumit et al., 2010b). They considered that they could no longer provide the best chances for their family, which included the nurturing of marriage opportunities for their unmarried female relatives (Elobaid et al., 2016; Doumit et al., 2010b).

Positive new roles

Arab women accepted that their diagnosis of breast cancer had fuelled a re-evaluation of what they valued in life (Assaf et al., 2017; Jassim and Whitford, 2014; Obeidat et al., 2013). For some, this led to the creation of a new post-diagnosis identity and role for themselves and others with breast cancer. Participants challenged society's presumptions about breast cancer and suggested that it should no longer be viewed as a death sentence, but rather as a curable or chronic illness (Hammoudeh et al., 2017; Doumit et al., 2010a). This new representation reinforced their argument that they and their families should not be stigmatised (Elobaid et al., 2016; Obeidat et al., 2013). The participants' new identity and status included being strong women, avoiding the label of being sick and weak, and being informal advisors to other women with breast cancer (Al-Azri et al., 2014a; Obeidat et al., 2013; Doumit et al., 2010a; Doumit et al., 2010b).

In contrast, there were occasions where Arab women rejected the idea of seeking re-entry into society's interpretation of roles and normality. Rather, they embraced the idea of breast cancer as a death sentence and were keen to demonstrate their acceptance before God and others (Hammoudeh et al., 2017;

Al-Azri et al., 2014a; Alqaissi and Dickerson, 2010). These women argued that death was the inevitable outcome for everyone, irrespective of whether someone had cancer or not (Assaf et al., 2017; Al-Azri et al., 2014a).

2.5.2 Quantitative findings

The 70 included papers employing quantitative methods of data collection represented 12,825 women with breast cancer from 16 Arab countries. A summary of the studies and their findings is provided in appendix 4. A range of scales, referenced (n=53) and non-referenced (n=11), were employed to measure experiences of breast cancer; such as, quality of life, body image, psychological, physical and spiritual well-being (see appendix 5 for which domains were explored in each study). The most frequently employed scales were the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (n=17), the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Breast Specific (EORTC QLQ-BR23) (n=15), the Hospital Anxiety and Depression Scale (HADS) (n=12), the Beck's Depression Inventory (BDI) (n=7), and the Functional Assessment in Cancer Therapy–Breast (FACT-B) (n=7). Complete scores from the EORTC QLQ-C30 and Br23 are included in appendices 6 and 7.

2.5.2.1 Psychological well-being

Psychological well-being was the most commonly measured experience in the identified literature. This was measured through psychological-specific scales, BDI, HADS, Depression Anxiety Stress Scale (n=2), Distress Thermometer (n=1), Hamilton Anxiety Scale (n=2), Taylor Manifest Anxiety Scale (MTAS) (n=2), and the Thomas Psychological Reaction Scale (n=1), and through sub-scales of HRQOL scales; such as the EORTC-C30, FACT-B and Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp) (n=2).

Rates of moderate to severe depression measured on the BDI ranged from 15.6% in Lebanon (Abou Kassm et al., 2017) to 40% in Egypt (Thabet et al., 2007) (see table 2.5). Women with breast cancer in Egypt were also found to have the high rates of depression and anxiety on the HADS (table 2.6 and figure 2.3), and the MTAS. HADS rates of moderate to severe depression ranged from 6.6% in Morocco (Berhili et al., 2019) to 30.4% in Egypt (Elsheshtawy et al., 2014); and rates of moderate to severe anxiety ranged from 5.6% in Morocco (Berhili et al., 2017) to 34% in Jordan (Abu Helalah et al., 2014). In Egypt, the rate of anxiety, measured by the MTAS, was reported to be 50% (El Missiry et al. 2011), and the rate of a generalised anxiety disorder, measured by the HAM-A, was reported to be 29.6% (El-Hadidy et al., 2012).

Data from the general HRQOL scales showed that women often scored lowest on the emotional or psychological well-being sub-scales; EORTC-C30 (Albabtain et al., 2018; Abu-Helalah et al., 2014; Jassim & Whitford, 2013; Awad et al., 2008), FACT-B (Akel et al., 2017; Kobeisi et al., 2014) and FACIT-Sp (Al-Natour et al., 2017).

These data suggest that depression and anxiety were common experiences for Arab women with breast cancer. Women in Morocco appeared to have higher psychological well-being than in other countries. Women in Egypt appeared to have lower psychological well-being. The heterogeneity across the sample and inconsistent reporting of data precluded meta-analysis.

Table 2.5: Results from the Becks Depression Inventory

Country	Author	Year	n	Level of depression (% of participants)				Definition of results
				Minimal	Mild	Moderate	Severe	
Egypt	El-Hadidy et al.	2012	54	NR	NR	38.8%[a]		[a] Major depressive disorder, score not defined
	Elmoez et al.	2016	37	NR				Mean score 19.14 ± 9.93 SD
	Missiry et al.	2011	100	46%		31%	6%	Normal (0-20), mild (21-31), moderate (32-41), and severe (≥42).
	Soltan et al.	2012	100	NR	NR	NR	NR	No data provided
	Thabet et al.	2007	50	NR	30%	28%	12%	Mild 10-15, Moderate 16-24, Severe - 25-39
Lebanon	Abou Kassm et al.	2017	102	61.7%	22.5%	11.7%	3.9%	No definition of scoring provided
Qatar	Bener et al.	2017b	678	27.7%		19.5%		Moderate (21- 30), severe (31-40) and extreme (≥41) Mean score provided 25.1 ± 7.7 SD

n, sample size; NR, not reported; SD, standard deviation

Table 2.6 Reporting on data from the Hospital Anxiety and Depression Scale (HADS)

Country	First author	Year	n	Anxiety			Depression			Definition of results
				Mild	Moderate	Severe	Mild	Moderate	Severe	
Bahrain	Al-Maskati	2003	11	NR	18%		NR	18%		Score ≥ 11
Egypt	Elsheshtawy	2014	56	26.8%	25%	1.8%	41%	30.4%	0%	Mild 8-10; Moderate 11-14; Severe 15-21
	Elsheshtawy	2015	104	28.1%	23.1%[c]	1.9%[d]	N/A	28.8%[e]		No numerical scores available; anxiety defined as mild, generalised [c] or panic disorder [d], and depression defined as major [e]
Lebanon	Abu-Helalah	2014	236	18%	20%	14%	19%	18%	8%	Mild 8-10; Moderate 11-14; Severe 15-21
	Akel	2017	150	21%	13%	7.3%	13%	7%	4.7%	Mild 8-10; Moderate 11-14; Severe 15-21
Morocco	Berhili	2017	446	NR	5.6%		NR	6.7%		Score ≥ 11
	Berhili	2019	122	NR	8.2%		NR	6.6%		Score ≥ 11
Sudan	Abasher	2014	89	NR	NR	NR	NR	NR	NR	Only a single result provided: a mean of 9.23 ± 4.79 SD
Tunisia	Daldoul	2018	70	NR	21.4%		NR	12.9%		Score ≥ 11
	Ellouz	2019	100	37% (mean score 8.26 ± 8.63 SD)			48% (mean score 10.1 ± 8 SD)			Presence of depression or anxiety (no definition provided)
	Leila	2016	50	42%			44%			No numerical scores available; anxiety and depression defined as present or not
UAE	Awad	2008	87	17.2%[a]	9.2%[b]		20.7%[a]	9.2%[b]		[a] Borderline 8-10; [b] Probable anxiety/depression 11-20

n, sample size; NR, not reported; SD, standard deviation

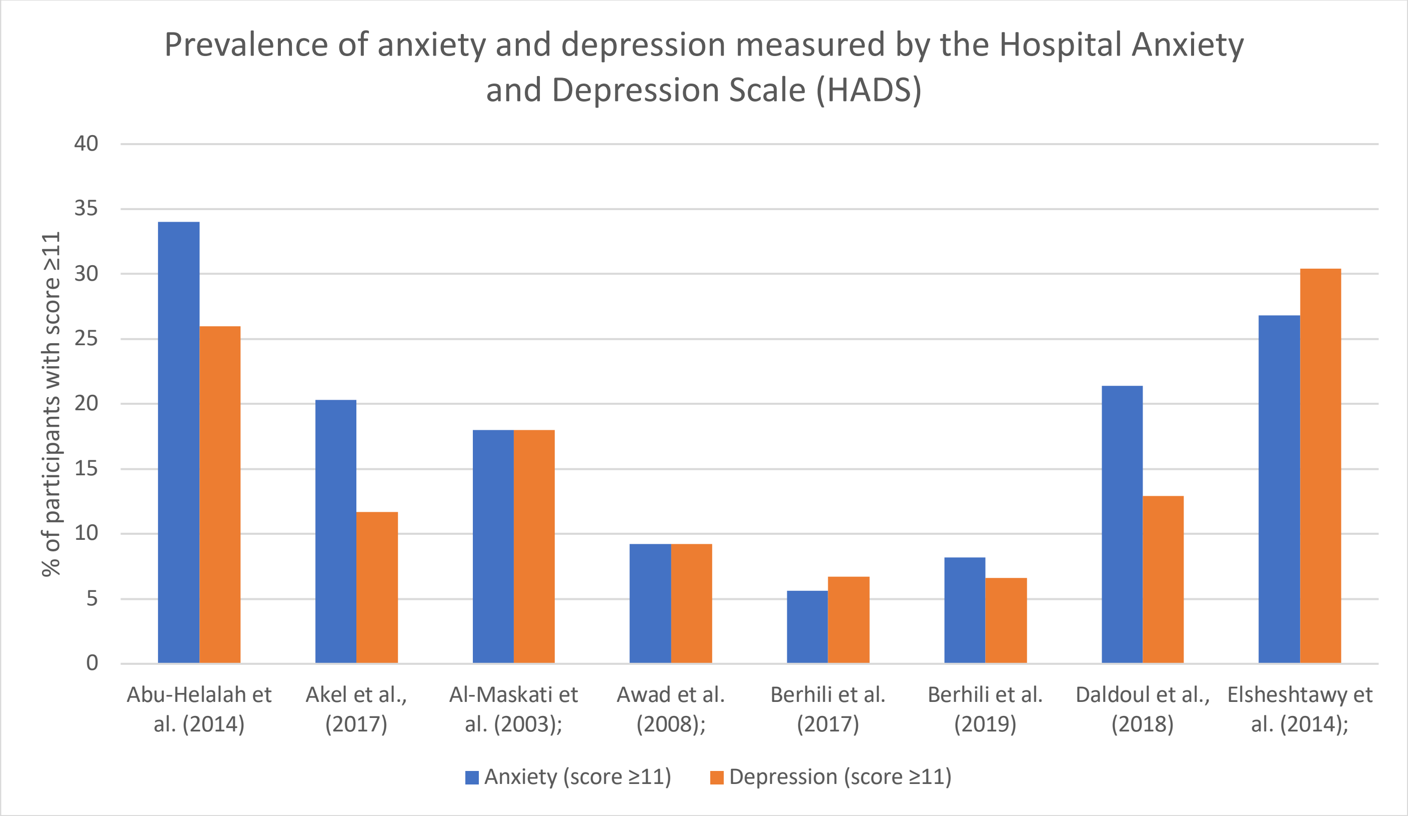


Figure 2.3: Prevalence of anxiety and depression measured by HADS

2.5.2.2 Health related quality of life

Health related quality of life was measured through several questionnaires, such as the EORTC QLQ-C30, EORTC QLQ-Br23, and the FACT-B. These measured quality of life, well-being and a range of general and breast-specific symptoms. There was variation in the range of global or overall QOL scores described in the identified literature. Mean EORTC QLQ-C30 global scores ranged from 28.38 in Egypt (Enien et al., 2018) to 76.02 in Morocco (Traore et al., 2018), on a scale of zero (lowest well-being) to 100 (highest) (see figure 2.4).

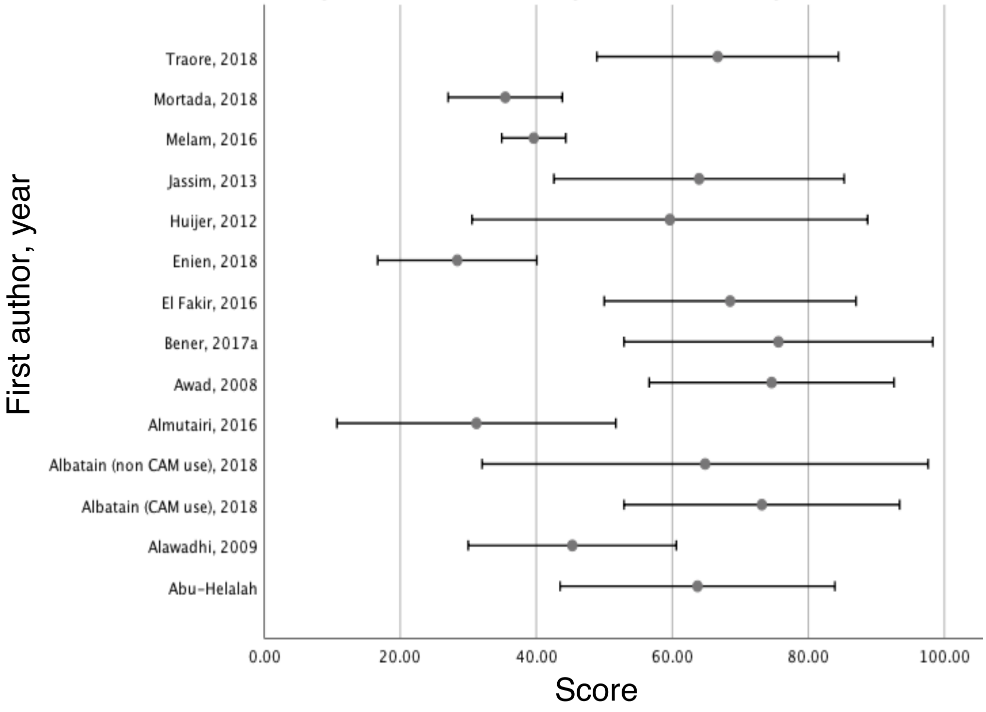


Figure 2.4 Forest plot of EORTC QLQ-C30 mean global scores with standard deviations

Data from the FACT-B also showed variation in overall quality of life. Mean scores ranged from 57.6 (Kobeissi et al., 2014) to 108.72 (Akel et al., 2017) on a scale of zero (lowest well-being) to 160 (highest) (figure 2.5).

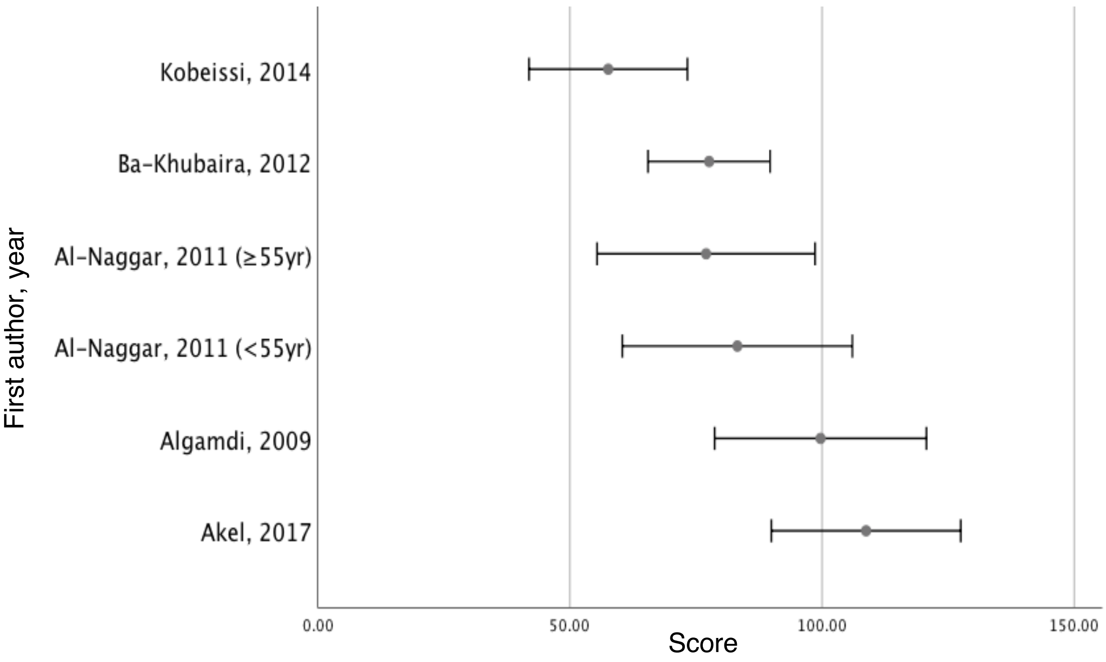


Figure 2.5 Forest plot of FACT-B: total mean scores with standard deviations

Data from the EORTC QLQ questionnaires demonstrated that social well-being received the highest functional scores, 89.1 (Masmoudi et al., 2009), 87.91 (Enien et al., 2018) and 87.85 (Traore et al., 2018) (see table 2.7). Future perspectives, sexual functioning and emotional well-being received the lowest scores; 19.71 (Mortada et al., 2018), 19.26 (Albabtain et al., 2018) and 20.2 (Moustafa et al., 2010) respectively. The most burdensome symptoms were hair loss, 89.67 (Mortada et al., 2018), insomnia, 84.1 (Almutairi et al., 2016) and loss of appetite, 80.9 (Almutairi et al., 2016le). Several authors suggested that Arab women reported good social well-being because of their strong and cohesive family support.

Table 2.7. EORTC QLQ-C30 and EORTC QLQ-BR23 data

Country	First author	Year	n	GDP (1) per capita ($)	Age (mean ± SD)	Stage (%)		Global QOL C30 score (2) (mean ± SD)	Social well-being C30 score (2) (mean ± SD)	Body image BR23 score (2) (mean ± SD)	Sexual functioning BR23 score (2) (mean ± SD)
						O, I, II	III, IV				
Bahrain	Jassim	2013	239	23,739	NR	74.3	25.3	63.93 ± 21.34	77.52 ± 30.2	75.64 ± 29.86	25.92 ± 29.77
Egypt	Enien	2018	172	2,412	50.32 ± 8.54	61.6	38.4	28.38 ± 11.70	87.91 ± 17.92	74.51 ± 13.21	74.45 ± 14.89
	Mortada	2018	142		NR	90.1	0.9	35.44 ± 8.40	46.71 ± 14.4	40.61 ± 7.50	78.87 ± 11.60
	Rostom	2012	120		NR	NR	NR	NR	NR	NR	NR
	Mostafa	2010	180		45.9 ± 10.6	NR	NR	NR	28.2 ± 37	NR	NR
Jordan	Abu-Helalah	2014	236	4,129	50.7 ±10.7	58.3	41.7	63.7 ± 20.2	78.1 ± 28.6	52.01 ± 36.8	NR
Kuwait	Alawadhi	2009	348	29,040	48.3 ± 10.3	41.3	58.7	45.3 ± 15.3	61.2 ± 22.7	61.8 ± 23.3	69.9 ± 23.6
Lebanon	Huijer	2012	89	8,808	49.2 ± 11.0	NR	NR	59.64 ± 29.09	60.29 ± 28.76	N/A	N/A
Morocco	Traore (3)	2018	1463	3,022	50.5 ± 10.9	57.8	42.2	66.67 ± 17.76	87.85 ± 21.76	81.88 ± 23.32	76.69 ± 23.68
	El Fakir	2016	1463		55.6 ± 11.2	NR	NR	68.5 ± 18.5	86.2 ± 22.7	79.80 ± 24.6	NR
	El Fakir	2014	105		48 ± 16	NR	NR	N/A	N/A	77.54 ± 25.82	61.11 ± 29.83

Country	First author	Year	n	GDP (1) per capita ($)	Age (mean ± SD)	Stage (%)		Global QOL C30 score (2) (mean ± SD)	Social well-being C30 score (2) (mean ± SD)	Body image BR23 score (2) (mean ± SD)	Sexual functioning BR23 score (2) (mean ± SD)
						O, I, II	III, IV				
Qatar	Al-Sulaiman	2018	201	63,249	NR	NR	NR	67.23	43.5	N/A	N/A
	Bener	2017a	678		47.7 ± 10.2	56	44	75.6 ± 22.71	51.3 ± 28.8	N/A	N/A
Saudi Arabia	Albabtain(4)	2018	77 CAM users	20,849	NR	NR	NR	73.16 ± 20.26	83.33 ± 26.3	80.63 ± 23.40	19.26 ± 25.23
			18 non-CAM users					64.82 ± 32.79	72.22 ± 33.82	66.67 ± 34.78	25.93 ± 31.43
	Almutairi	2016	145		NR	79	20	31.2 ± 20.5	65 ± 35.7	64.7 ± 35.7	52.3 ± 23.7
	Melam (3)	2016	30		56.3 ± 3.3	100	0	39.63 ± 4.71	NR	NR	NR
Tunisia	Leila	2016	50	3,464	52.1 ± 10.1	NR	NR	N/A	N/A	47.6 ± 26.4	45.3 ± 22.1
	Masmoudi (3)	2009	23		48	NR	NR	72.50	89.1	N/A	N/A
UAE	Awad	2008	87	40,698	48.6 ± 9.9	55	45	74.6 ± 18.0	85.1 ± 26	69.4 ± 26.5	62.6 ± 28.7

(1) Data from World Bank (2019b); (2) Scores range from zero to 100, with a higher score representing better well-being; (3) Baseline data or data from non-interventional group are presented; (4) Reporting of data was limited to that relating to the two distinct groups;
CAM, Complementary and Alternative Medicine; GDP, Gross Domestic Product; m, months; n, sample size; N/A, Not applicable; NR, Not reported; SD, standard deviation; UAE, United Arab Emirate

2.5.2.3 Patterns of experiences

There were occasions in the identified literature where authors investigated patterns between experiences, such as global QOL and psychological well-being, and socio-demographic context; such as income level, age and educational attainment. A limited number of predictive factors were found to be statistically significant. A positive correlation between higher income levels and global HRQOL was reported in seven studies (Berhili et al., 2017; Shouman et al., 2016; Abu-Helalah et al. 2014, Kobeissi et al., 2014; Huijer & Abboud, 2012; Al-Naggar et al., 2011).

There were contradictory findings concerning the associations of factors other than income level. Older age was identified as a predictor for better global HRQOL and lower levels of anxiety and depression in four studies (Enien et al., 2018; Berhili et al., 2017; Ba-Khubaira & Al-Kahiry, 2012; Alawadhi & Ohaeri, 2009), whereas elsewhere older age was associated with a worse global HRQOL and lower levels of sexual functioning (Mortada et al., 2018; Kobeissi et al., 2014; Huijer & Abboud, 2012; Abasher, 2009). Higher educational attainment was found to be associated with higher levels of global HRQOL, physical functioning and sexual functioning (Ahmed et al., 2017; Almutairi et al., 2016; Shouman et al., 2016; Kobeissi et al., 2014; Huijer & Abboud, 2012; Al-Naggar et al., 2011; Abasher, 2009; Awadalla et al., 2007), but also with higher levels of depression and anxiety (Elsheshtawy et al., 2015; Fido et al., 1992).

Studies represented specialist and generalist healthcare, and resource-rich and resource-limited contexts. Participants represented a range of familial income, age, time since diagnosis, stage of breast cancer and stage of treatment. The gross domestic product (GDP) of the studies' geopolitical context, the age of participants, staging of cancer, and time since diagnosis are presented alongside data for the EORTC QLQ C30 and Br23, FACT-B and HADS in tables 2.7, 2.8 and 2.9 respectively. It is evident from these tables that there is much heterogeneity of the study characteristics and the reporting of demographic data and results.

Weighted generalized least squares regression was performed for the meta-analysis of data from the EORTC QLQ and FACT-B scales. The model, using a mixed effects model (with random effects and restricted-information maximum likelihood), adjusted for the mean age of the participants. No statistically significant association was found for the EORTC QLQ scales (reg coefficient 6.426, upper CI 15.032, lower CI -10.159, p value 0.705) or the FACT-B scale (reg coefficient 1.151, upper CI 2.341, lower CI -2.171, p value 0.941).

Women with breast cancer in Egypt reported low global QOL scores for the EORTC QLQ C-30 (Enien et al., 2018; Mortada et al., 2018). This is consistent with the BDI and HADS data discussed above. Egypt has the lowest GDP out of the countries included in table 2.7. In contrast, the highest global QOL scores were reported in the two richest countries, Qatar (Bener et al., 2017a) and UAE (Awab et al., 2008).

Table 2.7 Total FACT-B scores and demographic data

Country	First author	Year	n	GDP (1) per capita ($)	Age (mean ± SD years)	Stage (%)				Time since diagnosis	Total score (mean ± SD)
						0/I	II	III	IV		
Egypt	Shouman	2016	64	2,412	51.1 ± 9.2	NR	NR	NR	NR	NR	NR
Lebanon	Akel	2017	150	8,808	53.5 ± 10.4 [median]	29.3	38.7	23.3	8.7	< 2 years 13.3% 2 to 5 years 68.7% >5 years 18%	108.72 ± 18.77
	Kobeissi	2014	33		47.2 ± 11.8	21.2	30.3	18.3	15.2	NR	57.6 ± 15.7
	Naja	2015	180		53.8 ± 9.9	55	0	24.4	20.6	<1 year: 39.4% 1-5 years: 36.7% >5 years: 23.9%	NR
Saudi Arabia	Algamdi	2009	167	20,849	NR	NR	NR	NR	NR	NR	99.7 ± 21
Yemen	Al-Naggar	2011	72	1,106	<55	64.2		35.8	0	<2 years 34% ≥2 years 66%	83.2 ± 22.8
			34		≥55						77 ± 21.6
	Ba-Khubaira	2012	58		43.8 ± 10.5	100	0	0	0	NR	77.6 ± 12.1

(1) Data from World Bank (2019b)

GDP, Gross Domestic Product; n, sample size; NR, not reported; SD, standard deviation

Table 2.8 Comparison of HADS scores ≥11 with demographic data

Country	First author	Year	n	GDP (1) per capita ($)	Mean age (years)	Stage (%)				Time since diagnosis	Anxiety score ≥11 (%))	Depression score ≥11 (%)
						0/I	II	III	IV			
Bahrain	Al-Maskati	2003	11	23,739.16	NR	NR	NR	NR	NR	NR	18	18
Egypt	Elsheshtawy	2014	56	2,412.73	52 ± 13.3	8.9	66.1	25	O	NR	26.8	30.4
Jordan	Abu-Helalah	2014	236	4,129.75	50.7 ± 10.7	12.8	45.5	34.6	7.1	1.9 ± 1.3 years	34	26
Lebanon	Akel	2017	150	8,808.59	53.5 ± 10.4 [median]	29.3	38.7	23.3	8.7	<2 years: 13.3% 2-5 years: 68.7% >5 years 18%	20.3	11.7
Morocco	Berhili	2017	446	3,022.93	50 ± 8	NR	NR	NR	NR	NR	5.6	6.7
	Berhili	2019	122		38.5 ± 5.6	100			0	NR	8.2	6.6
Tunisia	Daldoul	2018	70	3,464.42	NR	24.3	27.1	24.3	24.3	NR	21.4	12.9
UAE	Awad	2008	87	40,698.85	48.6 ± 9.9	9	46	44	1	NR	9.2	9.2

(1) Data from World Bank (2019b)

n, sample size; NR, not reported; SD, standard deviation; UAE, United Arab Emirates

2.5.2.4 Interventions

Experiences were, at times, measured in the literature to explore and compare the impact of interventions. These included different support services and treatment modalities; such as, comparing the experiences of women receiving hormone therapy with those receiving radiotherapy or chemotherapy. The provision of written information on treatments, distraction techniques, counselling services, breast conserving surgery as opposed to radical mastectomy, scalp cooling and lymphoedema specific therapy were associated with statistically significant higher global HRQOL and physical well-being (Bani Mohamed et al., 2019; Berhili et al., 2019; Melam et al., 2016; Abasher, 2014; Rostom, Y. et al., 2012; El-Sayed et al., 2011; Mostafa et al., 2010; Shoma, et al., 2009). In contrast, undergoing chemotherapy was associated with reduced physical well-being (Mortada et al., 2018; El-Sharkawi et al., 1997). A meta-regression analysis of effects was not carried out due to the non-comparable nature of interventions and reported data.

2.5.3 Synthesis of the qualitative and quantitative findings

The analyses of the qualitative and quantitative data provided a rich understanding of the experiences of Arab women with breast cancer. A major finding in the synthesis of these data was the evidence of heterogeneity across the identified literature; study design and methodology, geographical location, age of participants, stage of cancer, time since diagnosis, detail of data reporting, and the broad range of experiences described and measured.

Many of the experiences measured in the quantitative data were described in depth in the qualitative data. For example, the synthesis of data suggests that anxiety and depression were common negative experiences for Arab women with breast cancer. This finding was supported by data from the scales measuring psychological morbidity, the more general HRQOL scales which found low scores on the psychological or emotional sub-scales, and the descriptions and narratives in the qualitative data. These negative experiences appeared to be most troublesome at the time of diagnosis and during active treatments. This finding is consistent with research showing high rates of depression and anxiety in non-Arab women with breast cancer, with peaks of psychological distress at times of diagnosis, surgery and recurrence (Kenne Sarenmalm et al. 2009; Reich et al., 2008). HRQOL for women living longer with the disease is often influenced more by social rather than physical factors, with higher levels of social support being associated with higher HRQOL (Hill et al., 2010; Burgess et al., 2005).

The importance of social support was recognised in this review, with evidence of Arab women's appreciation of social support present in both the quantitative and qualitative data. Social well-being received consistently relatively high scores in the general HRQOL scales. It was proposed in the quantitative studies that this finding may reflect the high level of social support received by Arab women with breast cancer. This suggestion was supported by the qualitative data, which described the division of support according to gender and position in the family, the power imbalances experienced by women and the adverse impact on women when support was lacking.

On occasion, experiences identified in the qualitative data were not well illustrated in the quantitative data. The importance of the women's Islamic faith, the dislike and avoidance of pity, and fear of transmitting breast cancer onto daughters and granddaughters featured prominently in the qualitative data but were mainly absent from the quantitative data. It is proposed that this lacuna represents a limitation of the quantitative methods of data collection, which were insufficiently sensitive to detect or measure these experiences. The employed scales in the quantitative literature were originally developed and validated in resource-rich Anglophone contexts. The subsequent process of translation and validation for their use in an Arab context can fail to capture the experiences most relevant to Arab women with breast cancer (Oliveira et al., 2014). No scales were identified which were constructed and validated specifically for an Arab population. In contrast, most of the experiences measured in the quantitative data were described in the qualitative.

The identified literature demonstrated a diversity of Arab women's experiences of breast cancer. Negative experiences were consistently reported at the time of diagnosis. These early experiences then diverged with time following the diagnosis. Certain women were described as transitioning to a new identity as strong survivors, comparable with the many women who are successfully treated for early breast cancer in high-income regions (Mols et al., 2005). The imagery of survivorship can marginalise women whose experiences do not match the idealised concept (Gibson et al., 2016). Non-Arab women are less likely to self-identify as survivors when they are fearful of recurrence, prefer a private experience of breast cancer or feel that their experiences were insufficient to earn what they deem to be badge of honour (Kaiser, 2008). In contrast, the Arab women in this review struggled with the transition to survivorship when they remained uncertain of their diagnosis and their new role in their family and society.

The divergences in how women viewed their breast cancer journeys were explored in qualitative and quantitative papers in the literature review; for example, the effects of age, stage of cancer, educational attainment, income level, quality of healthcare, and access to reliable information and treatment choices. On synthesis of these data it appears that women with higher levels of income and educational attainment had better access to specialist cancer care and reliable information, either locally or abroad. Such women experienced higher levels of well-being, but also may have experienced higher levels of anxiety and depression. If valid, such a finding may be related to increased understanding of breast cancer leading to an increased awareness of the genetics of breast cancer and its sequelae, as described in the qualitative data. Alternatively, higher levels of anxiety and depression may result from a more open expression of emotions and answering of questions, which could be associated with age, income-level and educational attainment (Goldblatt et al., 2016).

The stage of breast cancer was an additional factor in the divergence of women's experiences. Advanced breast cancer was associated with more negative experiences for Arab women in the review, consistent with the experiences of non-Arab women with metastaic breast cancer (Reich et al., 2008; Mols et al., 2005). In addition to the associations between cancer stage and womens' emotional and physical well-being, this review also demonstrated that the cancer stage influences the womens' relationships with their families and health professionals. Women with advanced breast cancer had less access to cancer-related information than those women with earlier stages. This finding does not feature prominently in the wider literature. Women with early breast cancer were attributed, by their families and health professionals, with more power over information and treatment options than those women with advanced cancer. This was because there was a perceived higher chance of cure with early breast cancer with a subsequent lower risk of the women losing hope. This finding will be revisited in chapter six: *Discussion and conclusion.*

2.6 Strengths of the literature review

This review was strengthened by the comprehensiveness of the search strategy and the number and breadth of articles identified, both qualitative and quantitative. Included data represented 17 Arab countries, rural and urban populations, high and low-income families, all stages of breast cancer and all stages of treatment, including pre-treatment, active treatment and survivorship. The review was further strengthened by its inclusive approach to the literature.

Quantitative studies provided measurements of a wide range of experiences and qualitative studies provided descriptions of the depth and richness of these experiences. A further strength of this thematic synthesis was the importance attributed to the full surface area of the Venn diagram, shown in figure 2.1 on page 21, not just the small area of overlap. In this way, data have not been disregarded because they failed to correspond with other data.

2.7 Limitations of the literature review

There were several limitations to this review. Firstly, only studies published in English and French were included in this review and it is possible that relevant publications in other languages were not identified. Secondly, in the quantitative papers, the majority of employed scales had previously undergone translation into Arabic and a degree of validation for Arabic contexts. Data and references on these processes were lacking, and the quality and validity of such scales were not assessed. Thirdly, the literature search and synthesis were performed by a single reviewer which may have introduced bias. Finally, there was limited and inconsistent reporting of data in the studies which excluded direct comparison between groups. Meta-regression analyses were restricted to the relationship between the mean age of participants and their experiences, as presented above.

2.8 Conclusion

The purpose of the literature review was to understand what is known about the experiences of Arab women with breast cancer. The identification, analysis and synthesis of a range of interesting and useful qualitative and quantitative research provided a broader Arab context for interpreting the findings of this thesis, which are presented in chapters four and five. This review demonstrates that there is no single or typical journey with breast cancer for Arab women, illustrated in the heterogeneity of the literature and its findings. Experiences of Arab women with breast cancer are influenced by their family, social, healthcare, and religious contexts. Their journeys often start with shock and fear at the time of diagnosis; fear of death, social stigmatisation, losing their role in the family and society, and fear of introducing breast cancer into their family. From the point of diagnosis onwards, there is a divergence of breast cancer journeys. For some women, the diagnosis leads to renewed appreciation for life and acceptance of breast cancer as their destiny, a test from God, and at times as a simple chronic disease. In contrast, negative experiences characterised other journeys, where women continued to perceive breast cancer as a death sentence. These latter women struggled to move towards a new identity as a survivor, irrespective of the time since their diagnosis.

Researchers in the Arab region are interested in the experiences of breast cancer and publish relevant and useful research. There remains a need for further qualitative and quantitative exploration, with detailed reporting, of breast cancer journeys in Arab countries. This review illustrated a limited overlap between the qualitative and quantitative data. This is due, in part, to the use of scales originally constructed in Anglophone, high-income regions which fail to accurately measure the experiences most relevant to Arab women with breast cancer. The inadequacy of such scales was recognised by the African Palliative Care Association (APCA) who constructed and validated a HRQOL scale, the APCA African Palliative Care Outcome Scale (POS), specifically for African patients with palliative care needs, and their families (Harding et al., 2010; Powell et al., 2007). In a similar way, the regional construction and validation of an Arabic language breast cancer specific HRQOL scale would be useful to measure and explore the experiences of Arab women with breast cancer. Finally, relatively few studies from Arab LMICs were identified in the review, and so future research should be prioritised in these areas to address the gaps in knowledge. No papers were identified from Mauritania, the geographical focus of this thesis.

Chapter three will describe the methodology through which the experiences of Mauritanian women with advanced breast cancer were explored and understood. The findings from the literature review will be revisited in chapter six: *Discussion*.

Chapter 3: Methodology and methods

3.1 Introduction

The previous chapters have introduced the research context; women with advanced breast cancer in resource-limited, predominantly Muslim, Mauritania. The literature review described some of the experiences of Arab women with breast cancer. Such experiences are shaped over time by a complex network of influences; personal, familial, socio-cultural and religious. This chapter will explain how the study's design and approach helped understand how women in Mauritania experience advanced breast cancer, and how these experiences are shaped by their contexts and change over time. As introduced in chapter one: *Introduction,* the term quintain was employed, in place of phenomenon, to better reflect the complexity and contextuality of the multiple perspectives and experiences of advanced breast cancer in Mauritania (Stake, 2006). The study was guided by the research question:

> How is the quintain of advanced breast cancer experienced, over time, by Mauritanian women, their families and their healthcare providers?

This chapter outlines the epistemological framework of the study, describes and critically justifies the choice of research design, and presents the working methods including the study setting, recruitment, and analysis of data.

3.2 Philosophical paradigm

A philosophical paradigm refers to the ontological and epistemological positions of the research and the researcher. Ontology is the theory of reality and existence, and epistemology is the theory of how knowledge of such reality is created (Bryman, 2012). Different ontologies and epistemologies can be categorised by where they are located along a spectrum of how reality is perceived (Bryman, 2012). At one end, realism and positivism refer to the acceptance of an objectively verifiable, stable reality which exists independent of our attempts to describe it (Merriam, 2014). At the other end, interpretivism and poststructuralism refer to the co-existence of multiple realities, which can only be known subjectively (Denzin and Lincoln, 2011). Paradigms are not considered as right or wrong according to where they are located on the spectrum, but rather they are judged on their appropriateness and congruence to particular research aims and questions (Bryman, 2012).

An interpretivist approach to the research fitted well with the research question because of the incorporation of the perspectives of women, family members and healthcare providers. Such an approach accepts multiple realities as valid, and therefore supports the validity of each participant's experiences (Merriam, 2014; Lauder, 1999). For example, in constructivism, knowledge is considered as created as opposed to discovered, and is sustained through social processes and interactions between individuals and communities, including the researcher (Silverman, 2013; Best, 2007). Such a paradigm facilitates the exploration and understanding of constructed culturally bounded realities that exist in the real-world of experiences (Järvensivu and Törnroos, 2010). The constructivist paradigm is congruent and appropriate for this research for the following reasons.

Firstly, the constructivist paradigm is consistent with this research's objective of understanding perspectives and subjective experiences (Denzin and Lincoln, 2011). It recognises that knowledge and experiences are formed within a network of influences and are best understood through the production of rich descriptions.

> 'Constructivist inquiry starts with the experience and asks how members construct it. To the best of their ability, constructivists enter the phenomenon, gain multiple views of it, and locate it in its web of connections and constraints.'
>
> (Charmaz, 2006, p187)

Secondly, a constructivist approach can help balance the power between the researcher and the researched (Weinberg, 2007). The constructivist portrayal of findings as one interpretation of knowledge can mitigate the risk of the researcher perceiving themselves as the ultimate authority and knowledge keeper (Karnieli-Miller et al., 2008; Stake and Kerr, 1995).

Finally, the constructivist paradigm has encouraged a personal evaluation of my views of knowledge creation and experiences of illness. As a medical student and junior doctor, I was influenced by the pre-eminence of evidence-based medicine and its underlying positivist paradigm (Goldenberg, 2014; Bensing, 2000). My reflections on constructivism have encouraged an appraisal of the portrayed supremacy of this paradigm (Kukla, 2000). This is illustrated in my critique of National Institute for Health and Care Excellence's guideline 'Palliative care for adults: strong opioids for pain relief' which I argued was over-reliant on the positivist paradigm of quantitative research (Fearon et al., 2018a).

3.3 Cross-cultural and cross-language research

Cross-cultural and cross-language research requires the use of interpretation and translation, processes which influence multiple aspects of the research process. Attitudes to how translation should be approached in research differ depending on whether it involves quantitative or qualitative data. Established guidelines exist for quantitative data; for example, the translation and validation of PROMs in a new language and culture (Fearon et al., 2015; Sousa and Rojjanasrirat, 2011). In contrast, there is a lack of consensus on translation in qualitative research (Temple and Young, 2004).

Translation is perceived, by some qualitative researchers, as a threat to the validity of their research; and so they choose to hide the process or control it through the positivist approaches appropriated from quantitative research (Berman and Tyyskä, 2010; Temple and Young, 2004). Edwards (1998) argues that this encourages translators to be viewed as invisible, neutral conduits of data, positivist 'black boxes', into which data enter in one language and exit in the target language, with the same meaning maintained across languages and cultures. This reductionist approach is not congruent with the constructivist paradigm of this research. Instead, the challenges of translation are acknowledged with the interpreter or translator viewed as actors in the creation of knowledge, or as lens through which knowledge is created (Temple, 2002). In the same way that a scientist is not a neutral observer of an experiment, translators are not neutral mouth pieces of a participant because their work cannot fail to be influenced by their insights and understandings (Edwards, 2013). Researchers who are cognisant of these challenges to their own and the translators' objectivity, seek ways to strengthen the validity and trustworthiness of their research (van Nes et al., 2010). These include the choice of research design and practical approaches to translation which are discussed below, in sections 3.4 and 3.10.

3.4 The research design

There is a choice of research designs which are suitably congruent with the constructivist paradigm, cross-cultural longitudinal research, the research aims, and the use of mixed-methods. These include phenomenology, ethnography, grounded theory, narrative research, case study research, and participatory action research (Creswell, 2009; Creswell et al., 2007). Each of these designs have contributed to the heritage of qualitative research and would hold utility for this research (Bazeley, 2013). Of these, the most suitable design for answering the research question in this context was case study research (see table 3.1).

Table 3.1 Research designs

Research design	Brief description	Utility to this research
Interpretive Phenomenological Analysis/ Phenomenology	A deep reflection and exploration of phenomenon to understand the human essence of such experiences termed the lived-experience, usually employing interviews (Creswell, 2009).	The in-depth analysis of meaning making by the participant, and exploration of the participant's lifeworld would facilitate rich understanding (Smith et al., 2009). The approach's emphasis on the participants' use of words and phrases and their contextualised meanings would be challenging to maintain with the translation of interviews and their transcripts (Lindseth and Norberg, 2004). It is also unclear how data from multiple methods of data collection could be incorporated in this design.
Ethnography	Collection of observational and interview data on a defined cultural group over a prolonged period of time (Creswell, 2009).	This design has been shown to provide useful data in healthcare settings in Nouakchott (Kane, 2018a; 2016b). It can easily accommodate multiple sources of data and methods of data collection (Suter, 2012). The researcher's lack of language fluency could hinder observations, either covert or open. Practice would also likely be influenced by the presence of a foreign, male, medical doctor as researcher.
Grounded theory	Iterative process of data collection and analysis, usually employing interviews, with the purpose of the creation of theories grounded in the views and experiences of the participants (Creswell, 2009). A constructivist variant of grounded theory is available (Charmaz, 2006).	This design has been shown to be suitable for longitudinal collection of data from multiple participants (Hackett et al., 2016). It is unclear how data from multiple methods of data collection would be incorporated. The approach's objective of constructing theory may not be appropriate to answer the research question, which lends itself more to rich descriptions of experience (Creswell et al., 2007).

Narrative research	Collection of participants' stories to chronologically order and structure the meaning of experiences, usually employing interviews or document analysis (Creswell, 2009; Creswell et al., 2007).	This design is well-suited to the Mauritanian context, given the tradition of oral story-telling (Kane, 2016b). It is unclear how data from multiple methods of data collection, and stories from differing perspectives, for example women and health professionals, could be synthesised (Suter, 2012).
Case study research	An in-depth exploration of a phenomenon as experienced by a social unit or units, with a bounded case as a defining feature (Stake, 1995)	This design is well-suited to complex research situated in real-life, real-time contexts (Denzin and Lincoln, 2011; Swanborn, 2010). It can easily incorporate multiple perspectives and data from diverse methods of data collection (Suter, 2012).
Participatory action research	The researcher works with a community to identify issues which needs researched and addressed (Creswell et al., 2007).	This design is well suited to analysing data from different perspectives and from different methods of data collection (Hockley et al., 2013). It can facilitate change in practices, which can improve the experiences of the community which would fit with the motivations for this research (Hockley et al., 2013). It is reliant upon a strong community buy-in, which could be difficult in this research context. It would also be necessary to balance the hierarchical relationships between health professionals and patients. Finally, it would be preferable for the researcher to be fluent in the language of the participants, which was not the case in this research.

3.5 Case study research

Case study research was first proposed as an approach for complex educational interventions in the 1960s and 1970s (Simons, 2009). It is now employed in many areas of research including business science, political science and healthcare, including palliative care (Nazareth et al., 2008; James et al., 2007; Payne et al., 2007; Walshe et al., 2004; Krishnasamy, 2000). Merriam (1988) describes case study research as:

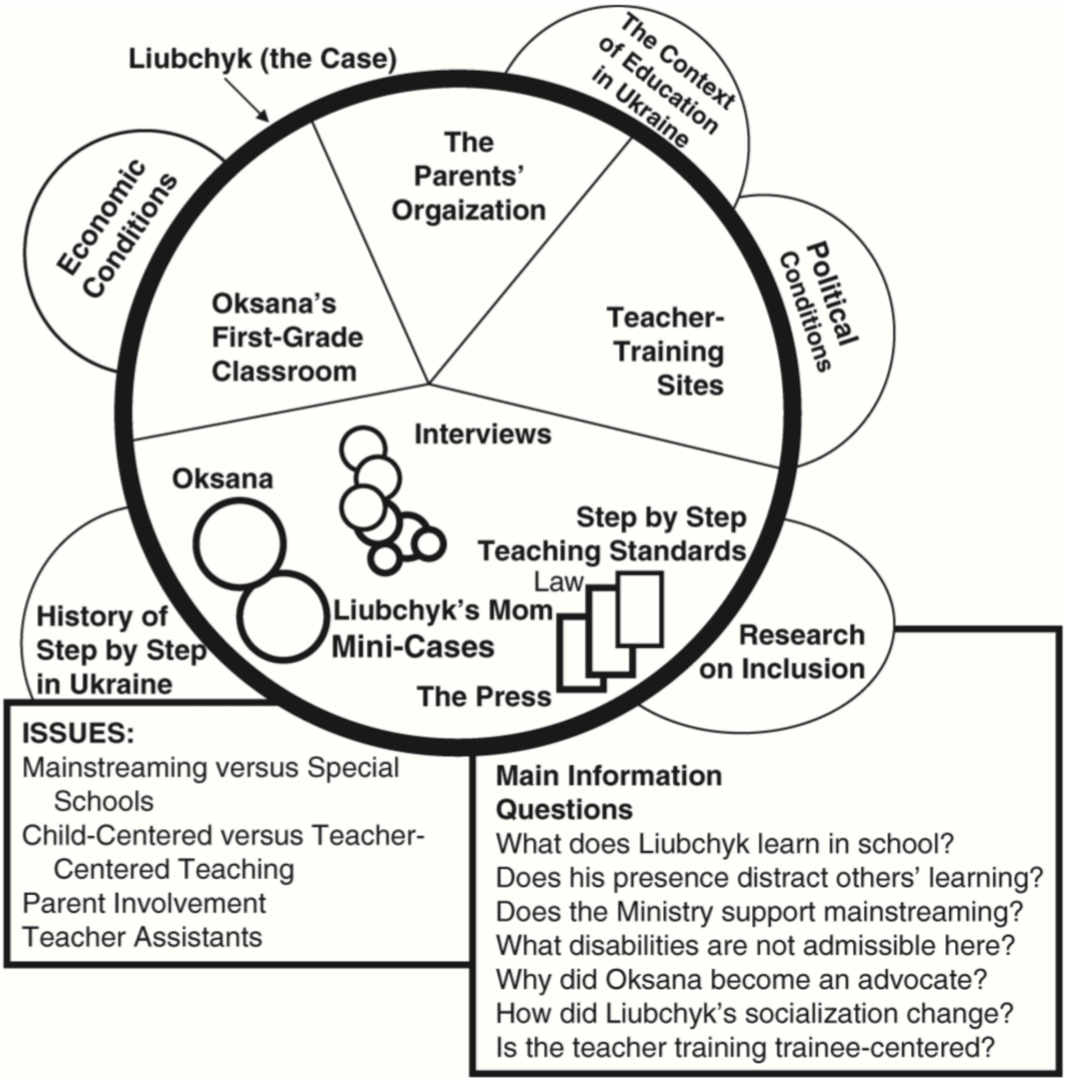
> ‘an intensive, holistic description and analysis of a single entity, phenomenon or social unit. Case studies are particularistic, descriptive, and heuristic and rely heavily on inductive reasoning in handling multiple data sources’ (p.16).

Case study research does not fit neatly into the traditional spectrum of ontological and epistemological paradigms as discussed above. For example, the approaches of two of the pioneering authors, Yin (2009) and Stake (1995), are considered as leaning more towards the positivist and the interpretivist ends of the spectrum, respectively (Boblin et al., 2013; Baxter and Jack, 2008; Appleton, 2002). The decision to use case study research is related more to what is to be studied, the case, rather than the underlying paradigm or methodology employed (Flyvbjerg, 2011). The centrality of the case as the defining feature positions case study research as a bridge between traditions and epistemologies (Luck et al., 2006; Walshe et al, 2004).

3.6 Stakian case study research

This research followed Stake's approach to case study (1995, 2006). This approach is congruent with constructivism, despite Stake avoiding an explicit label of a research paradigm (Boblin et al., 2013; Baxter and Jack, 2008; Appleton, 2002). The focus of Stakian case study research can be categorised using a typology of intrinsic, instrumental and multi-case study (Stake, 1995). An intrinsic case study is used when the researcher is interested in understanding the particularity, or uniqueness, and the situation of the case itself (Simons, 2009). In an instrumental case study, issues or problems as experienced within the case take prominence over the case itself. It moves away from the particular to the universal. A multi-case study is used to compare the initial case with other cases or to explore a phenomenon or quintain experienced across the cases (Swanborn, 2010; Stake, 2006).

Stakian case study research can consist of one or more cases. Each of these cases can be embedded with smaller cases, which Stake terms mini-cases. These mini-cases help the researcher to better understand the case or the quintain. Figure 3.1 illustrates an example from Stake's Ukraine case study, in which Liubchyk, a child, was identified as the case, and his mother and teacher, Oksana, were identified as mini-cases and embedded into the case.



ISSUES:
Mainstreaming versus Special Schools
Child-Centered versus Teacher-Centered Teaching
Parent Involvement
Teacher Assistants

Main Information Questions
What does Liubchyk learn in school?
Does his presence distract others' learning?
Does the Ministry support mainstreaming?
What disabilities are not admissible here?
Why did Oksana become an advocate?
How did Liubchyk's socialization change?
Is the teacher training trainee-centered?

Stake, 2006: p120

Figure 3.1. Plan for the Ukraine case study

Stake acknowledges that there are many valid approaches to case study research. Stake (2006) emphasises that a researcher's intuition and sensitivity to emerging data are important for successful case study research. His approach is characterised by suggestions of boundaries for the case, rather than a blueprint of methods. Prior to presenting the employed study methods, Stake's musings on three features of his approach are discussed; multi-case study and the quintain, mixed methods of data collection and crystallisation, and the role of foreshadowed issues.

3.6.1 Multi-case study and the quintain

The emphasis of this multi-case study was on understanding the quintain of advanced breast cancer as experienced within and across the cases. As presented in chapter 1: *Introduction*, Stake (2006) suggests that the term phenomenon is too narrow and proposes the term quintain to describe the relatively wider research target of a multi-case study. The word quintain originally referred to a medieval lancing target used by knights practising jousting, typically with a sandbag attached that would swing around and strike an unsuccessful jouster (Allen, 2006). Stake (2006) argues that while an aim to understand the quintain can help maintain the boundaries of the case study, it is a larger target than a phenomenon which Stake compares to a bull's eye on a dartboard (Bond, 2014; Hernández-Leo et al. 2010). It is not known whether Stake chose this term purposefully with a veiled warning, that if unsuccessful, multi-case study research could result in the researcher being knocked off their horse. The concept of the quintain is congruent with a constructivist paradigm, because its larger scope can accommodate the multiple realities constructed across the cases (Stake, 2006).

A focus on, and absolute acceptance of, the individual realities portrayed in the cases can distract the researcher from constructing an understanding of the quintain; whereas, an exclusive focus on the quintain can lead to the neglect of the particularity of the individual cases (Stake, 2006). To help navigate this predicament, Stake (2006) provides pragmatic suggestions which serve to maintain the study's balance between the validity of individual views and the broader socially-constructed concept of advanced breast cancer. This reduces the risk of extreme relativism, in which the researcher accepts all views as equally valid and that there is no reality external to the subjective (Järvensivu and Törnroos, 2010; Stake, 1995). Stake terms this process the 'case-quintain dialectic' (2006).

> 'I think it best that the issues of the individual Cases *not* merge too quickly into the main research questions of the overall multi-case study. They need to be heard a while, then put aside a while, then brought out again, and back and forth (the dialectic).'
>
> (Stake, 2006: p47, emphasis in original text)

The particularities of the cases are presented in chapter four: *Within-case findings*, and the quintain is described in chapter five: *Cross-case findings*.

3.6.2 Mixed methods of data collection and crystallisation

A common characteristic of the constructivist approach is the collection of data from multiple perspectives, explicit in the research question (Merriam, 2014). These data can help understand the quintain, but it can be difficult to draw data together from diverse views. One approach to this challenge is triangulation, the incorporation of more than one data point, methodology or theoretical framework in order to develop a deeper understanding of a phenomenon

(Torrance, 2012; Stake, 1995). Earlier interpretations of triangulation were based on a mechanistic, positivist search for a single objective truth (Simons, 2009; Koro-Ljungberg, 2008). Stake (1995) suggested there was limited congruence between these interpretations and constructivism.

> 'The stronger one's belief in constructed reality, the more difficult it is to believe that any complex observation or interpretation can be triangulated.' (Stake, 1995: p114)

More recent work on triangulation has repainted it for a constructivist audience (Denzin and Lincoln, 2011). Stake's later work demonstrates a shift in his thinking.

> 'The qualitative researcher is interested in diversity of perception, even the multiple realities within which people live. Triangulation helps to identify these different realities.' (Stake, 2006: p38).

This study subscribes to Stake's latter view of triangulation, and to better reflect its congruence with constructivism, the term crystallisation is employed. Crystallisation describes the unscheduled refraction of light and colours through a prism creating multiple fluctuating images, representing the multiple co-existing realities, rather than an empirical dot on a map associated with triangulation (Järvensivu and Törnroos, 2010; Ellingson, 2009; Simons 2009).

Crystallisation is not limited to multiple perspectives, it also refers to bringing together multiple genres of data collection which are capable of providing reflections of light without the need to complete the image (Ellingson, 2009).

These include quantitative methods which are often rejected in constructivist case study research because of their positivist heritage (Simons, 2009). In Stakian case study research, an intuitive, pragmatic approach to data collection is encouraged which values data for their utility in understanding the quintain, rather than the method through which they are collected (Stake, 2006). In addition, it would be contradictory to reject quantitative methods on the basis that their resulting data were partial and incomplete, when in constructivism all knowledge is considered to be limited and partial (Abma and Stake, 2014; Kukla, 2000).

3.6.3 Foreshadowed issues

Foreshadowed issues, a term coined by Stake, are theoretical orientations which direct the research towards certain concepts (Stake, 2006). They create a framework for the case study by maintaining its boundaries and feasibility, while emphasising the constructivist paradigm of Stakian case study research (Silverman, 2013). In contrast, Yin's (2009) corresponding propositions have been criticised as being positivist-influenced hypotheses requiring quantitative falsification (Boblin et al., 2013; Baxter and Jack, 2008; Appleton, 2002).

This multi-case study was guided by four foreshadowed issues (box 3.1). These were developed from literature on experiences of advanced breast cancer and other life-limiting illnesses in Arab and African contexts, and on my own experiences of palliative care across Africa. These provisional foreshadowed issues were modified and matured in response to the emerging data over the course of the research (Simons, 2009). The final multi-case assertions are presented in chapter six: *Discussio*n (Stake, 2006)

1. The belief in an omnipresent being is a comforting influence for the patient and their family as they face challenges to health and well-being
Banning et al., 2010; Taleghani et al., 2006
2. Healthcare providers have a sense of ownership and responsibility towards their patients, and this affects the care they provide
Walshe et al., 2008
3. Mauritanian extended families experience difficulty in adapting to crises and in supporting their members
Murray et al., 2003
4. There may be unacknowledged burnout, loss of hope and breakdown in the family cohesiveness
Gysels et al., 2011

Box 3.1. Provisional foreshadowed issues

3.7 Study setting

The Centre National d'Oncologie (CNO) in the capital, Nouakchott, is the single cancer centre in the country. It serves a population of nearly 4 million (Central Intelligence Agency, 2019). The adult oncology services are run by three radiation oncologists and one medical oncologist, supported by a team of non-specialist doctors, nurses and other staff.

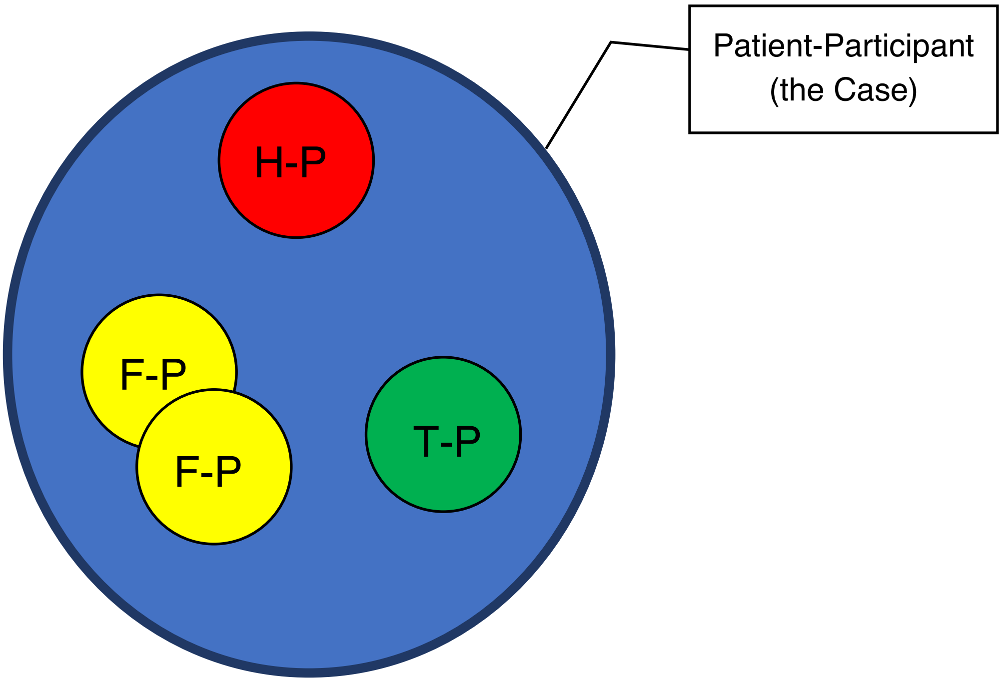
3.8 Study sample

3.8.1 The case, the quintain and the boundaries

In order to best answer the research question, participants were sought with personal experiences of advanced breast cancer and who were willing to share these experiences (Stake, 2006). The case, in this thesis, was defined as an individual Maure woman with advanced breast cancer. These study participants are referred to as patient-participants (represented by the blue circle in figure 3.2). The quintain of this multi-case study is defined as advanced breast cancer as experienced within and across the cases.

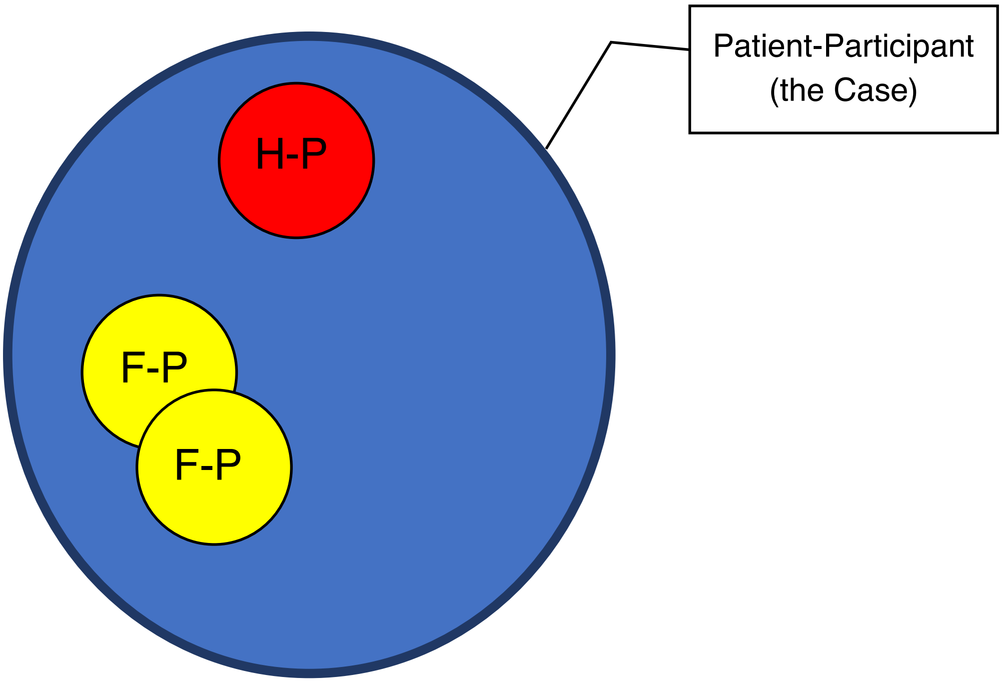
This multi-case study was bounded by methodological and theoretical boundaries (Elger, 2010). Methodological boundaries included the duration of study participation and the study setting, the CNO. Theoretical boundaries were shaped by the foreshadowed issues, the literature review, and the mini-cases embedded in the cases (Stake, 2015). Foreshadowed issues, introduced above, were established prior to the literature review. They served to guide the case study from design to writing up. Their role in the data analysis and the cross-case analysis are discussed below in section 3.12. In contrast, the literature review was perfomed synchronously with other aspects of data collection and analysis. Its findings iteratively helped shape and reinforce the case study's boundaries.

It was anticipated that each case would be embedded with mini-cases. These were defined as an individual family member, a traditional health practioner or a health professional with direct involvement in the care of the patient-participant (represented as red, yellow and green smaller circles in figure 3.2). These mini-cases were perceived as important and useful to answer the research question because family members and health professionals, both biomedical and traditional, are strongly influential over Arab women's experiences of breast cancer, as described in the literature review above (Jassim and Whitford, 2014; Taha et al., 2013). The updated case is shown in figure 3.3 which illustrates that no traditional health practitioners were recruited.



F-P, Family-participant embedded mini-case; H-P, Health-participant embedded mini-case; T-P, Traditional-participant embedded mini-case

Figure 3.2: Anticipated formulation of the case



F-P, Family-participant embedded mini-case; H-P, Health-participant embedded mini-case

Figure 3.3: Updated formulation of the case

3.8.2 Inclusion criteria for patient-participants

1. Mauritanian women with a diagnosis of advanced breast cancer (defined as presence of metastases or distant lymph node involvement)
2. Aged 18 and over
3. Cognition not impaired
4. Aware of the diagnosis

3.8.3 Exclusion criteria for patient-participants

1. Male
2. Brain cancer or brain metastases present
3. Eastern Cooperative Oncology Group scale 4 (Oken et al., 1982)
4. Registered with the palliative care service at the time of recruitment

3.8.4 Inclusion criteria for additional case participants

1. Aged 18 or over
2. A member of the patient-participant's household at time of recruitment (family member) or involved in the patient-participant's or their family's well-being (health professional or traditional practitioner)

3.9 Recruitment

3.9.1 Women with advanced breast cancer

Purposive sampling was employed to recruit patient-participants, consistent with qualitative research (Bryman, 2012). Such an approach identified women who were willing and able to provide opportunities to better understand the quintain (Governor et al., 2013). The medical oncologist at the CNO outlined the study details to patients who met the inclusion criteria at his Tuesday morning outpatient clinic. If interested, the researcher was introduced to them following their consultation with the oncologist. The study was explained in a private setting with the use of an interpreter. At this time, any questions were answered, and written information was provided (appendices 8 and 9). There were two ways in which a participant could consent, neither of which required the use of the unreliable local postal system. Option one: the women could choose to be provided with consent forms which could be completed at home and deposited, at a later date, in a secure, locked box at the CNO. Option two: women had the opportunity to provide written consent during the initial information-giving meeting. A cooling-off period of at least one week was provided between consent and the first interview.

3.9.2 Embedded mini-cases

Following giving consent, recruited patient-participants were asked to nominate family members, health professionals and traditional health practitioners to participate in the research. The recruited participants were embedded as mini-cases in the cases (Stake, 2006). No traditional health practitioners were nominated.

3.9.2.1 Family members

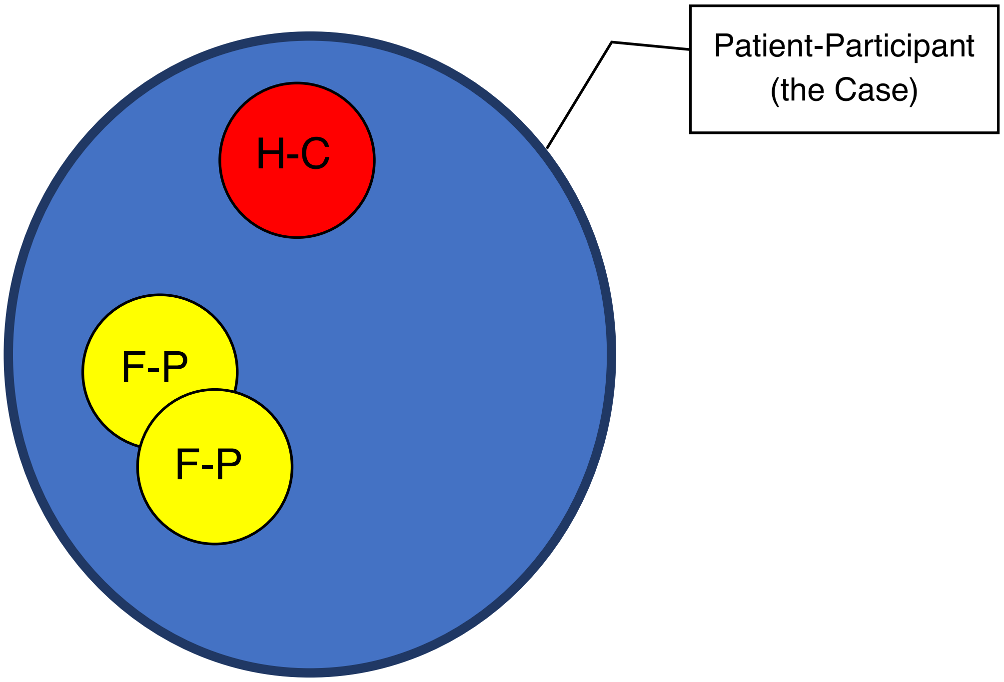
Nominated family members were approached at the time of the patient-participant's recruitment or during the course of data collection. These individuals were provided with verbal and written information on the research, and any questions were answered. Those willing to participate signed consent forms. Participating family members, referred to as family-participants, were embedded as mini-cases in their respective case.

3.9.2.2 Health professionals

Patient-participants were requested to nominate health professionals who were involved in their care. Multiple patient-participants initially nominated the same doctor. A broader range of health professionals were nominated with prompting. These individuals were approached at their place of work. If interested, the study was explained, and written information was provided. Those professionals willing to participate signed consent forms. Several of the health professionals nominated described having limited recall of their contact with the nominating patient-participants. This resulted in the re-evaluation of the role and utility of the health professional mini-cases, consistent with Stake's (2006) suggestion to revisit the usefulness and identity of any case or mini-case during a case study.

3.9.2.3 Health-care mini-case

It was anticipated that one health professional would be embedded in each case (see figure 3.2). For the reasons outlined above, this approach had limited utility. Instead, the recruited health professionals were grouped into a single health-care mini-case. This mini-case was embedded in each case (see figure 3.4). This decision was guided by Stake's Ukraine multi-case study (Stake 2006), in which a parents' association was identified as a mini-case and embedded in the case during the data collection phase (see figure 3.1).



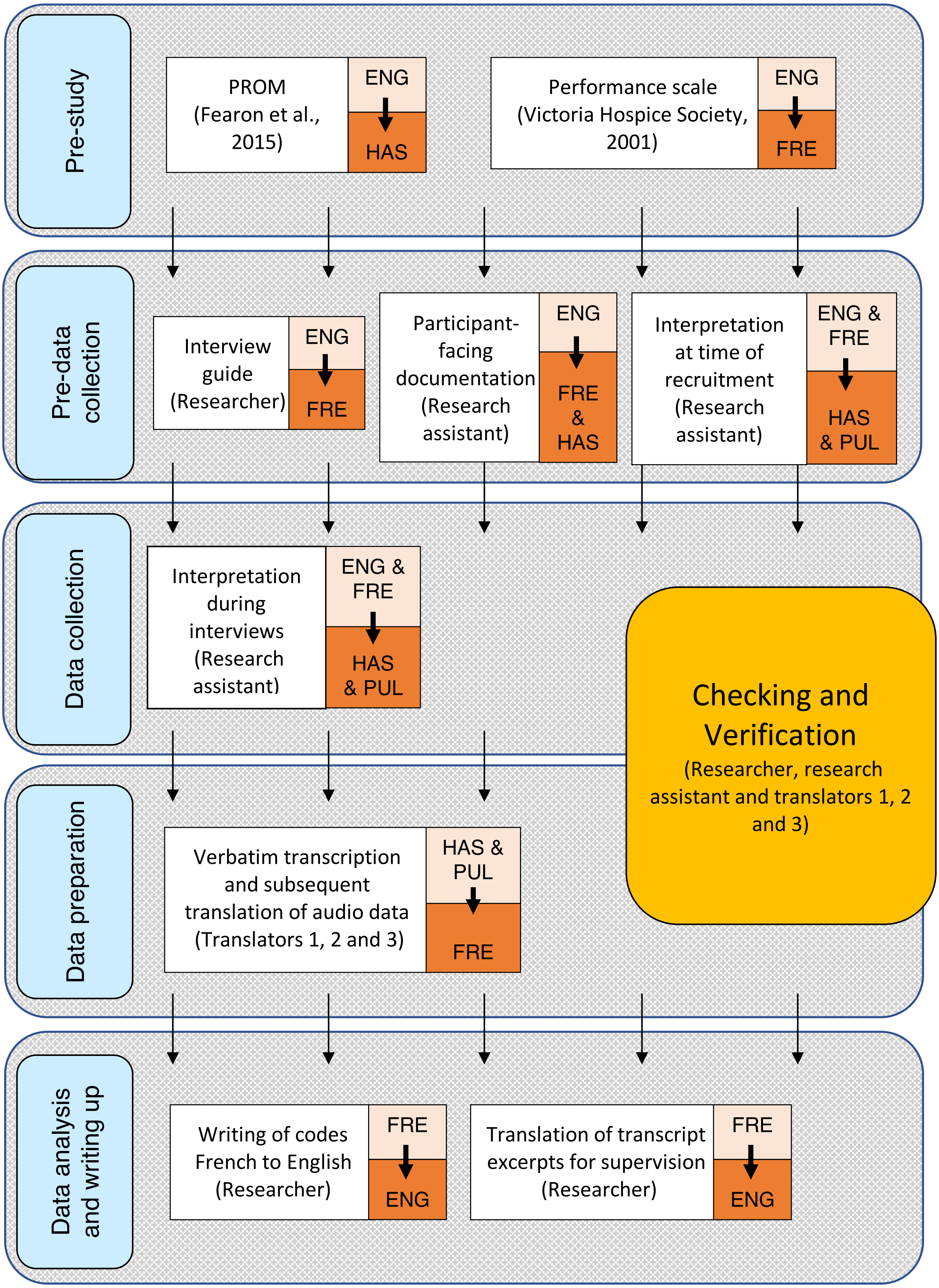
F-P, Family-participant mini-case; H-C, Health-care mini-case

Figure 3.4: Actual formulation of the case with health-care mini-case

3.10 Translation

Interpretation and translation featured throughout this multi-case study from conception to thesis writing (figure 3.5). Translation was approached in ways that strengthened its trustworthiness as opposed to positivist attempts to duplicate the participants' veracity in another language (Edwards, 2013). A core team of interpreters, translators, and transcribers were assembled to help manage the complexities related to the use of English, Arabic, Hassaniya, Pulaar and French. All parties involved signed confidentiality agreements.

Translation of participant-facing documentation and interpretation during recruitment and during interviews was performed by a research assistant who was employed throughout the study period (see figure 3.5). This was a male nurse and part-time imam who has worked in palliative care in Mauritania for several years in clinical work and qualitative research. He was fluent in Arabic, Hassaniya, French and Pulaar. He was competent in conversational English.



Eng, English; FRE, French; HAS, Hassaniya (dialect of Arabic); PUL, Pulaar

Figure 3.5: Flow chart of translation and interpretation

All audio data were transcribed in their entirety, and translated where required, into French because the researcher was fluent in French and there were no transcribers available who were sufficiently competent in English. Transcription and translation were carried out by three professional translators. Two were post-graduate qualitative researchers and one was a university professor, each fluent in the original and target languages. The research assistant carried out no transcription. The quality of the translation work was verified by the following steps. Firstly, the researcher was able to simultaneously listen to the audio and read the transcriptions to ascertain the accuracy of the transcription of the French portions of audio. This served as a proxy measurement for the accuracy of the transcription and translation of Hassaniya and Pulaar audio. Secondly, the transcription of the read-aloud PROM questions was compared with the prepared written questions. Thirdly, the translated participants' dialogue was compared with the transcribed interpretation provided by the research assistant within the interview. Finally, meanings of certain terms or phrases were clarified by the team of translators and research assistant with additional input from a local linguist and anthropologist. At times, transcription and translation of portions or complete interviews were repeated by a second transcriber/translator from within the team.

3.11 Data Collection

Observation, interviews and documentary sources are common sources of data in Stakian case study research (Stake, 1995, 2006). These are chosen to provide understanding of the case, the quintain, the foreshadowed issues and the broader context. Planned methods of data collection for this case study were semi-structured interviews, family-participant audio journals, PROM scale, performance status measurements, and examination of healthcare records. It was planned for data to be collected over six months to explore the changing experiences of advanced breast cancer (see table 3.2). An amendment to ethical approval was obtained to extend data collection up to nine months to accommodate the disruption of data collection around the time of the holy month of Ramadan.

Table 3.2. Schedule of data collection

Participant	Start	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Post death
Patient-participant	👥 📋 🚶 📂	👥 📋 🚶	👥 📋 🚶	👥 📋 🚶 📂	👥 📋 🚶	👥 📋 🚶	👥 📋 🚶 📂	
Family member 1	👥 📋 📓			👥 📋 📓			👥 📋 📓	👥
Family member 2	👥 📋 📓			👥 📋 📓			👥 📋 📓	👥
Health professional	👥			👥				

👥, Interview; 📋, Patient Reported Outcome Measurement; 🚶, Performance status; 📂, Health-care records; 📓, audio-journal

3.11.1 Interviews

Face-to-face interviews were carried out with participants in mutually convenient locations. An interview guide was employed (appendix 10). This was tested with an orderly at the CNO to confirm its clarity and cultural acceptability. The guide was individualised to different participants in response to data arising from within the case and to emerging themes across the cases. The researcher, interpreter and participant were arranged in a triangular formation. The interpreter verbally translated the interview to allow the researcher to follow the flow of conversation and guide the questions from the guide (Edwards, 1998). All participants granted permission to have the interviews digitally audio-recorded. All interviews were transcribed verbatim and translated into French where necessary, as discussed above.

3.11.2 Audio journals

Recruited family members were invited to keep a journal over the study period. They were provided with written instructions and a laminated aide-memoire (appendices 11 and 12). Family members were asked to record, at regular intervals, their experiences and events which they perceived as significant, and to answer the relevant PROM questions on the aide-memoire. An amendment to ethical approval was obtained to allow participants to record their journal entries through the use of Whatsapp, in addition to a provided dictaphone pen and notebook.

3.11.3 Patient reported outcome measurements

The majority of validated HRQOL scales have been developed in high-income, Anglophone regions, as discussed in chapter 2: *Literature review*. In contrast, the APCA African POS was developed and validated in eight African countries (Selman et al., 2013; Harding et al., 2012; Powell et al., 2007). It covers multiple domains relevant to patients with palliative care needs and their families in African contexts (Harding et al., 2010; Powell et al., 2007). This study used the Hassaniya version (Fearon et al., 2015). The English version is included in appendix 13.

3.11.4 Performance status

The Palliative Performance Scale version 2 (PPSv2) is a performance scale for ambulant populations with palliative care needs (Paiva and Paiva, 2014; Anderson et al., 1996). It measures functional status on a scale from 0% (death) to 100% (full performance). It takes into account self-care, oral intake and conscious level (appendix 14). This study used the French version (Victoria Hospice Society, 2001).

3.11.5 Healthcare records

Attempts were made to access the patient-participants' healthcare records at the CNO. They were found to have no utility for answering the research question because they were lost, incomplete, illegible or contained limited information. They were omitted from data analysis.

3.12 Preparation of collected data

All interview and journal audio-recordings were transcribed verbatim in their entirety and translated by professional transcribers and translators, as outlined in section 3.10. Transcriptions were formatted in three columns, the identifier of the speaker in the first column, Hassaniya dialogue in the second, and French dialogue or translation in the third (see table 3.3 and appendix 15). Contents of the third column, French, were exported into N-Vivo for Mac v.10.2.2 for analysis.

Data from the APCA African POS and PPSv2 were entered into a Microsoft Excel spreadsheet. To aid interpretation and presentation of APCA African POS data, scores were standardised so that high scores represented best status and items were grouped into domains previously identified and validated by factor analysis (Selman et al., 2013; Harding et al., 2012). These were physical and psychological well-being, interpersonal well-being and spiritual well-being. Scores from family members were grouped into a single domain referred to as family well-being.

Table 3.3 Example of transcription and translation of interview data

1	2	3	4(1)
Identifier	Hassaniya transcription	French translation/transcription	English translation
Interpreter	Ewol… manah ve tab moubatik eynte engalek saratan? (2)	La première fois… ça veut dire à l'hôpital, ta suivi, quand t'ont-ils dit que c'est un cancer ?	The first time ... it means that at the hospital, your follow-up, when did they tell you that it's cancer?
Lalla(3)	Ela 2014 leyn jeyt le ekhisa i emrad el nisa ve iyad tou houw ili galli ela the el marad. (2)	C'est en 2014 quand je suis venue voir le gynécologue à son cabinet c'est qui m'a dit que c'est cette maladie.	It was in 2014 when I came to see the gynaecologist at his [private] clinic. It's him who told me that it's this disease.
Interpreter	-	C'est lorsqu'elle a vu le gynécologue ici en 2014 c'est lui qui a dit que c'est un cancer. (2)	When she saw the gynaecologist here in 2014, he said it's cancer.
Researcher	-	Et comment ça s'est passé ? Elle était choquée ou…? (2)	And how was it? Was she shocked or ...?

(1) English translation provided for the reader; (2) Verbatim transcription; (3) Patient-participant from case two

3.13 Data analysis

Data analysis was performed between August 2017 and November 2018. Analysis and synthesis of the quantitative and qualitative data followed Stake's 'case-quintain dialectic' approach to multi-case study, in which the focus alternated between the uniqueness and particularity of the individual cases with that of the quintain as experienced across the cases (Stake, 2006). Quantitative data, APCA African POS and PPSv2, from each case were first plotted against time to help identify how reported well-being changed over the period of data collection. Secondly, these data were pooled across the cases and presented in frequency charts to identify patterns within the scales, such as the frequency of severe worry over all data points and cases. Qualitative data, interview and journal transcripts, were thematically analysed using NVivo for Mac v.10.2.2, as described below (Braun and Clarke, 2006).

3.13.1 Thematic analysis

Thematic analysis is an approach to qualitative data analysis, in which themes or patterns in the data are identified and described (Braun and Clarke, 2006). Following Braun and Clarke's guidelines (2006), all transcripts were read and re-read to enable familiarisation with the data. Individual interview and audio-journal transcripts were then coded line by line. Coding frameworks were created for each participant (an example is included appendix 16). NVivo's annotation function was used to record impressions and contemplations on aspects of the data which were considered to be unusual, surprising, interesting or being representative of common experiences (Saldana, 2012). Codes were written in English to facilitate discussion and accountability with the supervisors.

This multi-case study involved two techniques of thematic analysis, inductive and through the lens of the foreshadowed issues (Stake, 2006; Dinkelman, 2001). The inductive approach is described as data-driven by Braun and Clarke (2006), whereas the foreshadowed issues approach has similarities with Braun and Clarke's description of theory-driven thematic analysis, in which the foreshadowed issues are comparable to theories to be explored (2006). As can been seen in figure 3.6, the inductive approach was most prominent at the initial levels of analysis, for example the coding of transcripts. The foreshadowed issues became more influential at the case and cross-case levels of analysis. Transcripts, codes, and quantitative data continued to be revisited iteratively throughout the case study research.

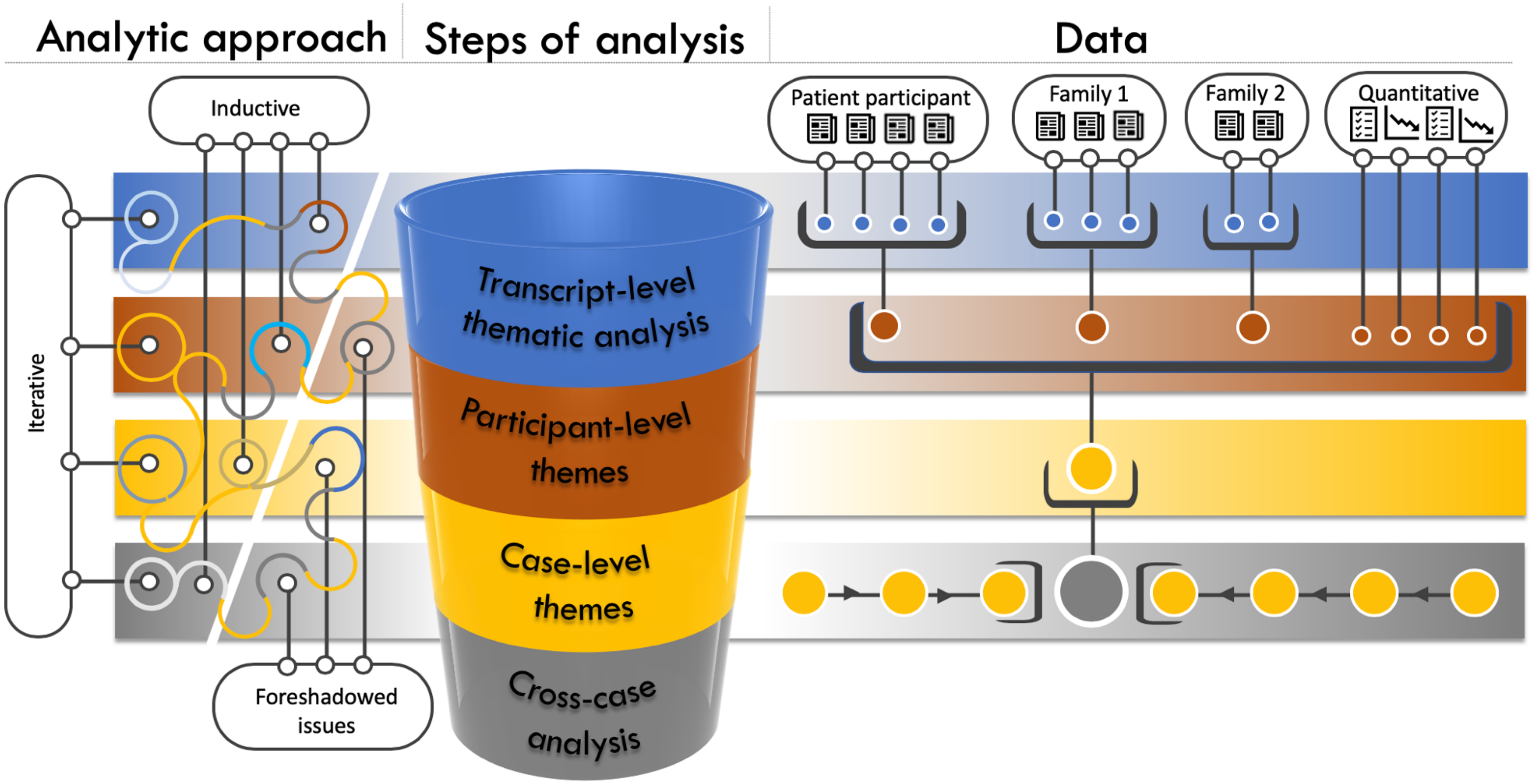


Figure 3.6: Illustration of data analysis

3.13.2 Within-case analysis

Data were analysed at the case level, within-case analyses, to explore and understand the contexts of the individual cases prior to seeking to understand the quintain (Stake, 2006). These analyses followed Stake's suggestions to use narratives and 'thick descriptions' to interpret and present findings (1995, p39). The steps of the within-case analyses were as follows;

1. The individual journeys and experiences were summarised in narrative descriptions to create rich accounts of how participants interpreted and experienced advanced breast cancer, with help from field notes and a reflective journal.
2. Data from the APCA African POS and the PPSv2 were plotted against time.
3. Qualitative data were thematically analysed at different levels as illustrated in figure 3.6 (Braun and Clark, 2006).
    a. Transcript-level: Individual interviews and audio journals were analysed and coded line-by-line.
    b. Participant level: Quantitative and qualitative data from each participant were analysed and synthesised in light of the chronological narrative and concurrent events described in the case such as, hospital visits and new symptoms. Analysis of the data from each patient-, family- and health-participant produced multiple themes specific and unique to each participant within the case.

c. Case level: The findings from the analyses of patient-participant data were then synthesised with the data arising from the embedded mini-cases. The identification and description of case-level themes were guided by the foreshahowed issues and tended to concentrate on the experiences of the patient-participant.

These within-case analyses were written up as reports. Each report included an introduction to the case and mini-cases, the coding framework, narrative descriptions, timelines, and commentaries on the provisional themes and the case's utility in exploring and understanding the foreshadowed issues. The findings of the within-cases analyses are presented in chapter four.

3.13.3 Cross-case analysis

The cross-case analysis sought to explore and understand the quintain; the experiences of advanced breast cancer in Mauritania. It was directed by the foreshadowed issues, which served as lenses and boundaries to the data, influencing which provisional themes were further explored and developed to best understand the quintain. The cross-case analysis built and expanded on the findings from the eight within-case analyses, as illustrated in figure 3.6. Throughtout this process, the transcript-, participant- and case-level data along with the quantitative data were iteratively revisited to seek deeper understanding of the developing interpretations and patterns in the data. Mind-mapping served to visualise and identify the relationships and variance between cases and themes (appendix 17). Finally, the four foreshadowed issues also helped in understanding the hierarchy of the identified themes and guided the order in which they are presented in chapter five: *Cross-case findings*. The foreshadowed issues and the resulting multi-case assertions will be visited again in chapter six: *Discussion*.

3.14 Reflexivity

The researcher is the primary tool in case study research (Simons, 2009). For this reason, and the subjective nature of the thesis, there was a need for reflexive practices, and their recording. As a male, medically trained, non-Mauritanian it was important to monitor and question how my identity and role changed the research process. The influences at play between myself and the participants and the emerging findings were considered. I routinely reflected on the cycles of experiencing, observing, learning and theorising; and how I and my views changed (Etherington, 2004).

> If human knowledge is co-constructed, then any research project must involve some degree of mutual exploration and discovery. The unmet challenge for qualitative researchers is to document this process in an open and honest way.
>
> (Walsh, 1994: p.383)

In this research, reflexivity was aided by a personal journal, field notes, conversations with others, and engagement with the primary data and existing literature. A reflexive journal was kept throughout the study to record observations and feelings (excerpts from the journal are presented in chapter four: *Within-case findings*). This served to monitor the development of my thinking and thought processes. It was recorded in a Microsoft Word document. Field notes were created during the interviews and immediately afterwards to record observations such as descriptions of participant, the interview location and comings and goings within the household. These were recorded on paper during the interview and transfered to a Microsoft Excel spreadsheet along with the recorded demographic and quantitative data. These entries were revisited prior to subsequent interviews with the participants of the case, and during data analysis.

Regular formal supervision sessions provided an opportunity to debrief on some of my experiences. Conversations with colleagues and friends in Mauritania provided new insights and questions for my reflexive processes; such as the viewpoints from anthropologists, doctors, nurses, sociologists, translators, and religious scholars. These reflexive practices continued during data analysis and writing up, with an awareness that my identity and background influenced how I perceived and interpreted the data and literature. The reflexivity employed in the study is further explored in chapter six: *Discussion*.

3.15 Ethics

Ethical approval was granted by the Faculty of Health and Medicine Research Ethics Committee at the University of Lancaster (appendix 18). An amendment was granted to allow participants to record their audio-journal using Whatsapp, the inclusion of the patient’s health records, and to extend the period of data collection, disrupted by the religious holiday of Ramadan. Local governance approval was granted by the director of the CNO (appendix 19).

Specific ethical concerns relating to this research included ensuring consent was maintained during the prolonged data collection, anonymity and confidentiality due to the relatively small number of participants involved, emotional distress for participants discussing sensitive issues, and the power imbalance between the researcher and participants.

3.15.1 Informed consent

The health of patient-participants was expected to fluctuate over the period of data collection, with the risk of transient loss of capacity (Higginson and Harding, 2007; Casarett et al., 2003). To address the risk that such losses could result in the withdrawal of consent, the researcher periodically confirmed the participants' understanding of the research and their ongoing consent. These reminders were informal, based on implicit ongoing consent because a more formal approach could have been detrimental to the participant-researcher relationship with a resulting dearth of information shared (Hammersley and Atkinson, 2007; Seymour and Ingleton, 2005).

3.15.2 Anonymity and confidentiality

Identifiable data were anonymised, and pseudonyms were allocated (Sheldon and Sargeant, 2007). Access to identifiable information was controlled in accordance with the ethical guidelines produced by the University of Lancaster. It involved:

a. Removal of identifiable personal details from transcripts and journal entries

b. All digital documentation and audio recordings were securely stored on encrypted computers

c. Audio files and transcripts were transferred in secure ways and stored in password protected encrypted folders

d. Personal details and audio-recordings will be kept until the thesis is assessed, and then destroyed.

e. Written documentation will be offered to the UK Data Archive and the University's data repository via PURE, where it will be preserved according to the University of Lancaster data policy for a minimum of 10 years.

3.15.3 Emotional distress

The researcher's duty to do no harm was addressed through the provision of verbal and written information to participants, which included contact details of a local breast cancer support group. Participants were informed that they were free to withdraw from the study at any moment, with no explanation required. Any emotional distress during interviews was managed according to a distress protocol, which was available in English and French to the researcher and interpreter (Appendix 20). This was used on one occasion where the interview was stopped because the patient-participant was experiencing upset and severe pain (case four).

3.15.4 Hawthorne effect and coercion

The Hawthorne effect, ‘the tendency for people to behave differently when they know they are being studied...’ (Davies and Shackleton, 1975: p55), can be more pronounced in case study research due to the close, prolonged involvement of the research team with the participants (Payne et al., 2007). Participants may view the researcher as a further member of their healthcare team, with a resulting shift of power in the relationship (Lawton, 2001). In this study, the researcher was the sole medical provider of palliative care in Mauritania. Patients already registered with the palliative care service were excluded from participation to reduce the risk that they may feel coerced to participate. It was, however, deemed unethical to deny access to palliative care for recruited patient-participants. Four patient-participants became registered with the service during the course of study participation. They received regular visits from the palliative care team, including from the researcher as clinician. Attempts were made to ensure interviews and palliative care visits were distinct and independent from each other. On occasion, when new symptoms or clinical questions arose in interviews, these were addressed after the completion of the interview.

3.16 Conclusion

This chapter has shown that a constructivist paradigm is an appropriate paradigm to answer the research question and that a Stakian multi-case study approach is a suitable study design to explore experiences of advanced breast cancer in Mauritania. The working methods, including recruitment and data collection and analysis have been presented. The findings from the within-case analyses and cross-case analysis will be presented in chapters four and five, respectively.

Chapter 4: Within-case findings

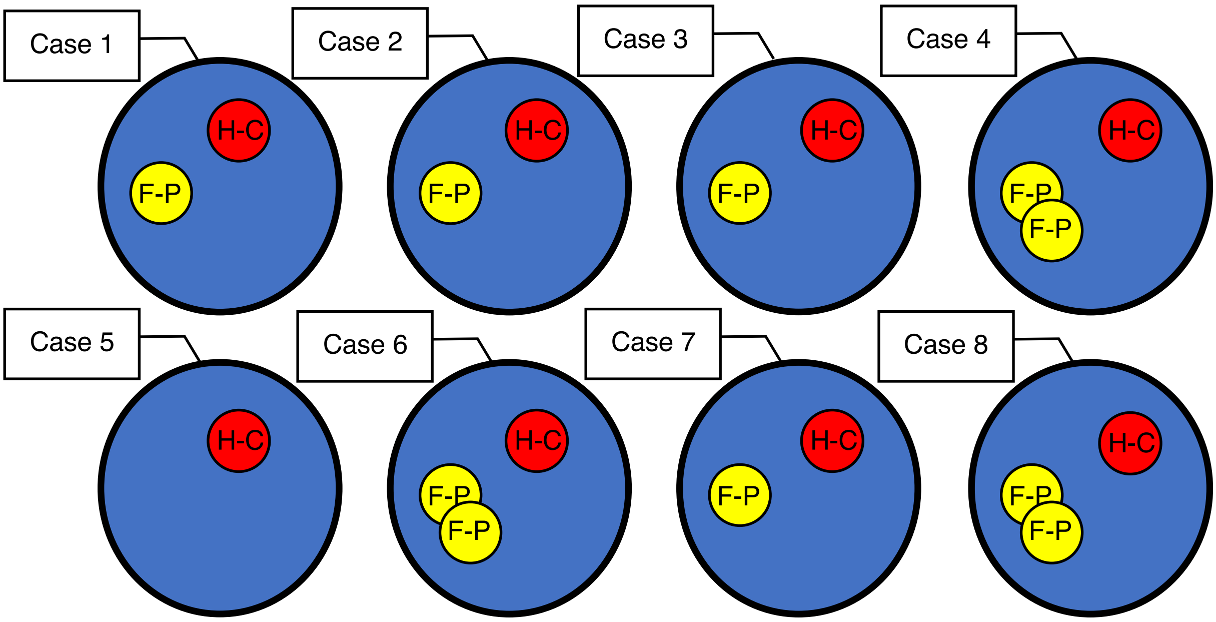
4.1 Introduction

The preceding chapter presented the methods of the within- and cross-case analyses. This chapter will describe the cases, the embedded mini-cases, the data collected and the findings from the within-case analyses. The cross-case findings and the quintain are presented in the chapter five.

4.2 The cases

This Stakian multi-case study research sought to understand the experiences of Mauritanian women with advanced breast cancer. In order to do this, cases were recruited over two phases; November 2016 to February 2017, and September to October 2017. Study information was provided to 11 women. One declined to sign the consent form and two women withdrew their consent in the cooling-off period prior to any data collection.

The multi-case study consisted of eight cases, six recruited in the first phase of recruitment and two in the second. Each case was embedded with mini-cases (see figure 4.1). Ten family-participants were nominated and recruited to mini-cases, which were embedded in seven cases. Eleven health professionals received information on the study. Nine, eight male and one female, consented and were recruited to the health-care mini-case, which was embedded in each case, as discussed above in section 3.10.2. The eight recruited patient-participants were from the Bhedane and Haratine ethnic groups, collectively referred to Maures, as discussed in chapter one: *Introduction*. The patient-participants will henceforth be referred to as Maure women, rather than Mauritanian women. The demographics of the eight cases and their embedded mini-cases are presented in tables 4.1 and 4.2.



F-P, Embedded mini-cases of family-participants; H-C, Embedded healthcare mini-case

Figure 4.1: Composition of cases

Table 4.1: Case demographics

Pseudonym		***Binata***	***Lalla***	***Binta***	***Oumou***	***Aissata***	***Alya***	***Meimouna***	***Khadija***
Age (1)		55	43	40	46	45	55	70	70
Marital status		Divorced	Married	Single	Widowed	Married	Widowed	Divorced	Married
Children		Yes	Yes	No	No	Yes	Yes	Yes	Yes
Moved home for treatment		Yes	Yes	No	Yes	No	Yes	No	No
Family went into debt because of the cancer		Yes	Yes	No	No	No	No	Yes	No
Time since diagnosis		2 years	3 years	2 years	3 years	3 years	4 years	6 months	2 years
Treatments	Mastectomy	Abroad	RIM	RIM	None	Abroad	RIM	RIM	Abroad
	Chemo-therapy	RIM	RIM	Abroad	RIM	Abroad	RIM	RIM	Abroad
	XRT	None	RIM	Abroad	None	None	RIM	None	None
	Traditional Medicine	Abroad	None	None	Abroad	RIM	Abroad	RIM	None
Place of death		Home	CNO	N/A	Home	N/A	CNO	CNO	N/A
Family Member		Son-in-law	Husband	Brother	Sister & Cousin	-	Daughter & Nephew	Daughter	Son & Husband

(1) Eestimation

CNO, Centre National d’Oncologie; N/A, Not Applicable; RIM, République Islamique de Mauritanie; XRT, Radiotherapy

Table 4.2: Mini-case demographics

Participant	Demographic
H1	Non-specialist doctor at the CNO
H2	Gynaecologist working at the CNO and general hospital
H3	Non-specialist doctor at the CNO
H4	Oncologist working at the CNO
H5	Nurse working at the CNO
H6	Non-specialist doctor working at the CNO
H7	Oncologist working at the CNO
H8	Oncologist working at the CNO
H9	Nurse working at the CNO

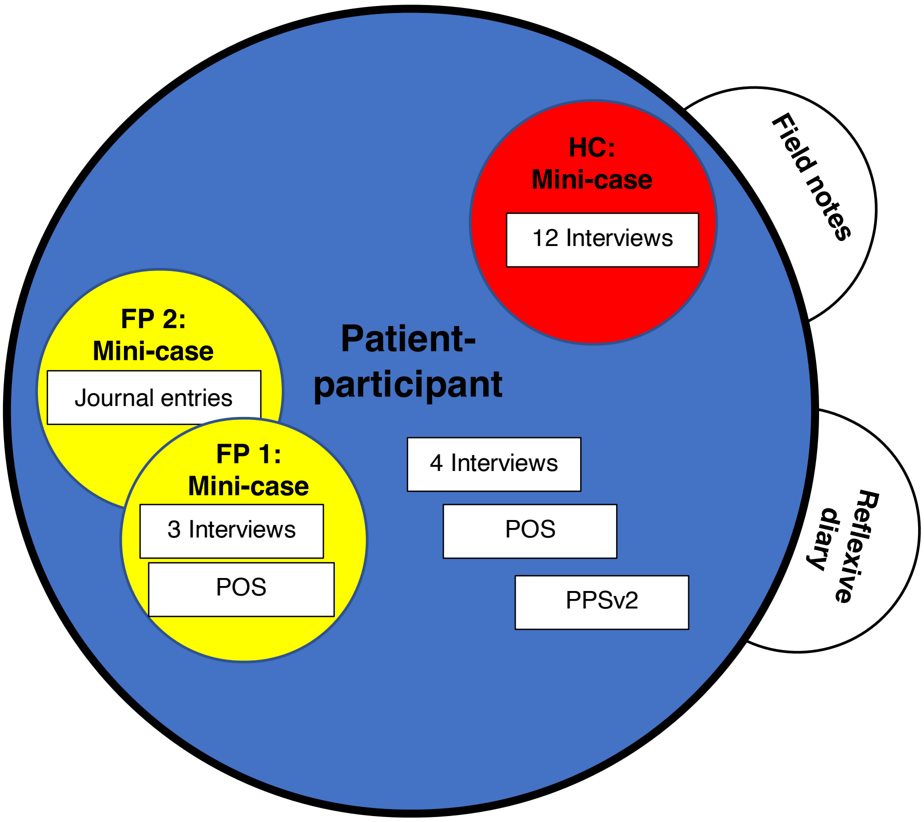
CNO, Centre National d'Oncologie

4.3 Withdrawal and closure of the cases

Three patient-participants died during the planned period of data collection. Two patient-participants withdrew during the course of the study. No reasons were provided for withdrawal.

4.4 Data collection

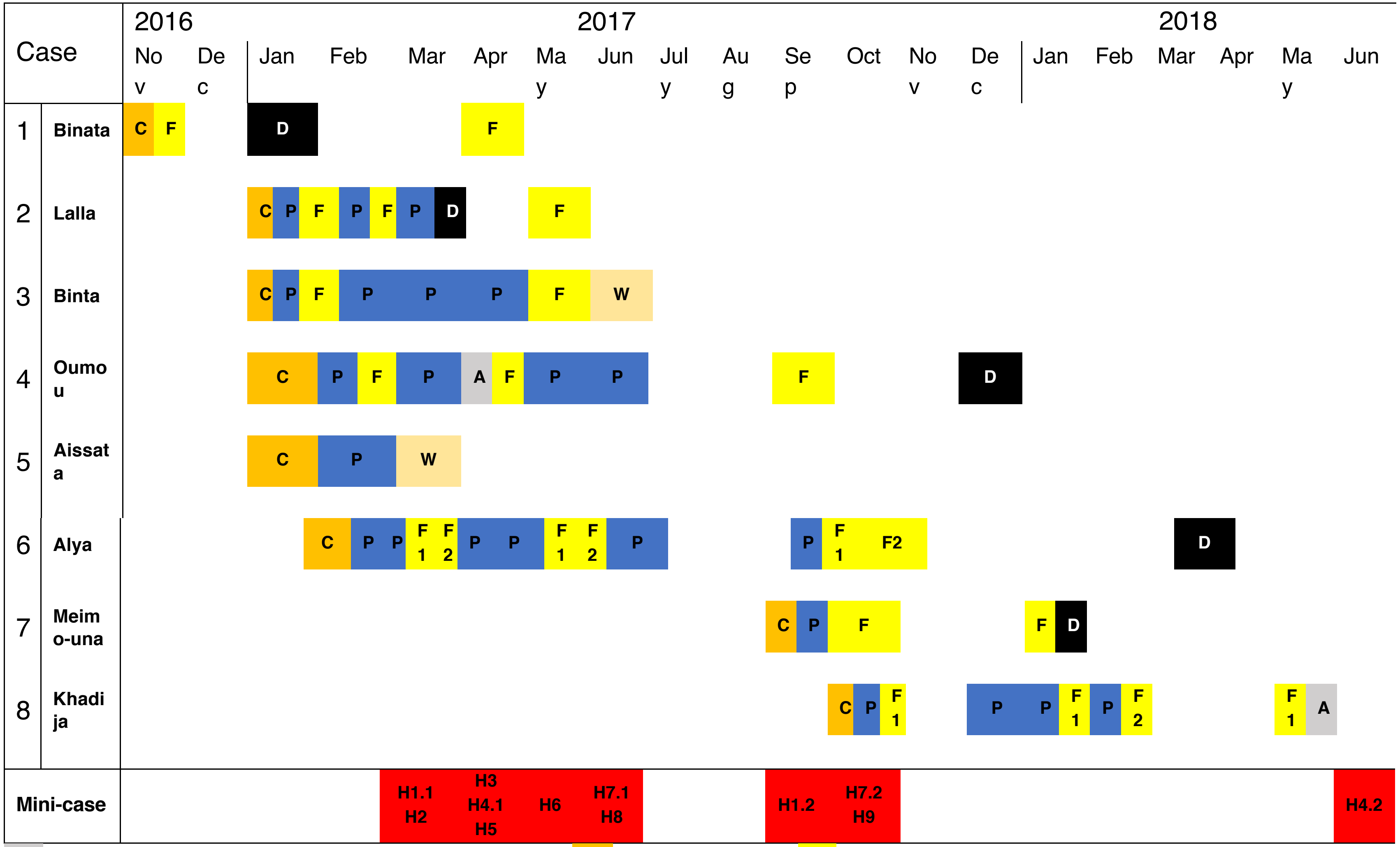
Case data were collected, through semi-structured interviews, audio-journals, and PROM and performance measurements, between November 2016 and May 2018 (see figure 4.2 and table 4.3). A total of 58 interviews were carried out. They lasted an average of 53 minutes with patient-participants, 52 minutes with family-participants, and 47 minutes with health-participants. Audio journal entries were recorded by six family-participants. APCA African POS data were collected in seven cases and eight family mini-cases. PPSv2 data were collected in seven cases (see table 4.4). The complete quantitative data set is included in appendix 21.



F-P, Embedded mini-cases of family-participants; H-C, Embedded healthcare mini-case

Figure 4.2: Exemplar of data collected in case four

Table 4.3: Overview of interview data collection



Case		2016		2017												2018					
		Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
1	**Binata**	C F		D			F														
2	**Lalla**			C P F	P F	P D		F													
3	**Binta**			C P F	P	P	P	F	W												
4	**Oumou**			C	P F	P	A F	P	P			F			D						
5	**Aissata**			C	P	W															
6	**Alya**				C P	P F1 F2	P P	F1 F2	P			P F1	F2					D			
7	**Meimo-una**											C P	F			F D					
8	**Khadija**												C P F1		P	P F1	P F2			F1 A	
Mini-case						H1.1 H2	H3 H4.1 H5	H6	H7.1 H8			H1.2	H7.2 H9								H4.2

A, Interview impossible due to deterioration of condition; C, consent obtained; F, interview with family-participant;
H, interview with health-participant; P, interview with patient-participant; W, withdrawal of consent; D,: death of patient-participant

Table 4.4: Collection of case data

Case		**Interview data**		**Audio journal**	**Scale data entries**		
		Number	**Duration mean (range)**		**APCA African POS**		**PPSv2**
					Patient	**Family**	
1	F-P	2 (1 PM)	36m (30 – 41)	-	-	1	1
2	P-P	3	36m (32 – 41)	-	3	-	4
	F-P	3 (1 PM)	31m (6 -61)	5	-	1	-
3	P-P	4	43m (27 – 55	-	-	-	-
	F-P	2	43m (26 – 59)	4	4	5	5
4	P-P	4	66m (57 – 74)	-	5	-	5
	F-P 1	3	51m (48 – 53)	-	-	3	-
	F-P 2	0	-	4	-	-	-
5	P-P	1	74m	-	1	-	-
6	P-P	6	58 (40 – 74)	-	7	-	10
	F-P 1	3	69m (59 – 87)	13	-	6	-
	F-P 2	4	59m (42 – 90)	2	-	5	-
7	P-P	1	48m	-	1	-	3
	F-P	2	56m (47 – 64)	3	-	2	-
8	P-P	4	38m (27 – 51)	-	4	-	5
	F-P 1	3	47m (22 – 69)	-	-	4	-
	F-P 2	1	49m	-	-	1	-
Healthcare		12	46m (29 – 72)	-	-	-	-
Total		**58**	**-**	**31**	**25**	**28**	**32**

F-P, family-participant; m, minutes; PM, post mortem; P-P, patient-participant

4.5 Within-case analyses and their utility

Data analysis in a Stakian multi-case study involves oscillating between the case and the quintain (Stake, 2006). The within-case analyses focused on understanding the contexts and particularities of the individual cases. The analyses followed four steps: narrative description, description of quantitative data, thematic analysis of qualitative data, and the layered synthesises of data (Stake, 1995; 2006). These analyses were then compiled into reports which ranged from 2,000 to 14,000 words. These consisted of narrative introductions to the case, presentation of the themes identified in the thematic analysis and graphical illustrations of data (examples provided below in the individual case presentations). Finally, the utility of each case was considered. This followed Stake's suggestion that each case should be evaluated for its usefulness in exploring and understanding the foreshadowed issues (box 3.1). He recommends a three-point rating scale of utility; low, middling, or high utility recorded as 1, 2 or 3, respectively (Stake, 2006). These utilities are depicted on radar charts in which the outer diamond represents the maximum utility (3) and the inner diamond the minimum (1). These ratings of usefulness helped the identification of themes in each case and the evaluation of how well each foreshadowed issue had been addressed.

4.6 Cases

4.6.1 Case 1: Binata

4.6.1.1 Narrative description

After a short history of pain in her left breast, Binata travelled abroad where she stayed with her extended family. She first underwent traditional treatments. When these did not help, she had tests and, latterly, a left mastectomy at a hospital. On returning to Mauritania she had chemotherapy and symptomatic treatment at the CNO. Her mastectomy wound never healed and she was often breathless and in pain. Her right breast became swollen. She was found to have cancer in the right breast and travelled abroad again where she underwent a right mastectomy in December 2016. She died at home in Mauritania in January 2017. She was always surrounded by her family throughout her journey, either in Mauritania or abroad. Her son-in-law, the family-participant, took on much of the responsibilities for her while she was in Mauritania because her sons were

- The belief in an omnipresent being is a comforting influence for the patient and their family as they face challenges to health and well-being
- Healthcare providers have a sense of ownership and responsibility towards their patients, and this affects the care they provide
- Mauritanian extended families experience difficulty in adapting to crises and in supporting their members
- There may be unacknowledged burnout, loss of hope and breakdown in the family cohesiveness

Box 3.1. Foreshadowed issues

away. The son-in-law worked at the CNO as a health care assistant and was well placed to communicate with the doctors and provide some medical care for her at home. He gave advice and would give her intravenous paracetamol infusions at her home, avoiding the need for her to travel to the CNO.

4.6.1.2 Description of quantitative data

There were limited data collected in case one, because of the deterioration in Binata's condition shortly after recruitment, represented by a PPSv2 status of 30%. The APCA AFRICAN POS was completed on one occasion with the son-in-law, and on no occasions with Binata (figure 4.3). These data suggest the family were content and confident in caring for her.

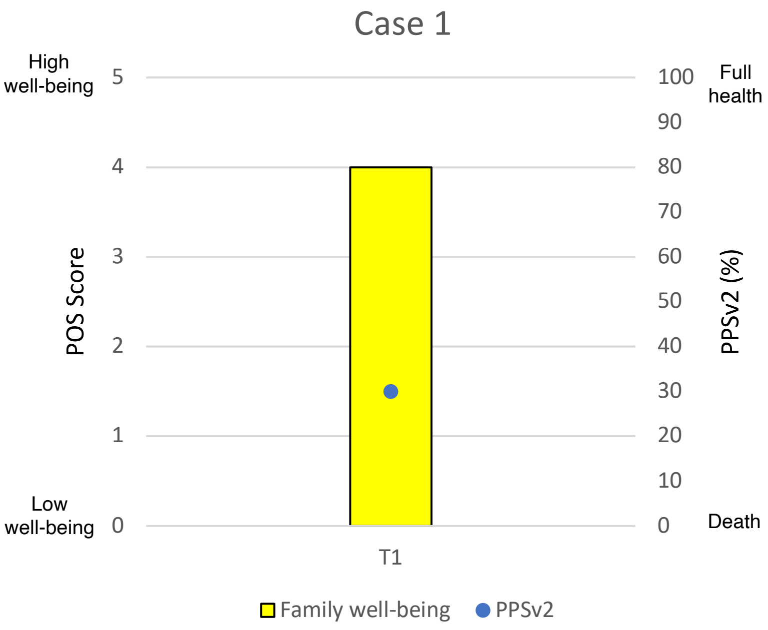


Figure 4.3. Quantitative data in case one

4.6.1.3 Utility of the case in understanding the foreshadowed issues

The utility of case one was limited because data were collected from one perspective, that of the son-in-law. The two interviews held utility in understanding two of the foreshadowed issues, (see figure 4.4). These were his insights into the duties of health professionals because of his position at the CNO, and his role in leading his wife's family due to the absence of sons. In addition, the bereavement interview (of two across the cases) provided a retrospective perspective on experiences during the life and death of Binata.

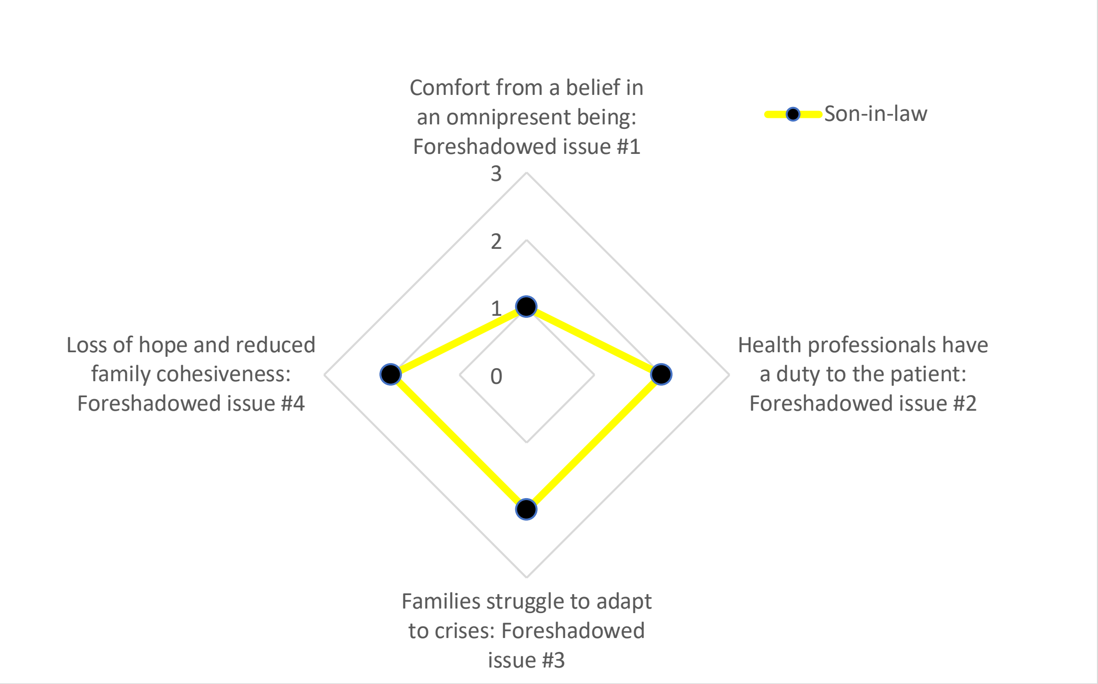


Figure 4.4: Radar chart depicting the utility of case one

4.6.2 Case 2: Lalla

4.6.2.1 Narrative description

Lalla went to a local doctor because her breast had been swollen for over a year. She was referred to a private clinic, where a needle biopsy was performed.

Following this, a doctor informed her that she needed treatment at the CNO without disclosing her cancer diagnosis. Due to a lack of confidence in the CNO, she and the wider family decided that it would be better to travel abroad for care. A second biopsy was performed in a neighbouring country, after which a doctor told the husband, the family-participant, that she had breast cancer. He informed her of this news the same day. She suspected that her cancer started at the time of the first biopsy, when it was introduced in her body by the doctor's use of a metal needle.

She and her husband returned to Mauritania after realising care abroad would be expensive, in contrast to free at home because of their health insurance with his low-level government job. Back in Nouakchott, she refused to undergo a mastectomy, but her husband organised with the surgeon for her breast to be removed during what she was told would be a removal of a simple breast lump. She learned of the mastectomy on waking from the anaesthesia. She did not express anger at this, and she accepted that her husband had done it for her benefit. She understood that she was cured following the courses of chemotherapy and radiotherapy.

She began to doubt her cure when she developed back pain and paralysis several months later. She was angry about the care she received at this time, perceiving that the doctor's negligence and lack of care delayed the diagnosis and

> She is not feeling well, and her condition is not reassuring, but there's no pain.

Box 4.1 Excerpt from husband's journal

treatment of her paralysis by several weeks. She later learned that the cancer had spread to her bones and lungs. This left her afraid that the cancer would spread further and so she was vigilant for any signs of this. She observed and questioned much of what happened to her during her contact with health professionals. She was suspicious of any medical staff at the CNO, considering them to be dismissive and negligent. Her physical well-being and strength continued to deteriorate (box 4.1). Her pain became increasingly problematic and she became frightened by her increasing shortness of breath and cough because she perceived them as having no cure. Aspirations of pleural fluid at the CNO were traumatic and failed to bring lasting relief (box 4.2 and figure 4.5). She died at the CNO in March 2017, two days after the third interview.

Researcher: How did it go when they took away the water last time?
Lalla: It was painful, painful in a way that I even fell unconscious, twice... He was removing almost a litre or so.
Researcher: And how long did this take?
Lalla: Not long, just a few minutes. I told them to fan me and give me water to drink.

Box 4.2 Lalla, interview 3

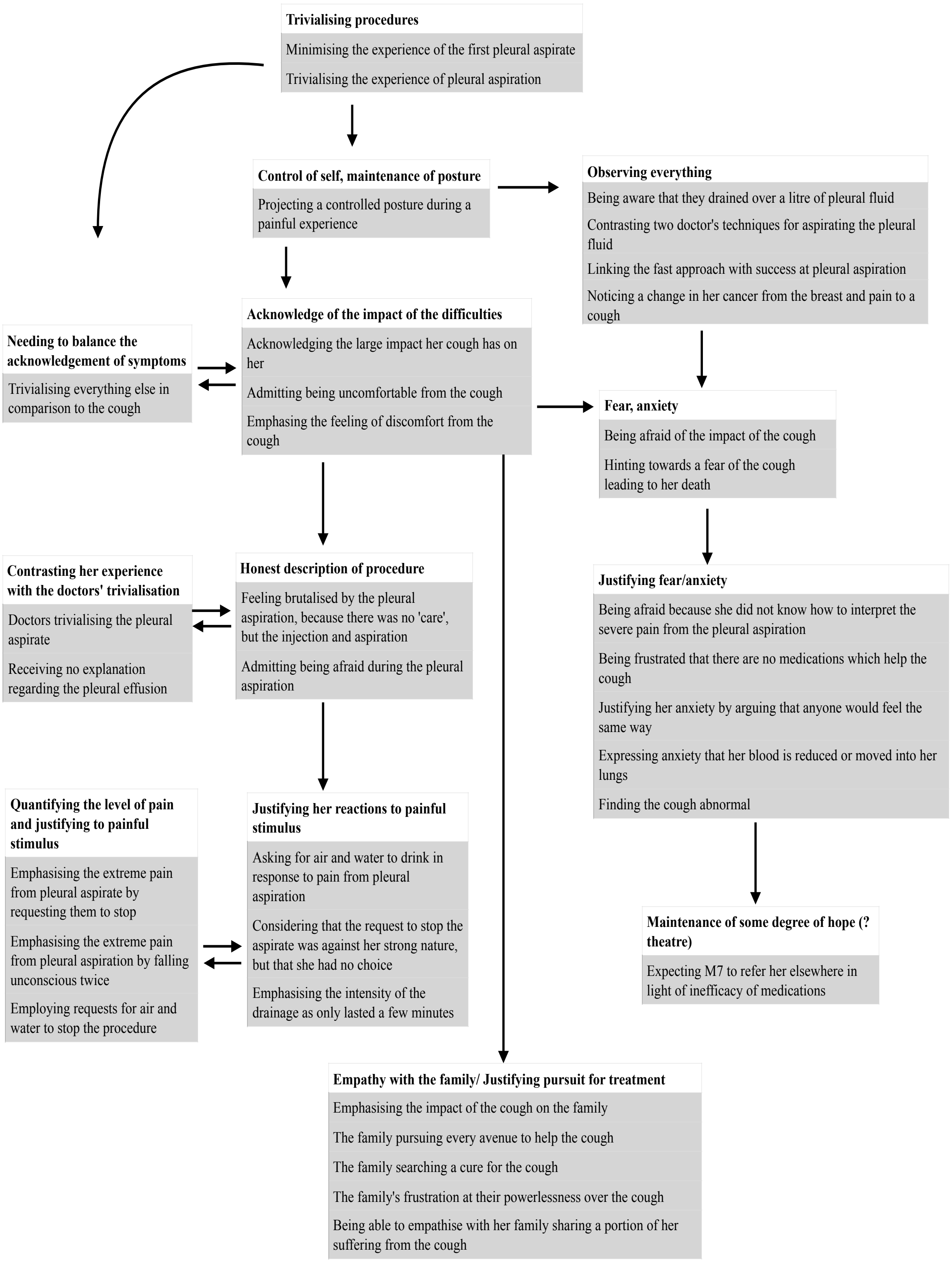


Figure 4.5. Mapping of Lalla's understanding and experiences of cough and pleural aspiration

4.6.2.2 Description of quantitative data

Lalla experienced a gradual deterioration in her physical, psychological and interpersonal well-being over the course of data collection (figure 4.6).

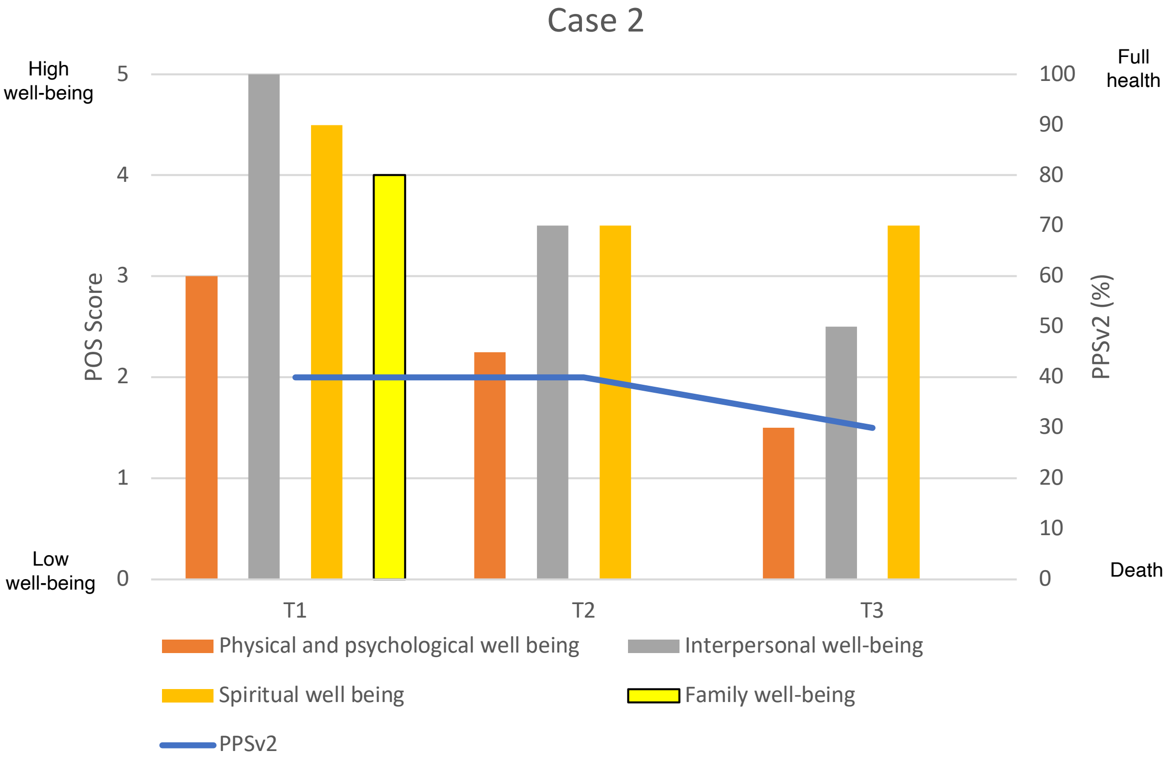


Figure 4.6. Quantitative data in case two

4.6.2.3 Utility of the case in understanding the foreshadowed issues

Data from case two proved useful in understanding the foreshadowed issues. Lalla was a well-educated woman who sought to understand her situation and expressed her frustrations when she felt these attempts were blocked. Qualitative data were rich and deep and covered much of the four foreshadowed issues (figure 4.7). She managed to maintain her familial responsibilities of running the household and being a mother, but from a distant, sitting position. Practical help came from sisters and young female cousins who relocated from the village to help with childcare and domestic chores. Case two provided detailed descriptions of experiences which helped understand the more guarded expressions in other cases; for example, her belief that metal caused breast cancer and her frustration at the negligent and trivialising attitudes of staff at the CNO.

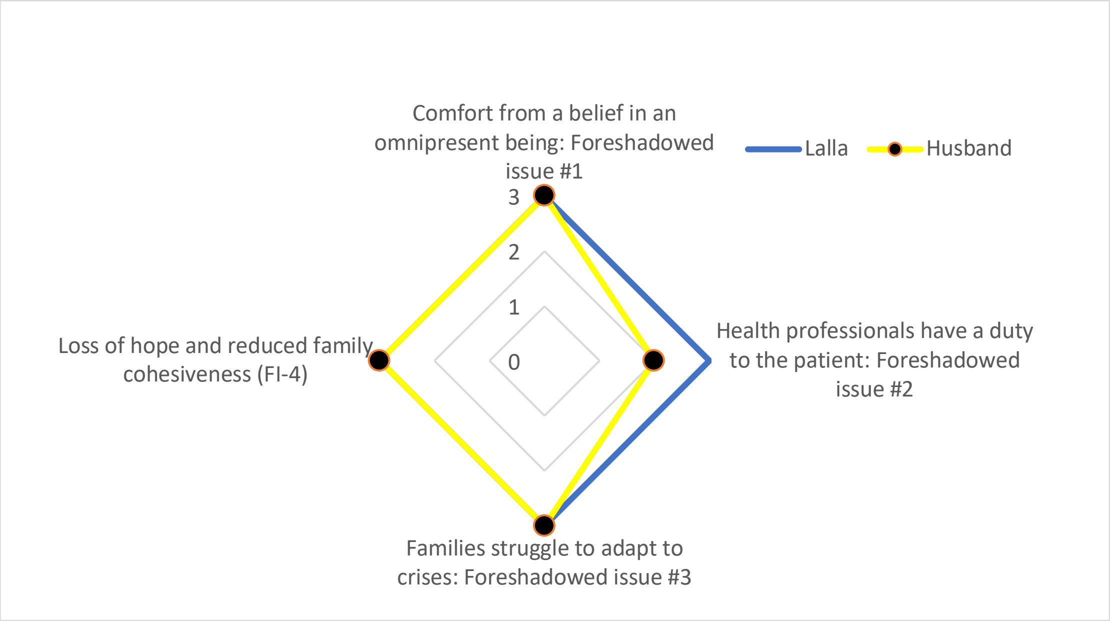


Figure 4.7: Radar chart depicting the utility of case two

4.6.3 Case 3: Binta

4.6.3.1 Narrative description

Binta had a long history of chronic illness which required regular medical consultations, including abroad. She was found to be anaemic on one of these routine appointments in Mauritania. The doctor then found a breast lump on examination, which she was told needed further investigation under general anaesthesia. On waking from this procedure, she discovered that they had removed the whole breast. This was how she learned she had breast cancer. She and her family lost confidence in the Mauritanian cancer services following a failed and traumatic insertion of a central venous catheter prior to starting chemotherapy. Her brother, the family-participant, then accompanied her to a nearby country where they stayed for eight months undergoing chemotherapy and radiotherapy.

Binta was a strong character who perceived herself as having a strong faith and found it frustrating when doctors treated her as ignorant. She felt that she should have been entrusted with information at an earlier stage because of her steadfast acceptance of destiny. She was convinced that she would not have panicked or doubted her faith like those with a weak faith. She often encouraged me to become a Muslim, but she became less open to talk of spiritual things over the study period (box 4.3).

> I told you that I won't answer the questions on faith, I don't answer you anymore [laughs]. The question of faith is between me and Allah and I don't associate you with it.

Box 4.3 Binta, interview 3

4.5.3.2 Description of quantitative data

Binta described a relatively stable well-being and quality of health over the period of data collection, as illustrated in the PPSv2 and the physical and psychological subscale of the APCA African POS data (see figure 4.8). Spiritual well-being appeared to improve, and interpersonal well-being appeared to deteriorate over time. The family’s well-being, as reported by the brother was consistently high.

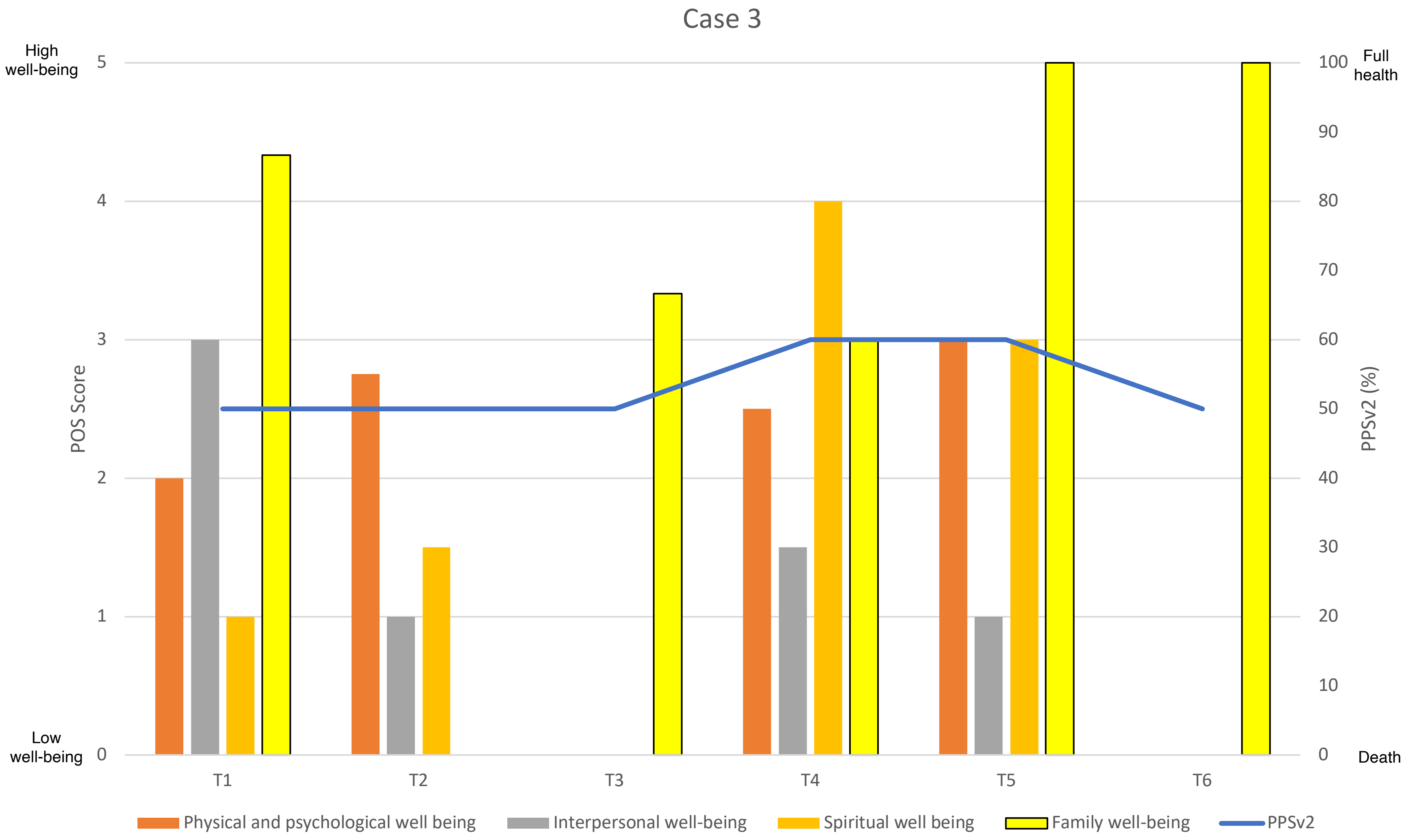


Figure 4.8. Quantitative data in case three

4.5.2.3 Utility of the case in understanding the foreshadowed issues

Binta consistently portrayed herself as a strong Muslim (box 4.4). She was perhaps the most guarded patient-participant, remaining careful of how she expressed her experiences, especially those related to her faith and spirituality. Case three held utility for observing and understanding some of the cultural and religious boundaries for the expression of negative experiences, tending towards a trivialisation. It also provided some unique perspectives on the experiences of single, unmarried women with breast cancer because Binta was the only patient-participant who never married.

Wednesday, 5 September 2018:

Destiny vs. fatalism

Binta sometimes seems more fatalistic than others - that nothing matters what we do because it is only what God wishes, whereas others give a more nuanced approach with the obligation towards treatment which she considers as nothing.

Box 4.4 Excerpt from reflective journal

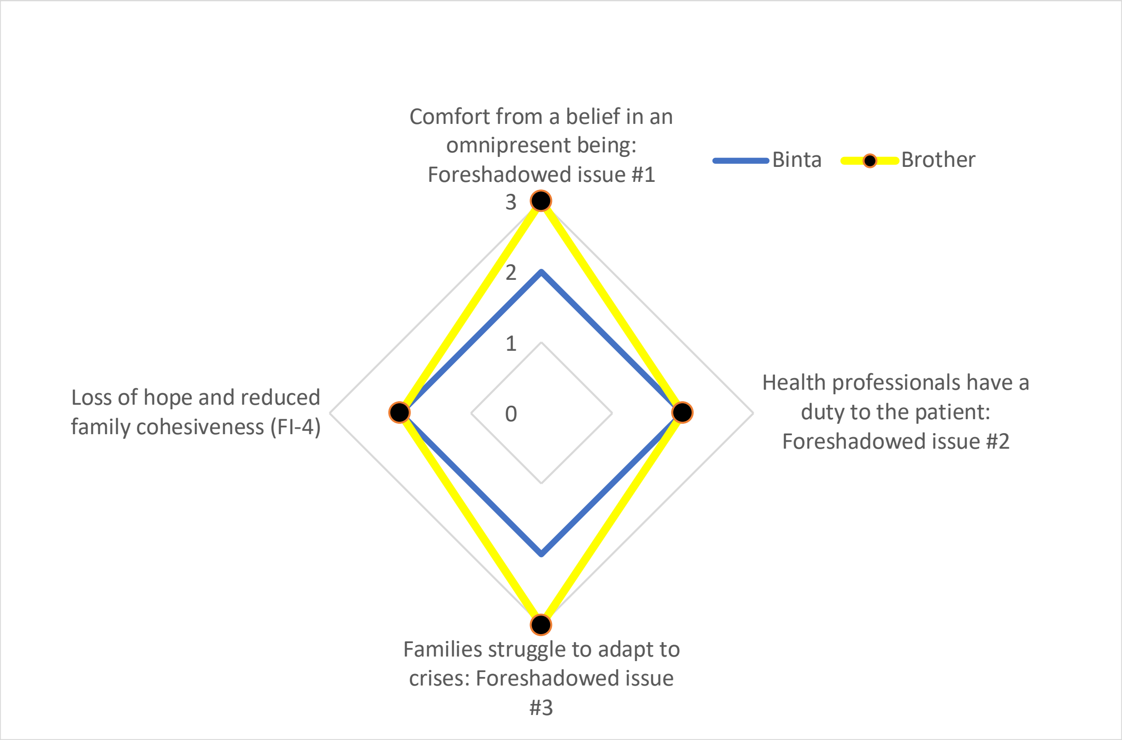


Figure 4.9: Radar chart depicting the utility of case three

4.6.4 Case 4: Oumou

4.6.4.1 Narrative description

After Oumou discovered a breast lump, she consulted multiple non-specialist doctors and traditional practitioners in Mauritania and a neighbouring country. She became frustrated that no-one explained the problem to her and that none of their treatments were effective. She described some of these practitioners as criminals because they stole her money with false claims of being able to cure her. Over time, the lump opened up to become an ulcer. Finally, she was referred to a larger hospital in Mauritania where it took numerous failed visits before she saw the appropriate doctor. A biopsy was taken from the ulcer. She waited three months for the result. The uncertainty and fear during this wait were exacerbated by very difficult experiences at the hospital where she attended for frequent dressing changes. These were performed in a painful way by a physically and emotionally abusive nurse.

The cousin of Oumou, the family-participant, eventually obtained the biopsy result and understood her diagnosis. He was then required to recruit a doctor-friend to pressure the doctor at the large hospital to refer her to an oncologist. Oumou considered that things got much better on arrival at the CNO where she received treatment for her problem (chemotherapy) and discovered that dressing changes did not need to be painful. It was during the chemotherapy sessions that she first understood that she had breast cancer, by overhearing conversations of other patients. She described suffering with severe pains prior to starting morphine tablets during the period of data collection. She died at home in December 2017.

4.6.4.1 Description of quantitative data

Oumou had much pain in her experiences of breast cancer, rating her pain as five out of five on three occasions. In contrast, she rated other aspects of her physical and psychological well-being relatively higher. It was questioned whether this pattern may have reflected her reticence to ‘complain’ of more than one aspect of her suffering, choosing to emphasise her pain. There was marked variability in her spiritual and interpersonal well-being, which seemed to correlate with her contemporaneous interactions and treatments at the CNO.

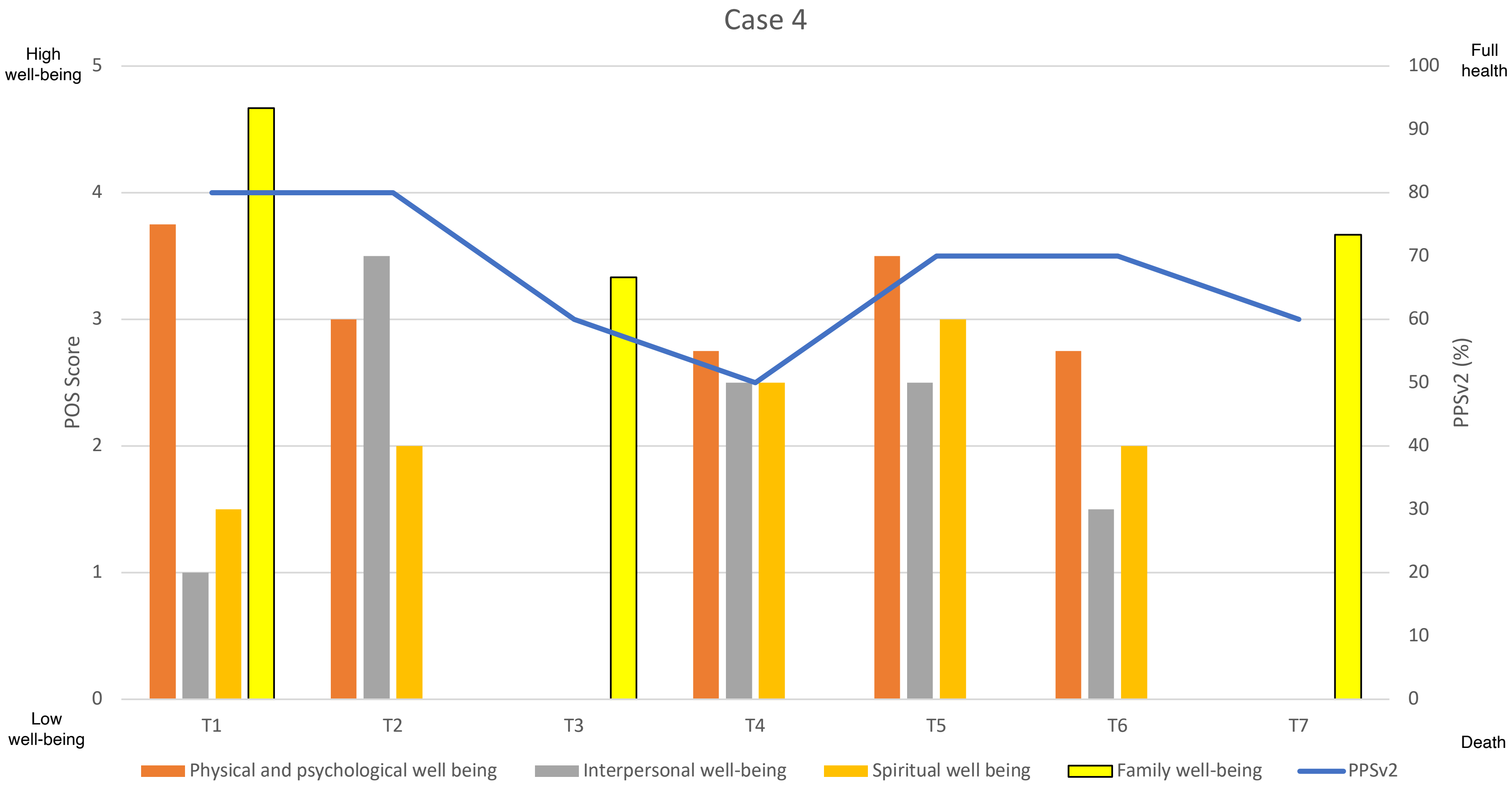


Figure 4.10 Quantitative data in case four

4.6.4.3 Utility of the case in understanding the foreshadowed issues

Case four was useful in exploring the foreshadowed issues, because of her willingness to express negative experiences, which was perhaps related to the extent of her suffering (figure 4.11). There were certain characteristics of case four which distinguished it from the other cases. Firstly, Oumou was the only patient-participant from the Harratine ethnic group, who were originally slaves to the Bhedhane, or White Maures, as discussed above in chapter 1: *Introduction*. Secondly, there were occasions where data from the healthcare mini-case directly related to Oumou and her situation (boxes 4.5 and 4.6). These data were useful to understand the positive and negative experiences of healthcare interactions. For example, the cousin and a health-participant (H1) provided descriptions on their differing experiences of an altercation between them at the CNO, which necessitated police involvement.

> The man [the cousin of Oumou], he hit the policeman, he hit the policeman in uniform. If he [the policeman] was in civilian clothes, it wouldn't matter but he was in uniform; but when you talk to the administration here, they say you have to let things go, it doesn't matter. That's the problem here [at the CNO]. First, he's going to hit the orderly, second, he's going to hit the policeman, and thirdly it's the doctor, that's it!

Box 4.5 H1, interview 2

> Yesterday when we were with him [H7], he asked us questions, it was different. He asked how the pain was, he joked with us and he chatted. Before, he would just prescribe something, and we would leave [...] I was so surprised to see that he was joking with me [laughs] that I wasn't able to ask any questions.

Box 4.6 Oumou, interview 3

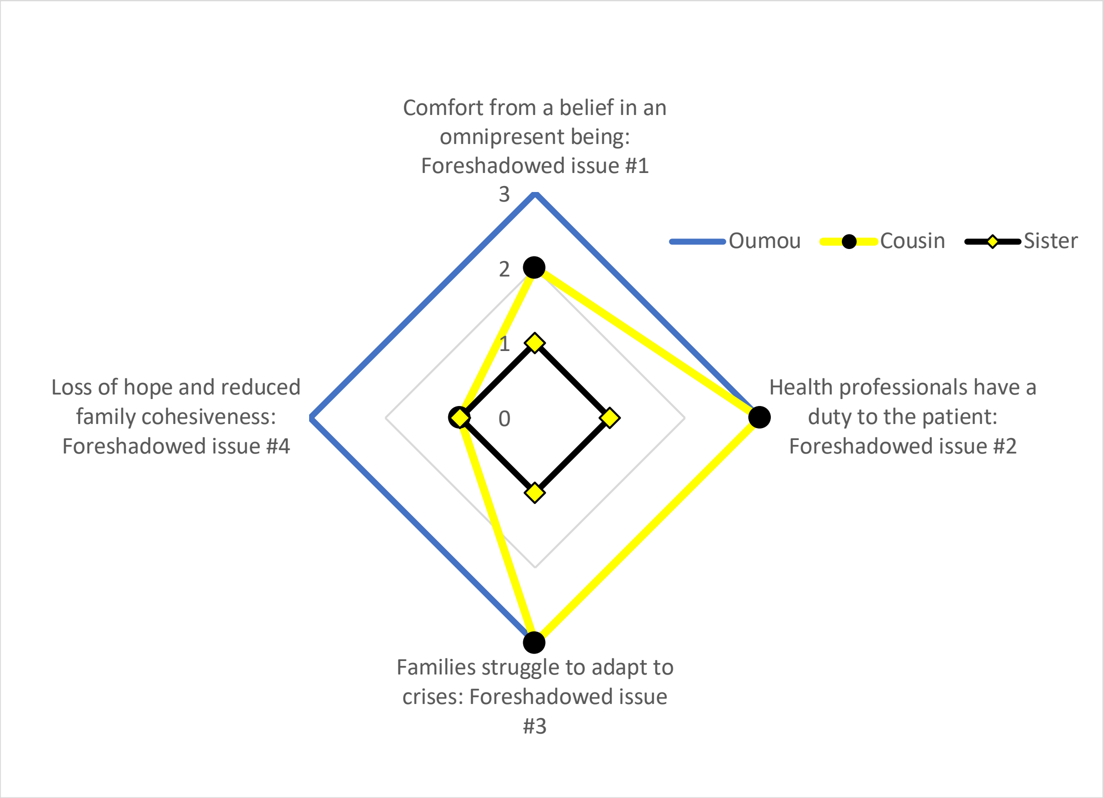


Figure 4.11: Radar chart depicting the utility of case four

4.6.5 Case 5: Aissata

4.6.5.1 Narrative description

Soon after Aissata noticed her breast to be swollen and painful, she consulted a local non-specialist doctor and then a traditional practitioner. Due to the lack of improvement, she suspected she needed more specialist help and consulted a doctor in a larger hospital. From there, she was referred to a specialist who performed a needle biopsy. At this moment, her family took her to a nearby country for a mastectomy and chemotherapy. She felt that she never received a clear, direct diagnosis from a doctor, but over time she deduced that she had breast cancer. A surgeon later confirmed this for her, when she told him of her suspicions.

4.6.5.2 Description of quantitative data

The quantitative data from the one interview with Aissata are presented in figure 4.12. There were no family members recruited in case five.

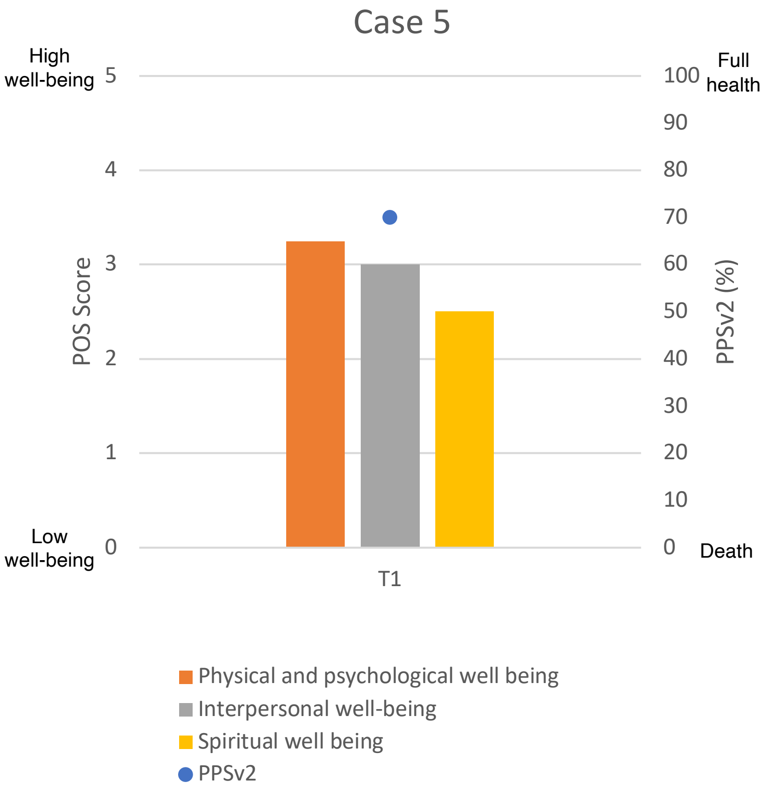


Figure 4.12: Quantitative data in case five

4.6.5.3 Utility of the case in understanding the foreshadowed issues

Case five provided useful insights into experiences of advanced breast cancer (figure 4.13). Her descriptions of the role destiny played in her life and how healthcare decisions were made by the family were helpful to understanding the foreshadowed issues. The utility of the case was rated relatively lower compared to other cases because no family perspectives were collected and because of her withdrawal from the study following the first interview.

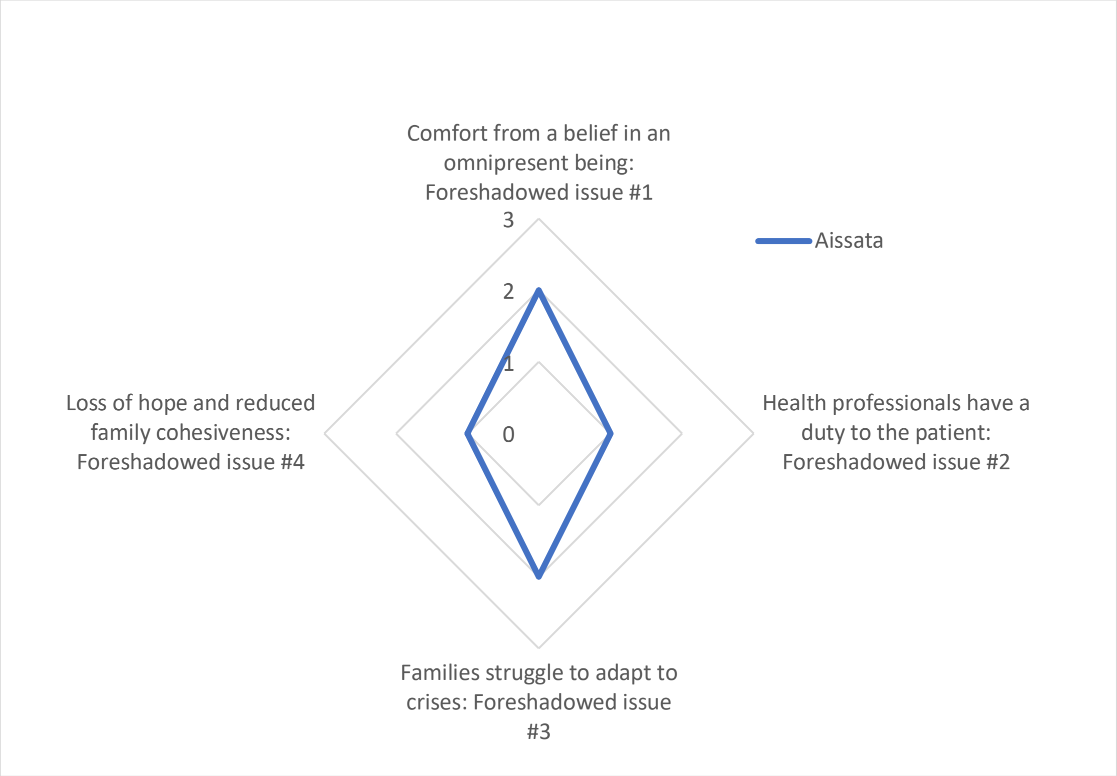


Figure 4.13: Radar chart depicting the utility of case five

4.6.6 Case 6: Alya

4.6.6.1 Narrative

Alya sought care for a long-standing, non-painful breast lump after it opened up into a painful ulcer. She visited local doctors and a traditional practitioner in a nearby country, whose treatments made no difference. She eventually saw a specialist in Mauritania, who organised for her to have an operation on her breast. On waking after the anaesthesia, she received bad and good news. Bad news that it was cancer, and good news that she was cured because they had removed all the cancer and all the breast. She subsequently underwent chemotherapy and radiotherapy at the CNO. During this time, her family were very attentive and supportive. Alya's daughter, family-participant 1, divorced her husband, and Alya's nephew, family-participant 2, left his Quranic studies so they could be with her and care for her. By the time of recruitment, Alya was aware that her cancer had spread to her bones and lungs which explained her paralysis. During study participation, she suffered from persistent pain and nausea and was frustrated that she received no relief despite her frequent complaining and attendances at the CNO's emergency department. Her daughter struggled to accept Alya's frequent calls for help and would have preferred her mother to endure in silence, especially when the CNO treatment resulted in no, or minimal benefit. Her nephew was nervous that she would cause offense to Allah through her complaining (box 4.7). Despite Alya describing herself as fearful and cowardly, she felt at peace and every night she would prepare herself in case she died in her sleep. She died at the CNO in March 2018

> It's normal for me to be very afraid. Of all that Allah has given us, there is no gift more precious than to be a Muslim. It is the most precious gift and it's normal that I was scared... [of Alya saying the wrong thing]. The problem is that we have limited knowledge and we do not know what could exit us out of Islam.

Box 4.7: Nephew, interview 1

4.6.6.2 Description of quantitative data

Alya experienced a gradual decline in her performance status over the course of data collection (figure 4.14). The APCA African POS data showed fluctuations in all domains. The physical and psychological well-being data correlated with her experiences of symptoms and treatments. There was stability of her spiritual well-being in the last four APCA African POS data collections from Alya, which may illustrate her increasing acceptance that she was unlikely to recover from the cancer.

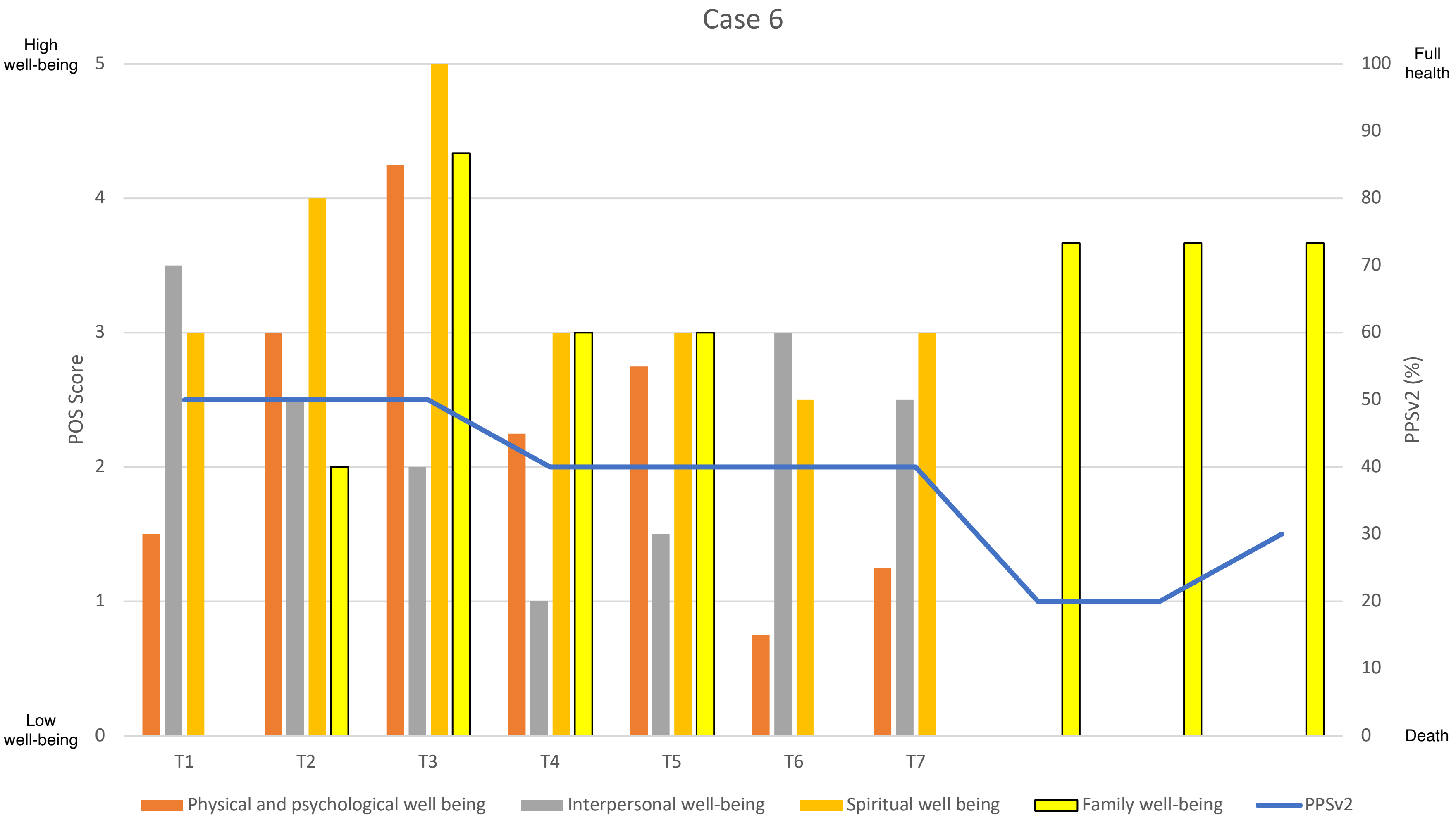


Figure 4.14. Quantitative data in case six

4.6.6.3 Utility of the case in understanding the foreshadowed issues

Case six held high utility for understanding the foreshadowed issues (figure 4.15). It had the longest period of data collection and active participation from two family-participants. The utility of case six was further enhanced by the corresponding data collected from a health-participant, H7, on the experiences of Alya and her family (box 4.8).

> [Alya] always comes to the hospital with pains, so it's really, you know... I can't be there each time every patient comes. There's a structure, there is the emergency room [at the CNO], there are doctors there. I think that the fact that I don't always see the patient at each visit leaves an impression with the patient towards me. That's one way, I think, it's a way of saying to patients and their families that it's a palliative situation and we've reached a stage where we can't do anything else.

Box 4.8 H7, interview 2

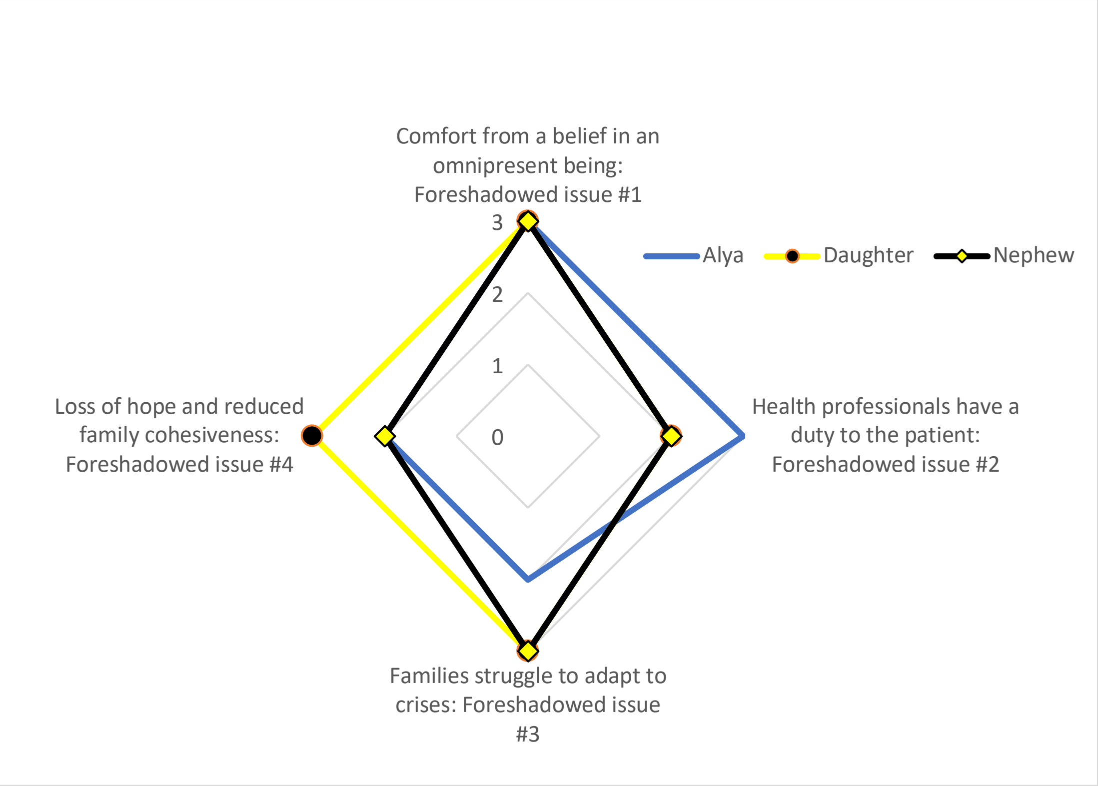


Figure 4.15: Radar chart depicting the utility of case six

4.6.7 Case 7: Meimouna

4.6.7.1 Narrative

Meimouna's problems with her breast started forty years previously. At that time an envious neighbour cursed her with the 'evil eye' which resulted in a breast abscess. This was successfully cured by a combination of treatments from a traditional practitioner and a medical doctor. She perceived this same problem returned when a non-painful lump developed in the same breast. She initially kept it hidden from her family because she did not want to cause extra costs for them.

The breast lump increased in size over time and she was no longer able to hide it. When her family discovered it, they took her to a general hospital where a specialist performed a needle biopsy. The family failed to access the result at the hospital and so they paid to see the doctor in his private clinic. He informed them that the lump was nothing serious, but that the breast should still be removed. Following mastectomy, the surgeon informed the family that it had been cancer. They passed the news onto Meimouna the same day. She then underwent chemotherapy and radiotherapy. She did not like chemotherapy and regularly pleaded with her family to stop it. This was difficult for the family who recognised that the chemotherapy did make things worse for her but that it was the only option available to cure the cancer. The daughter, the family-participant, suspected that the real cure for cancer was available but that the negligent government had failed to make it accessible in Mauritania. She died at the CNO in January 2018.

4.6.7.2 Description of quantitative data

Meimouna's performance status and overall well-being were low at the time of data collection (see figure 4.16). Her performance status continued to deteriorate.

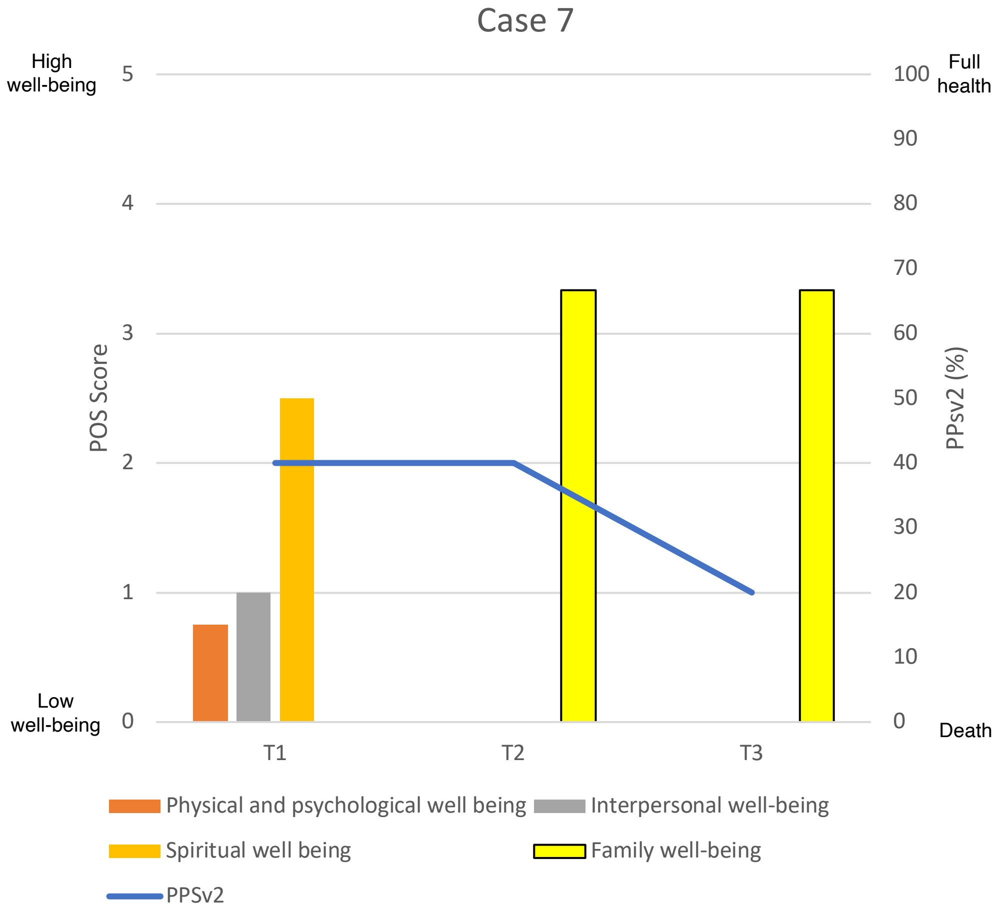


Figure 4.16. Quantitative data in case seven

4.6.7.3 Utility of the case in understanding the foreshadowed issues

Case seven had utility for understanding the foreshadowed issues, as depicted in figure 4.17. Although data collection was limited to one interview with Meimouna and two with the daughter, there were several aspects of the case which differed from the other cases. These included the prominence of the evil eye in the narrative (box 4.9), and the daughter's explicit anger against the doctors, the government and the president because she blamed them for withholding the cure to cancer.

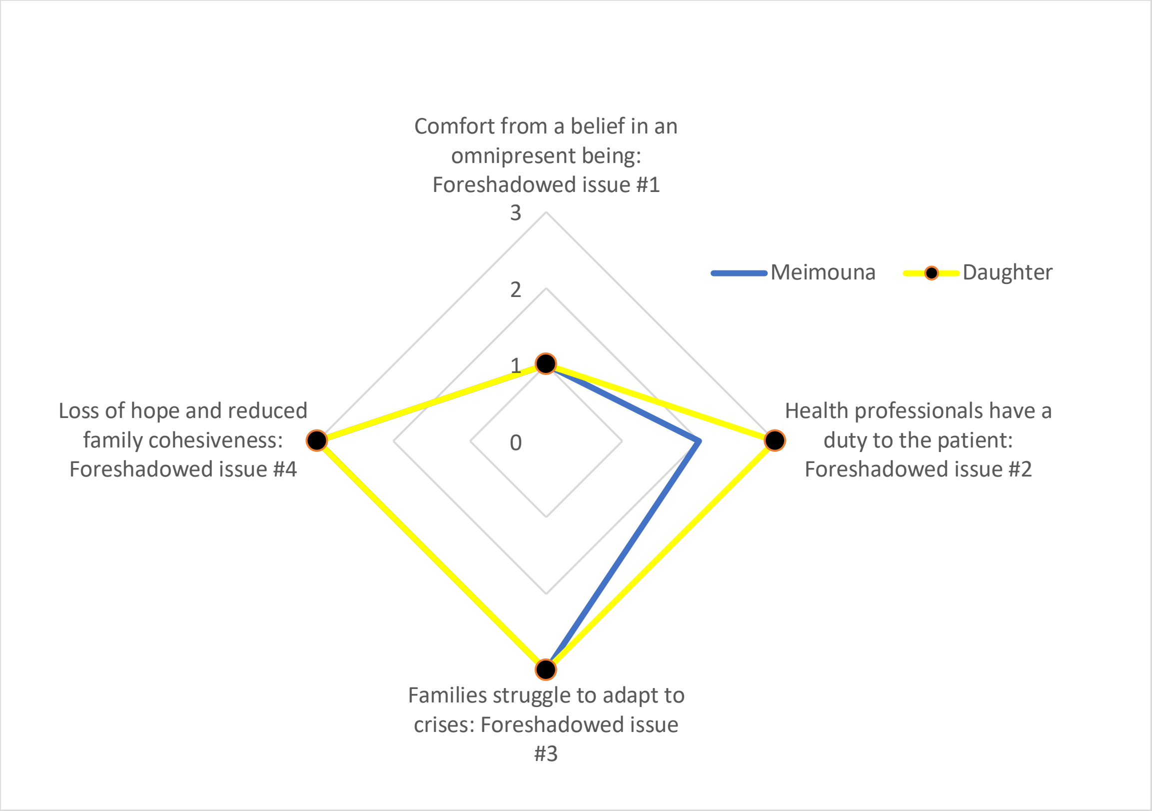


Figure 4.17: Radar chart depicting the utility of case seven

> The doctors, despite their research, could not know the sources of the disease [breast cancer]. But the scholars who have consulted the Qur'an, the word of Allah, and have made their analysis have come to the following conclusion: that the causes are the evil eye and the maraboutage [sorcery]

Box 4.9 Daughter, interview 1

4.6.8 Case 8: Khadija

4.6.8.1 Narrative

When Khadija noticed that she had painful breast lumps, she saw a local specialist who quickly removed one lump for testing. She was reassured when the result was reported as normal. Several months later, however, she returned to the same doctor because of further breast swelling and pain. A needle biopsy was performed which panicked her family, including two cousins who had recently undergone breast cancer treatment abroad. They feared that the metal needle would cause breast cancer. Within days, Khadija travelled with one of the cousins and her son, family-participant 1, to a nearby country where she had mastectomy, chemotherapy and radiotherapy over eight months. The son implied that he covered these costs; whereas Khadija suggested that everything was paid for by a very rich relative, possibly very high in the government.

A doctor informed Khadija of her diagnosis following the mastectomy, which he explained had removed all the cancer. Back in Mauritania, the son was told by a CNO doctor that the cancer had spread to her lungs. He concealed this information from everyone in the family, as part of his efforts to keep this secret from Khadija. He acknowledged this was difficult, but necessary to protect her emotional well-being and hope, which he perceived as necessary for her to be cured.

Sunday, 25 February 2018

Case 8

After the interviews with the patient and her husband, we stopped the dictaphone and I thought she was just talking about how I should become a Muslim. But afterwards in the car Ndiaye [interpretor] said she was actually comparing here with what she has heard about Europe. She highlighted that in Europe it was possible to go to hospital alone, without a family member. Initially I thought this was negative that the family had rejected the patient, but in fact it was a sign of the competence and the trust you can have in the staff.

Box 4.10 Excerpt from reflexive journal

4.6.8.2 Description of quantitative data

Khadija experienced reasonably stable levels of interpersonal and spiritual well-being over the course of data collection (see figure 4.18). Deterioration was seen in her physical and psychological well-being, which corresponded to new headaches which she described in the interviews as worrying.

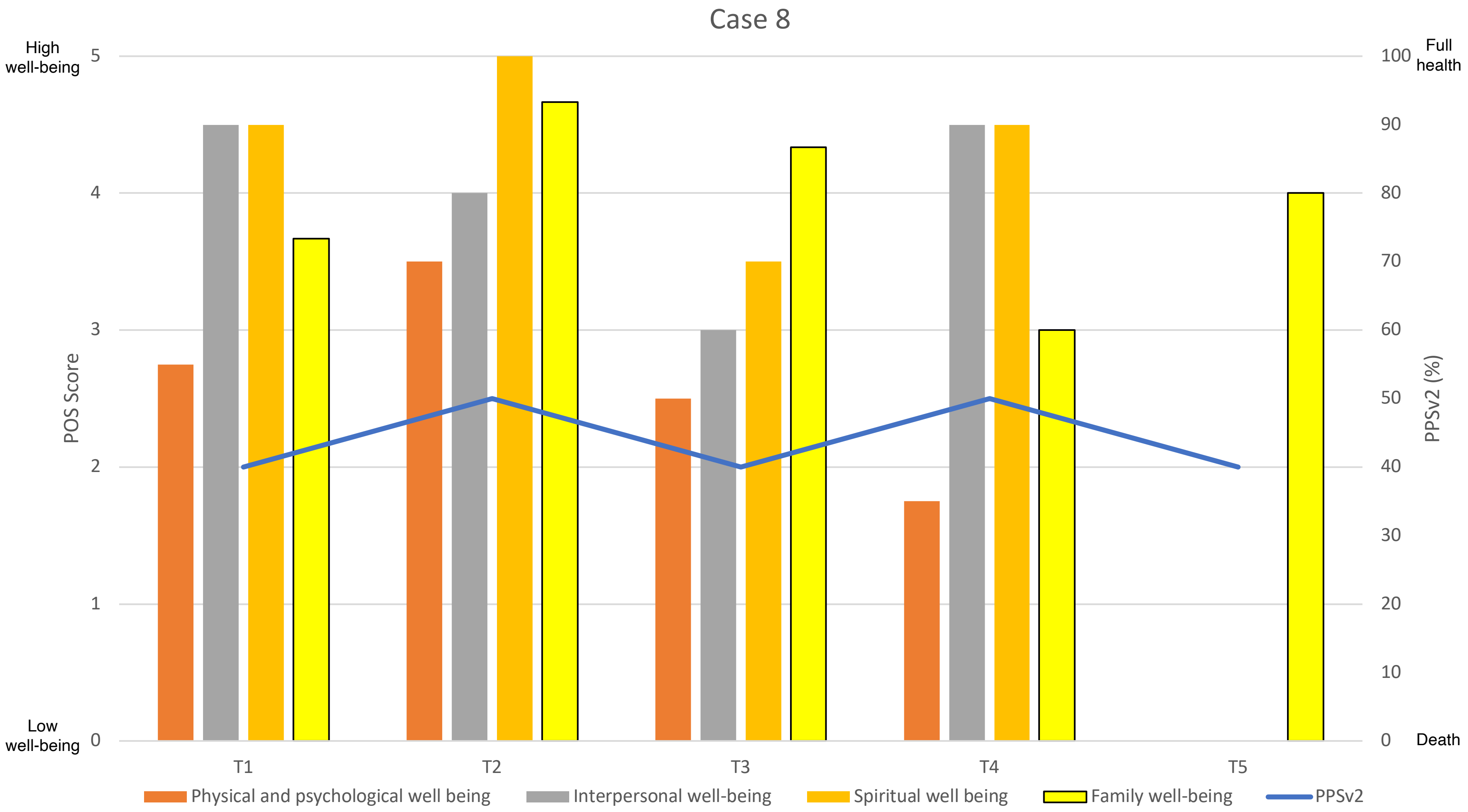


Figure 4.18. Quantitative data in case eight

4.6.8.3 Utility of the case in understanding the foreshadowed issues

Case eight held utility for understanding the foreshadowed issues (figure 4.19). The longitudinal data collection allowed the tracking of how Khadija interpreted and understood the arrival of new symptoms. Case eight provided rich descriptions of how and why details of breast cancer were hidden from Khadija. Data from the son demonstrated how he prioritised her spiritual and emotional well-being and how he was willing, at times, to sacrifice her physical well-being for these. These data were useful for the analysis of the healthcare mini-case, as health professionals tended to actively participate in, and encourage the non-disclosure of cancer diagnoses to Mauritanian women.

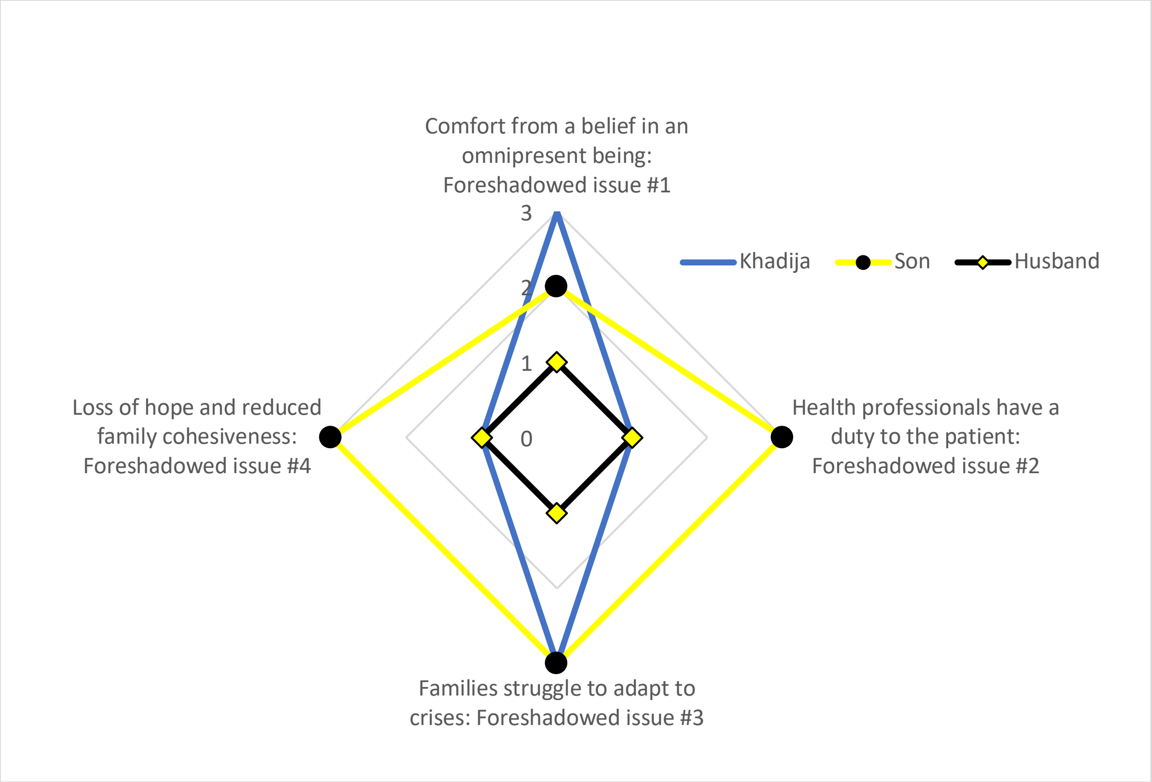


Figure 4.19: Radar chart depicting the utility of case eight

4.6.9 The healthcare mini-case

The nine health-participants in the healthcare mini-case provided rich descriptions of their experiences caring for Mauritanian women with advanced breast cancer. The mini-case comprised a diverse range of experiences and attitudes towards women with breast cancer and their families. Paternalistic and condescending attitudes towards women were frequent. Women were, at times, blamed for their breast cancer being advanced because they had been slow to seek medical care and wasted time seeking traditional treatments. Some health-participants expressed frustration that the presence of metastases made their job more difficult.

Health-participants applied informal criteria to decide how much information they disclosed and to whom. For example, they preferred to communicate information to male relatives if they considered the woman with breast cancer as ignorant and uncultured, or they feared a negative emotional reaction.

4.6.9.1 Utility of the mini-case in understanding the foreshadowed issues

The healthcare mini-case held utility for the exploration of the foreshadowed issues and understanding the experiences of advanced breast cancer in Mauritania (figure 4.20). The data provided a broad context in which to interpret the experiences described in the cases. For example, women's frustrations of accessing symptom control and information from health professionals were congruent with the data from the healthcare mini-case. Other congruences included the reticence towards expressing negative experiences and the belief in destiny and Allah's control over life, cure, and death. Finally, the mini-case provided data on understanding the sense of responsibility the health professionals felt towards their patients and the families (box 4.11). The identified themes from the analysis of the mini-case data is included in appendix 22.

Monday, 19 June 2017: Data collection

Interviewed [H7] today. Was in his office for one hour prior to starting the interview. Interesting how he states he treats all patients the same. A staff member came to see him about a relative with a breast lump. He reviewed the medical file and then straight away he phoned the surgeon who was going to see the patient at 9am the following day in the surgical department of the mother and child hospital (not private). He then advised her to send the biopsy to a private lab because at the general hospital it will take 3 months to get the result

Box 4.11 Excerpt from reflexive journal

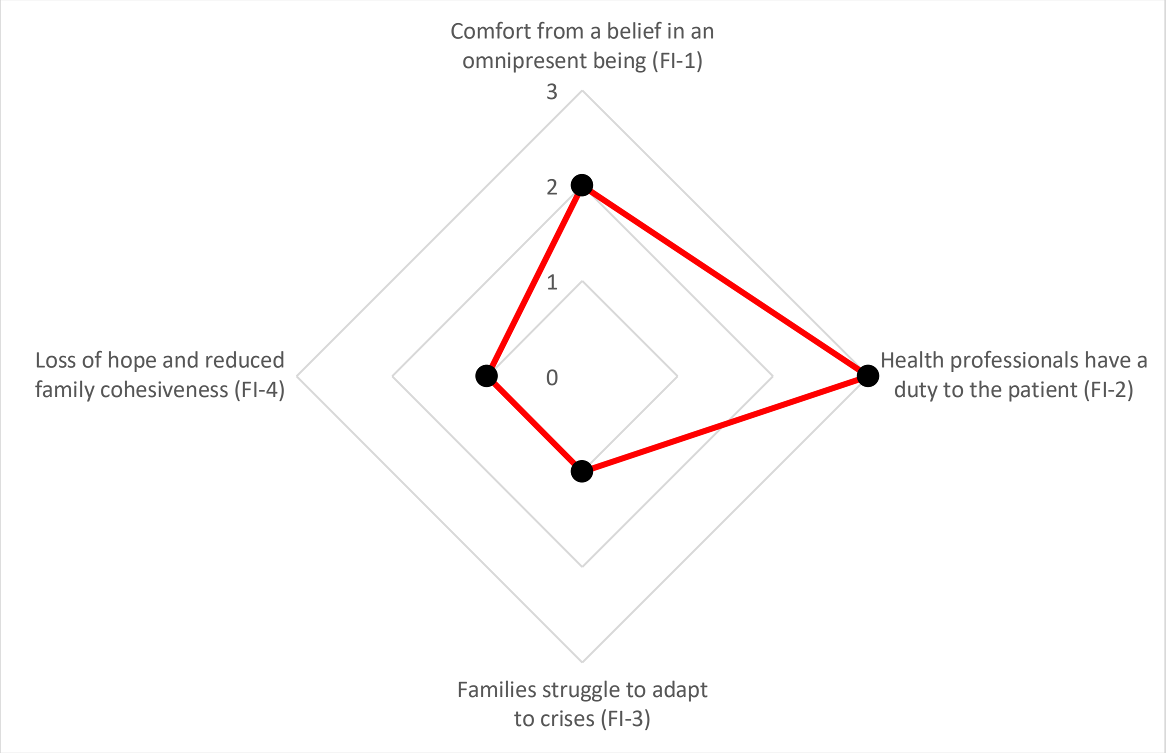


Figure 4.20: Radar chart depicting the utility of the healthcare mini-case

4.7 Conclusion

This chapter has presented the formulation and demographics of the eight cases and the healthcare mini-case. It has summarised the findings of the within-case analyses, and their utility for understanding the foreshadowed issues. The findings of these within-case analyses provided the context for the cross-case analysis which is presented in chapter five.

Chapter 5: Cross-case findings

5.1 Introduction

The previous chapter described the eight cases and their mini-cases, and the findings from the within-case analyses. This chapter presents the findings of the cross-case analysis. Firstly, it will present the utility of the cases in exploring the quintain. This is followed by a description of the cross-case quantitative data. Analysis of data from the PPSv2 and the APCA African POS provided an understanding of the particularities of each case and an awareness of patterns of experiences across the cases. Finally, a synthesis of quantitative and qualitative data is presented, in which the quintain is presented; the socially constructed reality of experiencing advanced breast cancer in Mauritania.

5.2 Utility of cases in understanding the quintain

As noted in chapter four, analysis in a Stakian multi-case study involves oscillation between the case and the quintain (Stake, 2006). The utility of each case for understanding the foreshadowed issues has already been presented (chapter four). This chapter raises the analysis to a higher level; synthesising the alternative manifestations of the quintain found within each case, the experiences of advanced breast cancer (Stake, 2006). Stake (2006) suggests that rating each case's utility, or usefulness, can help in evaluating the extent to which identified themes may represent the quintain as opposed to the localised contexts of selected cases or participants.

The rating scores of the individual cases' utilities, presented in chapter four, were summed for each foreshadowed issue. These utilities provided a proxy measurement of the utility of this multi-case study for answering the research question and understanding the quintain. Scores were plotted on radar charts where the outer diamond depicted the maximum possible (highest) utility and the inner diamond the minimum possible (lowest) utility. Data from patient-participants and family-members provided medium to high utility for understanding each foreshadowed issue (figures 5.1 and 5.2). Data from the healthcare mini-case provided high utility for understanding the third foreshadowed issue, the health professionals' duty towards their patients, and low to medium utility for understanding the remaining foreshadowed issues (figure 4.20 on page 142).

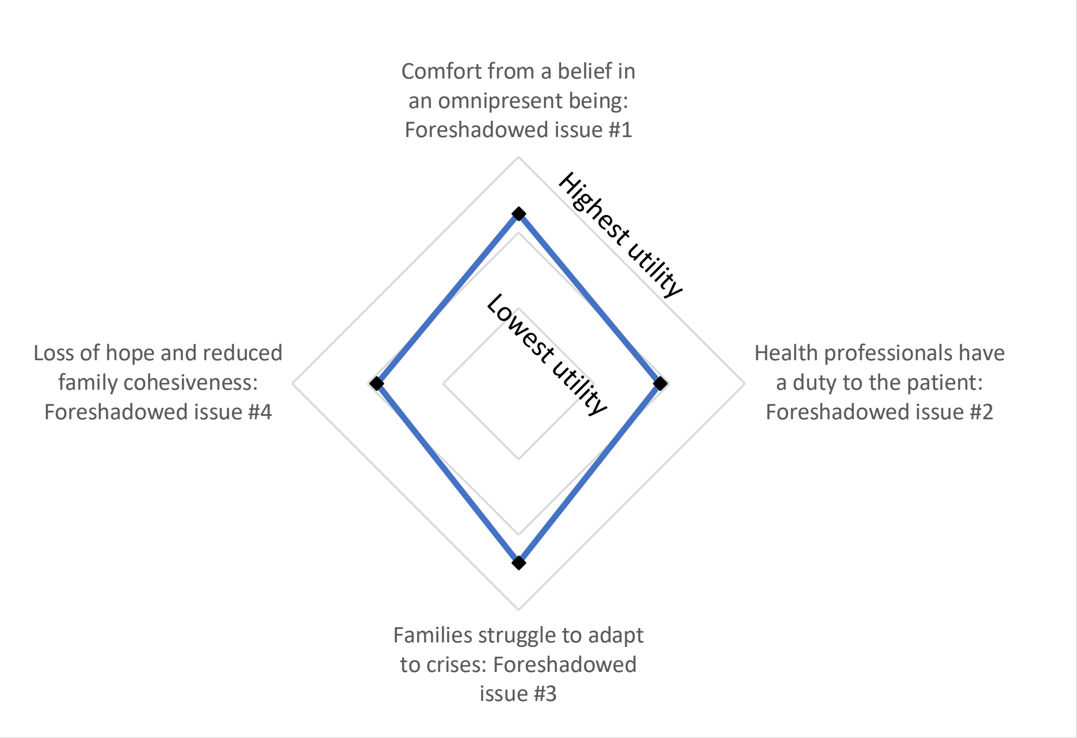


Figure 5.1. Radar chart depicting the utility of data from all patient-participants

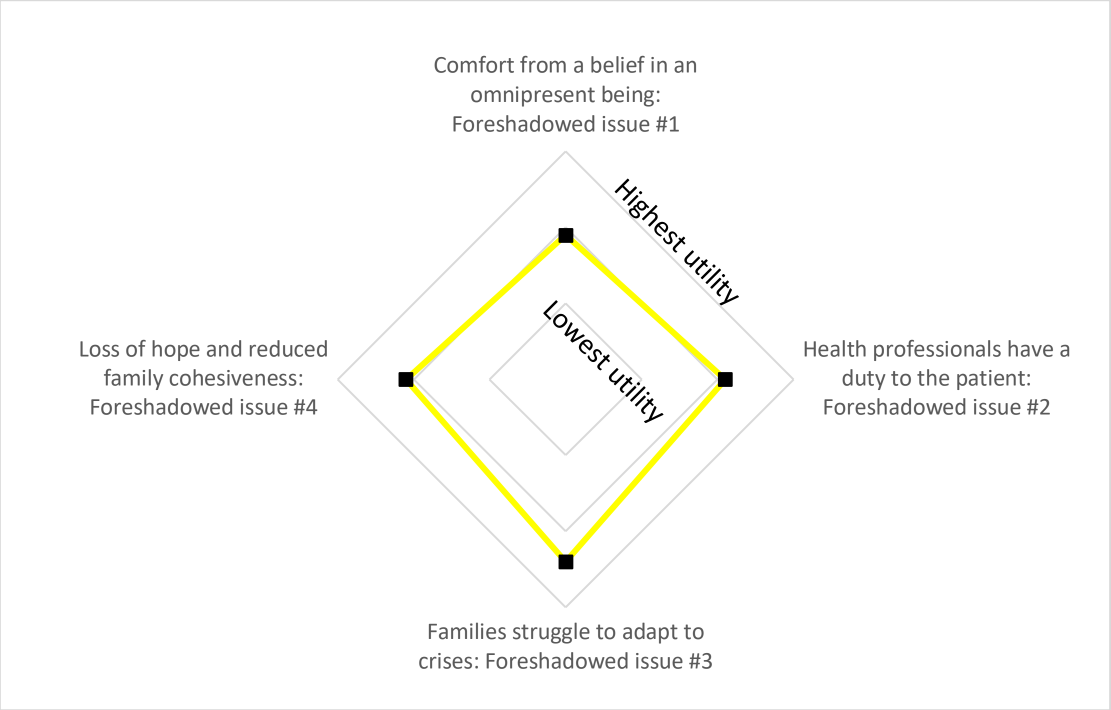


Figure 5.2. Radar chart depicting the utility of data from all family members

5.3 Findings: quantitative data

There was variation in the performance levels across the cases at the start of data collection. Over time, there were minor fluctuations of performance with a trend towards deterioration and, at times, death. The steepest declines were seen for those patient-participants who died during the data collection, who started with low performance levels.

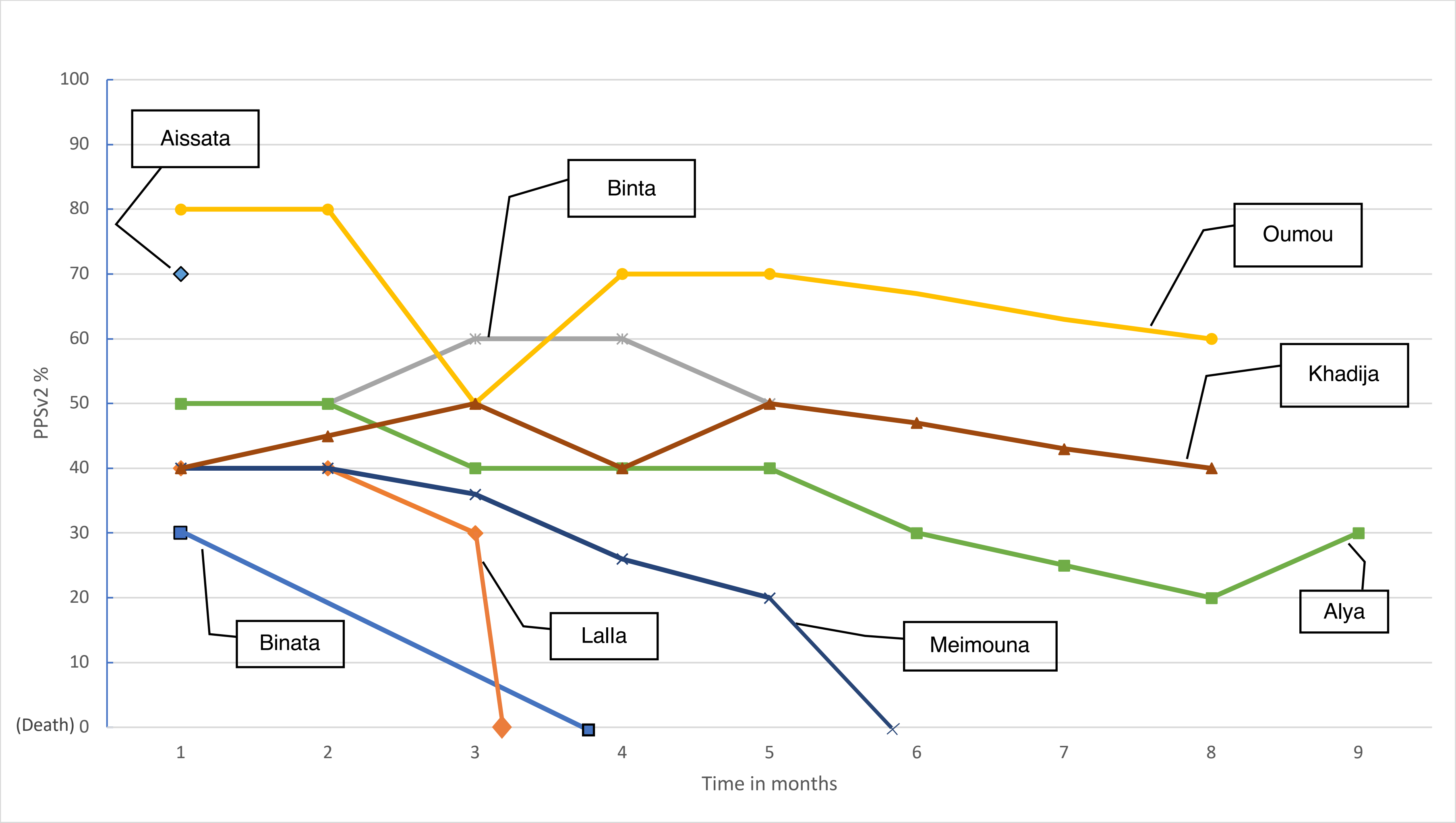


Figure 5.3 Data from the PPSv2

5.3.1 African APCA POS

The African APCA POS, a PROM constructed and validated for an African context, measures the experiences of patients and their families with palliative care needs. Items are scored on a scale of 0 to 5, with high scores representing both high and low well-being for different questions. These scores were standardised so that high scores consistently represented best status. Its ten items cover physical, psychological, interpersonal, spiritual, and familial well-being, presented in the following sub-sections. Questions are directed to the patient or to the family member, represented as blue and yellow, respectively, on the charts below.

5.3.1.1 Physical well-being

Pain and other symptoms were common experiences for Maure women with advanced breast cancer and were at times overwhelming (see figures 5.4 and 5.5). The mean pain score, from all measurements, was 3.28 (range 1 - 5, median 3 and mode 3). The mean score for other symptoms was 3 (range 0 - 5, median 3 and mode 4).

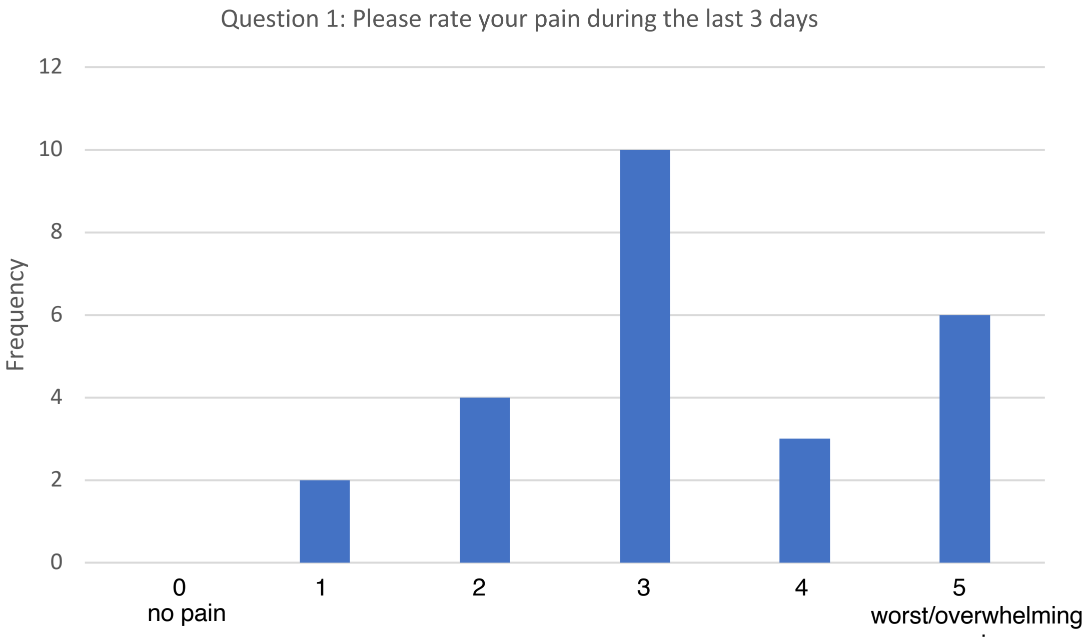


Figure 5.4. Frequency chart for responses to question one of the APCA African POS

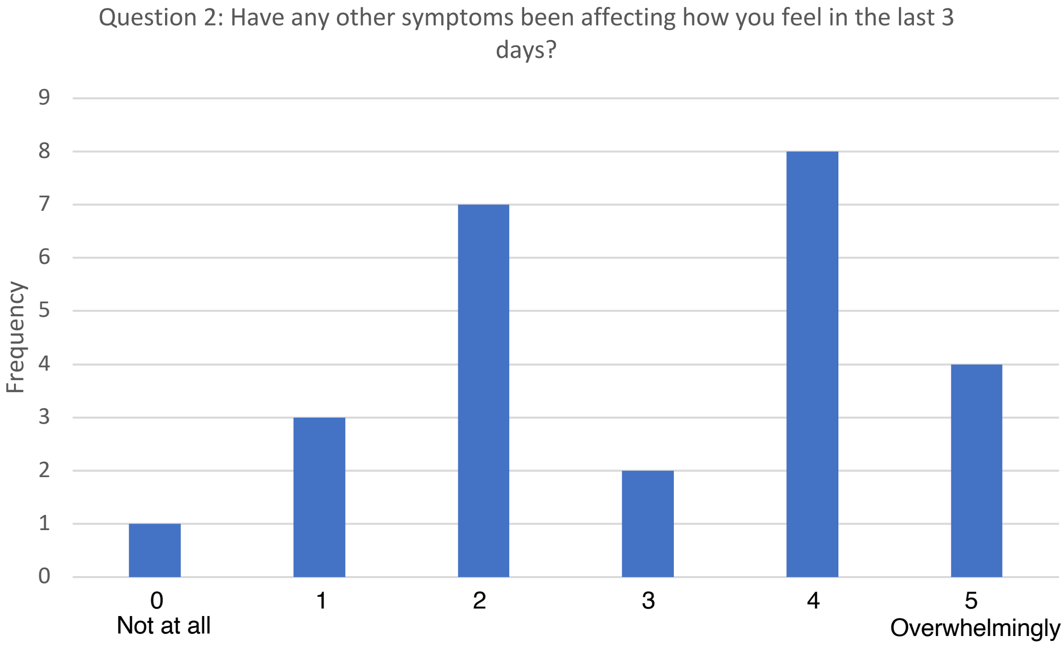


Figure 5.5. Frequency chart for responses to question two of the APCA African POS

5.3.1.2 Psychological well-being

Psychological well-being was reported as good across the cases (see figures 5.6 and 5.7). Not being worried and feeling at peace were reported to be common experiences for the women. Mean score for worry was 1.76 (range 0 - 5, median 1, mode 0), and mean score for feeling at peace was 1.88 (range 0 - 5, median 2, mode 1 and 3).

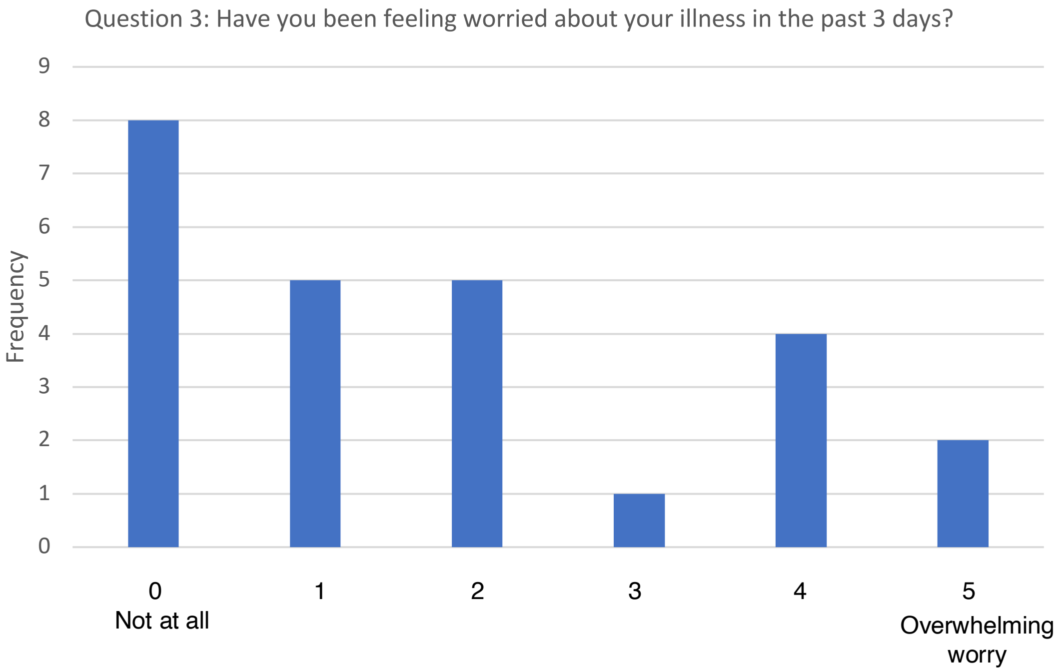


Figure 5.6. Frequency chart for responses to question three of the APCA African POS

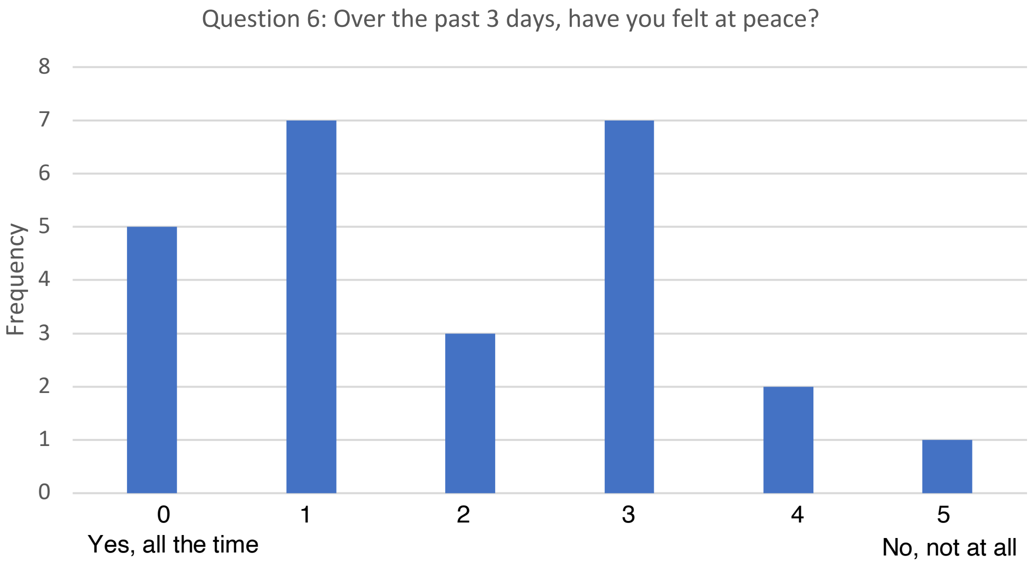


Figure 5.7. Frequency chart for responses to question six of the APCA African POS

5.3.1.2 Interpersonal well-being

Patient-participants reported reasonable interpersonal well-being (see figure 5.8 and 5.9). This domain was covered by two questions which measure the sharing of feelings with family and friends, and the satisfaction with the help and advice received (Harding et al., 2012). Mean score for sharing feelings was 2.92 (range 0 - 5, median 3, mode 3). Mean score for receiving advice and help was 2.75 (range 0 - 5, median 3, mode 2). Question seven was not answered on one occasion.

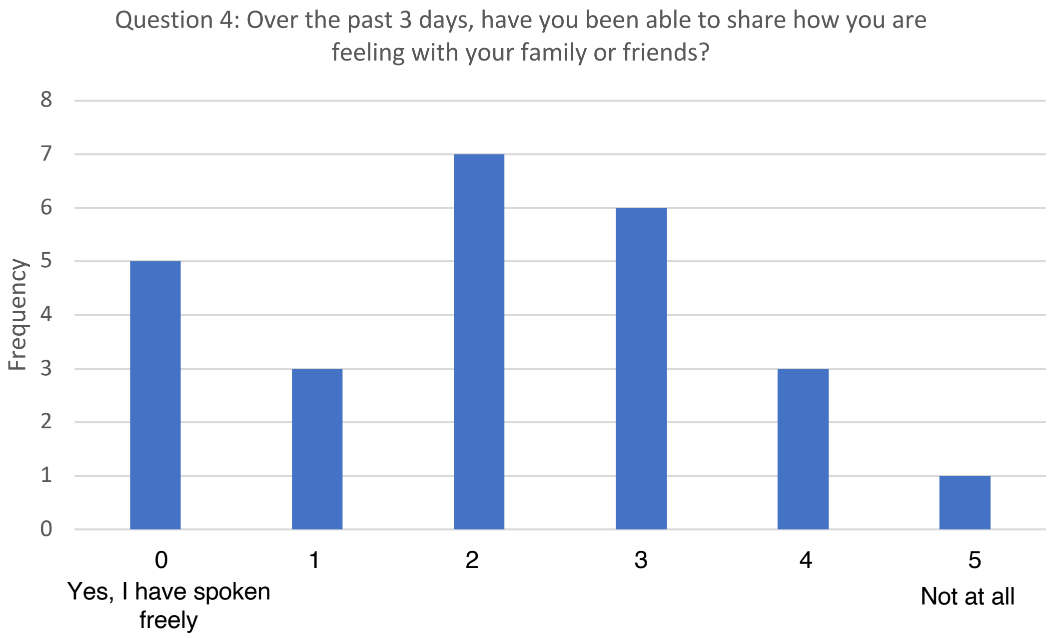


Figure 5.8. Frequency chart for responses to question four of the APCA African POS

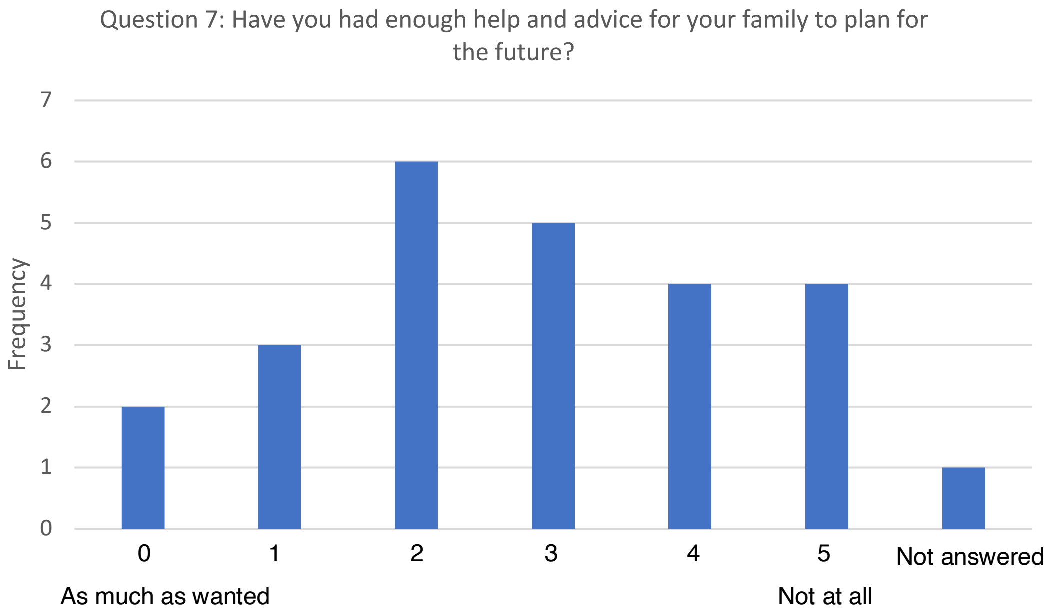


Figure 5.9. Frequency chart for responses to question seven of the APCA African POS

5.3.1.3 Spiritual well-being

Spiritual well-being was covered by two questions on feeling at peace and life being worthwhile. Patient-participants reported high levels of feeling at peace and that life was worthwhile (see figure 5.7 and 5.10). Results from question six concerning peace were described above in psychological well-being (Harding et al., 2012). The mean score for question five, on life being worthwhile, was 1.5 (range 0 - 4, median 1, mode 0 and 1). This question was controversial for some participants who chose not to answer it. They suggested it was against their religious beliefs to question the worth of life. This issue is expanded on in the following section and revisited in chapter six: *Discussion.*

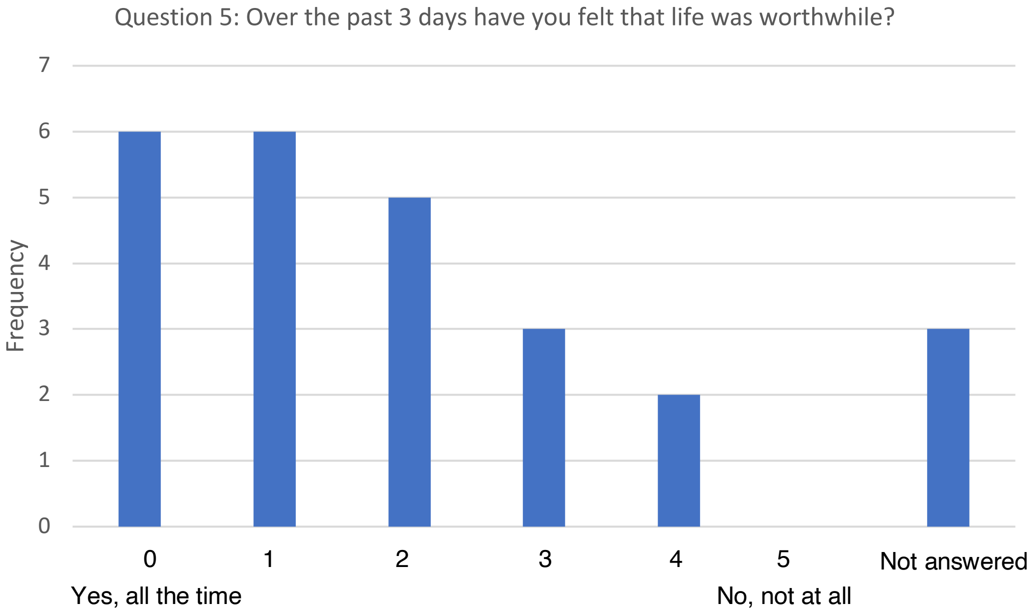


Figure 5.10. Frequency chart for responses to question five of the APCA African POS

5.3.1.4 Familial well-being

Three questions covered the well-being of the family, questions on information received, confidence in caring for the patient and worry about the patient. Family-participants reported feeling satisfied with the provision of information (see figure 5.11). The mean score for information received was 1.39 (range 0 - 3, median 1, mode 2)

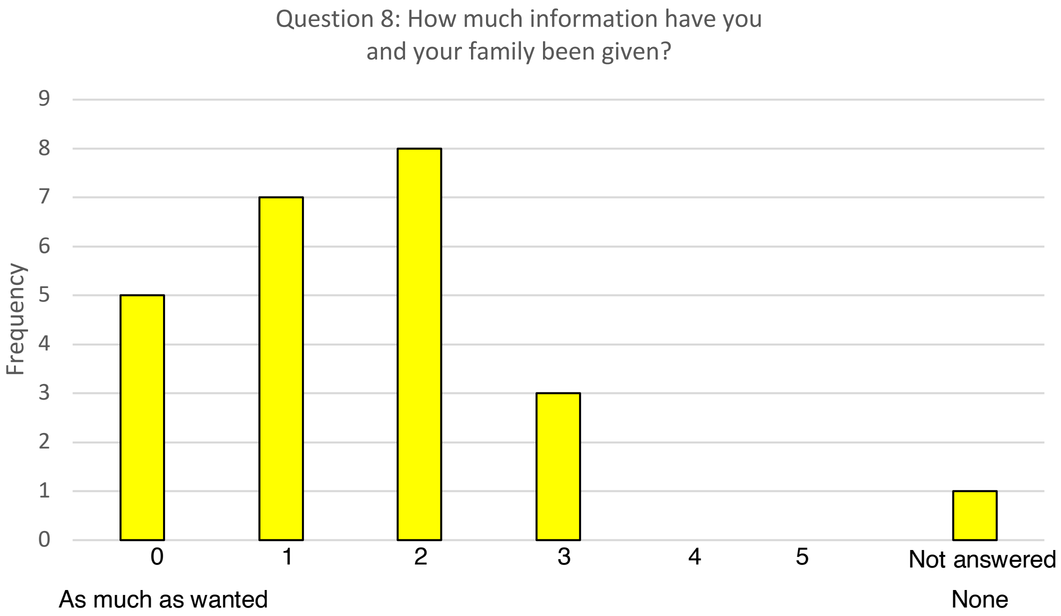


Figure 5.11. Frequency chart for responses to question eight of the APCA African POS

Families reported feeling strongly confident in caring for their relative with advanced breast cancer (see figure 5.12). The mean score for confidence was 0.42 (range 0 - 2, median 0, mode 0). Reports of worry were more varied, with occasional reports of severe worry (see figures 5.13). The mean score for worry was 1.92 (range 0 - 5, median 2, mode 0).

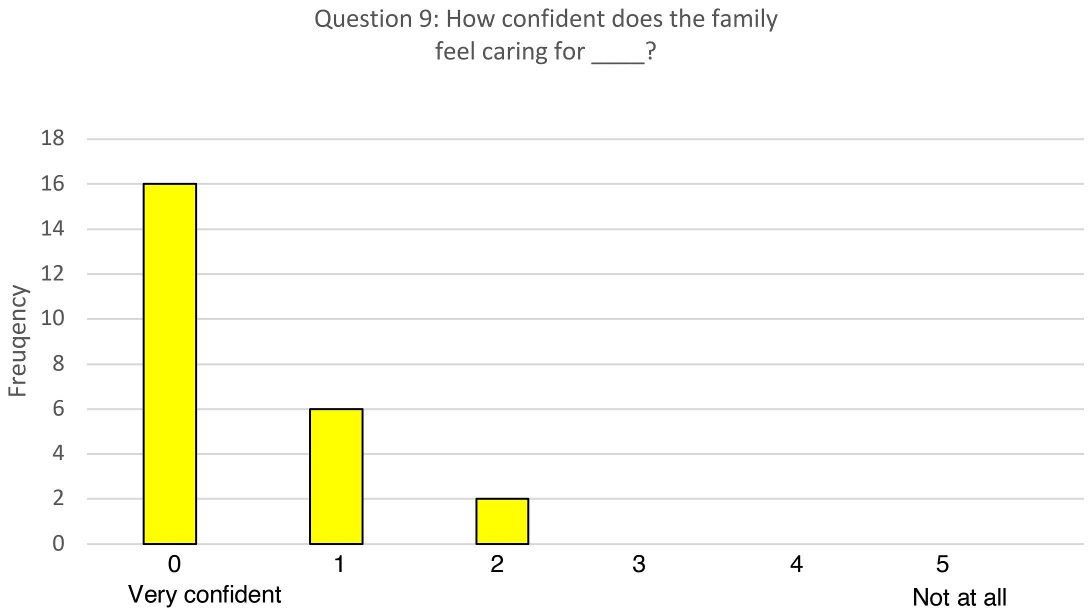


Figure 5.12. Frequency chart for responses to question nine of the APCA African POS

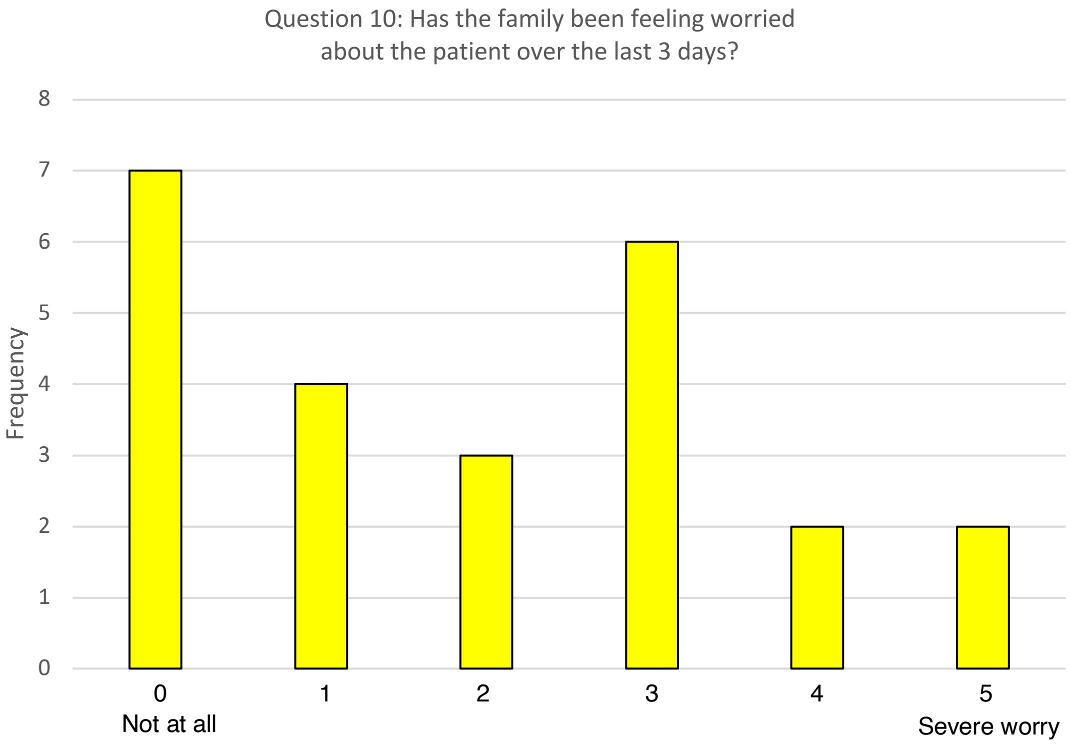


Figure 5.13. Frequency chart for responses to question ten of the APCA African POS

5.4 Findings: The quintain

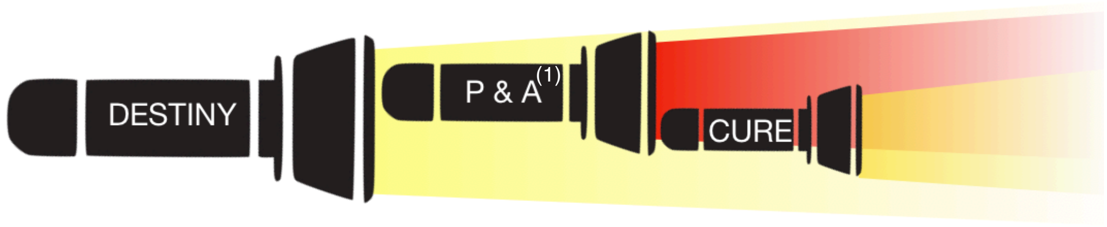
This section provides an overview of the experiences of advanced breast cancer in Mauritania, the culmination of the cross-case analysis. The cross-case analysis explored and synthesised the findings from the within-case analyses to construct a higher-level understanding of the quintain. Connections and variances across the within-case themes and the quantitative data were considered, as described in chapter four: *Methodology.* This iterative analytic process was bounded by the foreshadowed issues which influenced which provisional themes were explored and developed to best describe the quintain.

Three major themes and ten subthemes about the experiences of Maure women with advanced breast cancer were identified. The themes, their associated sub themes are presented in table 5.1.

Table 5.1 Themes and sub-themes

Theme	Sub-theme
Destiny	• Breast cancer is normal because Allah controls it • Death is inevitable and unpredictable • Fatalism and human agency
Patience & Acceptance	• Appreciating the gift of life • Concealing and expressing difficulties • Eternal perspectives of experiencing breast cancer
Journeying in search of a cure	• Seeking suitable empty actions • Building knowledge of breast cancer and its cure • Negotiating access to the cure • Navigating the journey's diversions

The three major themes, destiny, Patience & Acceptance, and journeying in search of a cure, are inter-related and illuminate each other. The first theme, destiny, is the most dominant because it provides the necessary context for the subsequent themes and subthemes to be understood. The second theme, Patience & Acceptance, refers to how Maure women perceive and respond to the diagnosis of breast cancer and its associated challenges. This theme provides the context for the third theme, journeying in search of a cure, which describes the search for treatment and information. The relationships between these themes are illustrated by a series of torches producing a beam of light for the following torch (see figure 5.14).



(1) Patience and Acceptance

Figure 5.14 Hierarchy of themes

5.4.1 Theme 1: Destiny

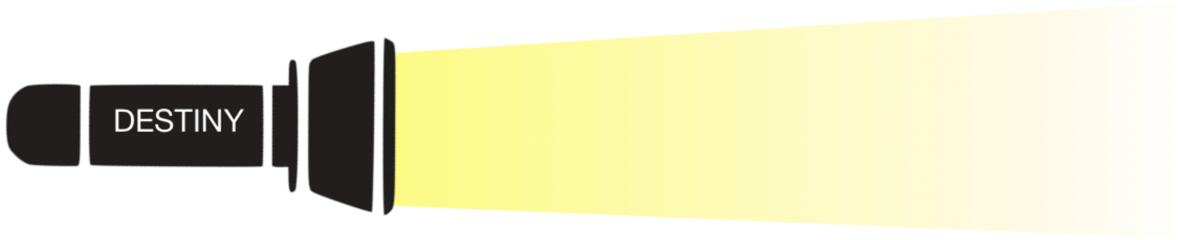


Figure 5.15 Hierarchy of themes: torch 1

Destiny was defined as Allah's foreknowledge of events and His contemporaneous controlling of an individual's circumstances. Participants viewed belief in and acceptance of destiny as non-negotiable foundations of being a Muslim. This theme will be presented, and illustrated using participant quotes, under the following sub-themes, breast cancer is normal because Allah controls it, death is inevitable and unpredictable, and fatalism and human agency.

5.4.1.1 Breast cancer is normal because Allah controls it

Destiny was considered to be the unavoidable and unchangeable will of Allah. This resulted in patient-participants accepting that Allah had consciously and purposefully given them breast cancer; deciding its location, size and spread. Most often, breast cancer was perceived as Allah testing their faith.

> He [Allah] makes you sick and He makes it so that you can't move or do anything. What else can do you? [...] Will you bang your head against a wall?
>
> *Case 3, Binta: interview 4*

> It [breast cancer] is a test; it's only something that Allah has used to put his slave to the test [...] Allah will reward her. He will reward her so that her bad mistakes will be reduced; they will crumble from her.
>
> *Case 6, daughter: interview 3*

The belief that breast cancer came as part of their destiny was appreciated by patient-participants. They affirmed that because breast cancer was under Allah's control then everything was ordered as it should be, and that He remained capable of removing it. Participants referred to a hadith (a saying attributed to the prophet Mohammed) to support this view; 'There is no disease that Allah has created, except that He also has created its treatment' (al-Bukhari, n.d.).

> When you know that it's Allah who brought the disease to you, you are calm because he can take it back the same way as he has given it. In thinking of Allah, you are relieved, and it helps you to cope with the disease. So, by counting on Allah and imploring him, I can better manage to get through it. It helps me a lot.
>
> *Case 5, Aissata: interview 1*

5.4.1.2 Death is inevitable and unpredictable

Death was seen as a central element of destiny; normal, natural and inevitable for every person. Death was equated with Allah deciding to kill an individual, and subsequently its timing, manner and place were considered as exclusively determined by the person's destiny.

> It's part of his faith to believe that only Allah can kill. There is no need to tell him that he will die in two months or two years, because that doesn't change anything, he will always tell you that only Allah kills.
>
> *Case 4, cousin: interview 3*

> We tried to comfort her by telling her that sickness doesn't kill, it's Allah who brings death and who gives life, we tried to play on her faith.
>
> *Case 1, son-in-law: interview 2*

Death was perceived as both ordered and unpredictable. Ordered and organised because of Allah's conscious control over destiny, and random and unpredictable because Allah is distant, and His ways are unknowable for humans. Death could occur at any moment with no relationship to illness, symptoms or behaviours. The patient-participants emphasised that there was no relationship between their breast cancer and their inevitable death.

> Everyone believes in death; but nobody knows whether the disease is going to kill this or that person, because nobody knows what God is going to do.
>
> *Case 6, Alya: interview 5*

> The human being... as for me, all I know is that I could die in an hour, right away, or in a minute. I remind her of this every day because I know that for the human being, death can find us lying down, or we can die even while crawling [...] Death and life are in the hands of Allah. It's Allah who takes life and gives it.
>
> *Case 2, husband: interview 1*

5.4.1.3 Fatalism and human agency

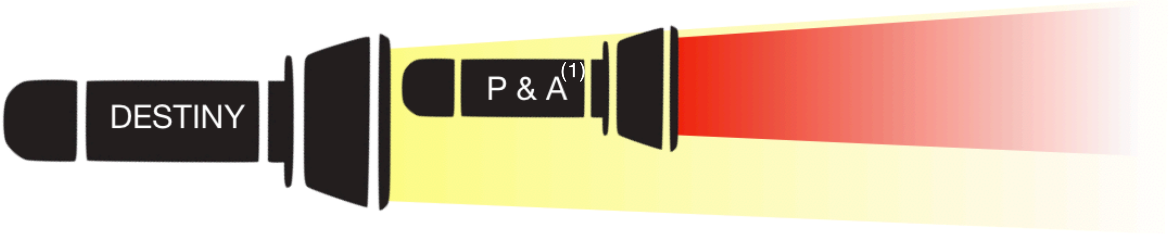
Patient-participants portrayed a fatalistic view of breast cancer, with an emphasis on destiny's inevitability and unpredictability, to reinforce their innocence for having breast cancer. They had breast cancer exclusively because it was their destiny; it was not a punishment, and nor should they be blamed or stigmatised for having it. Participants emphasised this lack of relationship between their actions and their breast cancer because destiny did not nullify blame for illness in general. Certain diseases were viewed as consequences of a person's life choices, their agency; for example, HIV infection was seen as being caused by behaviour rather than destiny, and this justified its stigmatisation in Mauritania.

> In all those diseases that are due to contamination, the person is the cause. I did not cause this; it was Allah who brought it to me like this [...] That’s how it happened to me [...] It’s Allah who wanted it, and nobody can do anything about it.
>
> *Case 4, Oumou: interview 1*

A middle area, between destiny and human agency, was also evident in the data. This was the domain of spirits and encounters with supernatural powers, forces of both good and evil. Participants sought influence over this domain by consulting with traditional health practitioners and marabouts (spiritual healers) who used amulets, powders, and plants to wield power within the spiritual realm. This view was most clearly articulated by Meimouna in case seven, in which the cause of the breast cancer was traced back forty years to an encounter with a neighbour. She perceived that her neighbour cursed her, allowing evil spirits to cause a breast abscess at the time and subsequently her cancer.

> I became sick and had a fever, I was ill [...] It was because of the woman there, it's she who gave me the evil eye
>
> *Case 7, Meimouna: interview 1*

5.4.2 Theme 2: Patience & Acceptance



(1) Patience and Acceptance

Figure 5.16 Hierarchy of themes: torches 1 and 2

The first theme, Destiny, presented the dominant spiritual and religious contexts which frame how life, death and breast cancer are understood by Maure women with advanced breast cancer. The second theme refers to how participants responded to, and expressed, their experiences of breast cancer, within this framework. This theme, Patience & Acceptance, comprises three sub-themes, appreciating the gift of life, concealing and expressing difficulties, and eternal perspectives of breast cancer.

5.4.2.1 Appreciating the gift of life

This sub-theme presents how the womens' views of Allah and destiny influenced their understanding, and expressions, of their experiences of breast cancer. Allah was considered to be set apart from humans, distant, unknown, and unknowable, while simultaneously involved in and controlling of an individual's life, illustrated by the analogy of slaves and slave master described above. Patient-participants considered their life as a gift from Allah and because of the unpredictable nature of destiny, it was deemed to be a fragile gift, one which He could take back at any moment.

> Researcher: Would it be possible to ask Allah, ‘why am I ill’?
>
> Participant: It’s not fear. It’s how can I ask a question to Allah? How can you ask Him a question when you can’t have a response? When you ask someone a question, you expect a response, but with Allah you cannot ask. It’s Him alone who decides. He does not ask your opinion; He does what He wants. [laughs]
>
> *Case 4, Cousin: interview 2*

Patient-participants considered that their life was a gift from Allah which required His continuous sustenance. They were dependent on Allah making their every heartbeat and breath happen. They feared that any lapse of respect or disregard for this gift could result in Allah reclaiming their life, with no recourse for complaint or argument. Life was to be cherished, irrespective of any experiences or circumstances. Patient-participants remained thankful, polite and respectful to Allah, and never blamed Him for any wrongdoing. They attempted to demonstrate patience as they accepted that their breast cancer came from Allah, their destiny (the foundation of this theme). They avoided giving the impression of fighting against breast cancer, because it risked being interpreted by others or by Allah as fighting against their destiny.

> I would advise her [a hypothetical woman with breast cancer] to have patience, to have confidence in Allah and to be indebted to Him. It’s simple.
>
> *Case 2, Lalla: interview 3*

5.4.2.2 Concealing and expressing difficulties

Participants acknowledged that there were numerous negative experiences associated with breast cancer. For example, pain and the impact of symptoms were at times rated as overwhelming on the APCA African POS (see figures 5.4 and 5.5 above).

> It's terrible. The fear of the disease is bigger, and stronger than the disease itself. The pain is there, it changes. Sometimes it's unbearable, sometimes it's okay. Sometimes it’s heavy to bear the pain because it overcomes your forces... The impact of the disease on the person is heavier than the pain itself.
>
> *Case 5, Aissata: interview 1*

Such expressions risked negating the women’s outward demonstrations of patience and acceptance in response to their breast cancer. Life was a fragile gift, and to question the quality of a gift risked causing offense to the giver, Allah. Patient- and family-participants were, at times, uncertain of what and how experiences of breast cancer could be expressed. They felt an obligation to demonstrate thankfulness in all circumstances because of the fragility and unpredictability of life. Participants were aware of boundaries guiding which expressions were permissible, prohibited and obligated. Many of these boundaries were ill-defined, and so they feared that any offence, even accidental, to Allah could result in Him killing them or exiting them from Islam. To critique the quality or worth of their lives was perceived as dangerous because it risked crossing a boundary. This was illustrated in the responses to the APCA African POS question on whether life was felt to be worthwhile, presented above.

Silent endurance of negative experiences was considered by participants to be the most ideal response because it most clearly exhibited Patience & Acceptance and avoided the risk of appearing impolite to Allah. Patient-participants concealed, denied and trivialised much of their experiences and emotions.

> Thank God there is nothing which can hurt Muslims. Thank God there is nothing which can hurt Muslims. If he says he is in pain, his faith has weakened.
>
> *Case 3, Binta: interview 1*

> I don't tell them anything. I don't tell them anything. I hide everything I feel from them [the family]. I don't tell them.
>
> *Case 7, Meimouna: interview 1*

Silent endurance was on occasion perceived as overly challenging or less useful to patient-participants. In these moments, alternative approaches to expressing negative experiences were employed. The approaches are discussed below in order of their congruency with Patience & Acceptance (numbered one to six in figure 5.17).

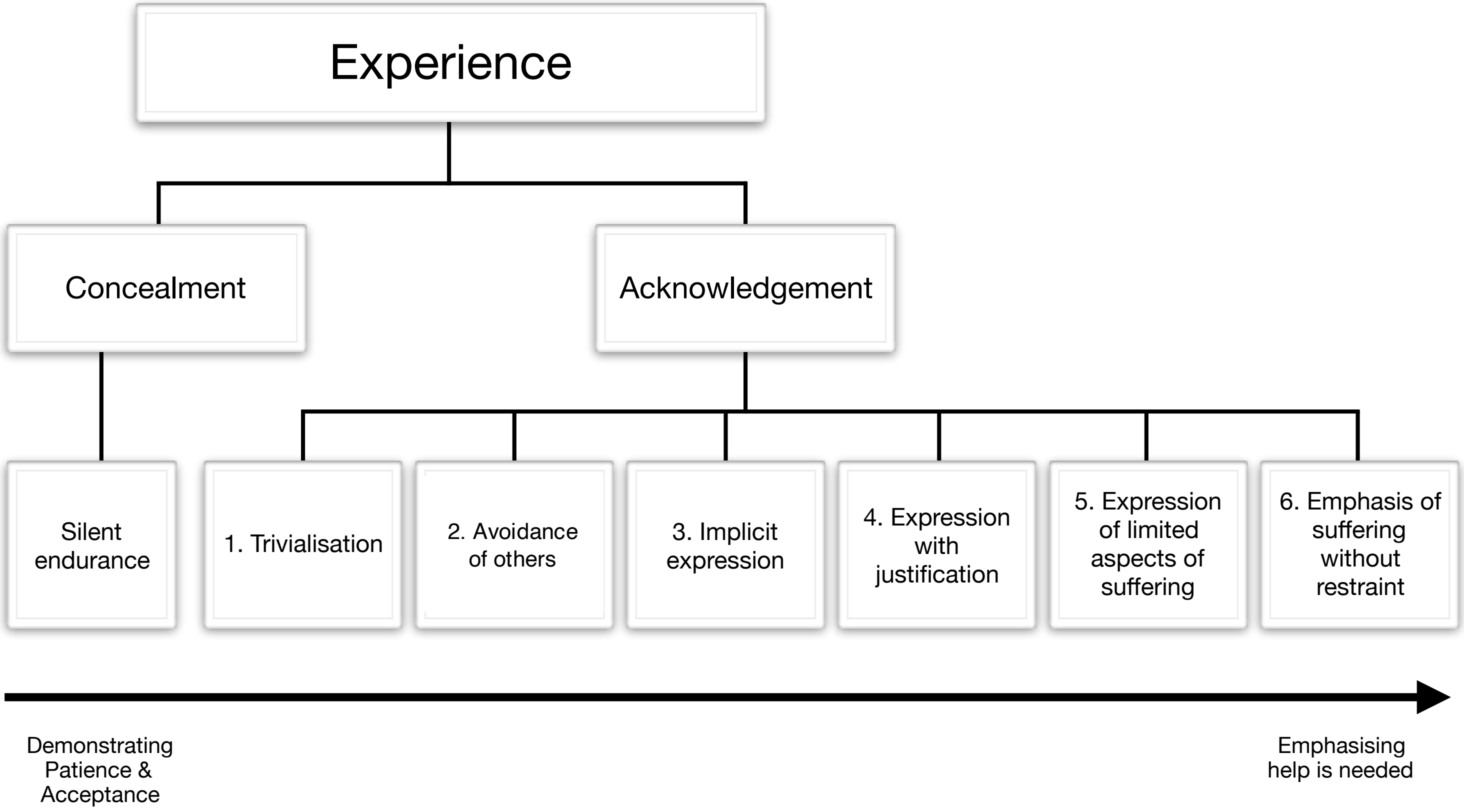


Figure 5.17: Approaches to expressing experience

Trivialisation

The response to negative experiences which most closely demonstrated Patience & Acceptance of breast cancer and destiny, after silent endurance, was trivialisation. Patient-participants dismissed experiences as minimally disruptive; for example, physical symptoms, fear, anxiety or the impact on the family.

> They [her children] only know that I'm sick. They don't understand the situation, but they're used to it now. They've no problem with it.
>
> *Case 2, Lalla: interview 1*

Avoidance of others

The second approach was for patient-participants to avoid others, or hide their suffering, to maintain the external impression of silent endurance. They managed this for short periods of time.

> Once a visitor comes, she must have thick skin until the person leaves, she acts as if she doesn't have pain
>
> *Case 3, Binta: interview 3*

> Researcher: Did you try to hide your illness?
> Oumou: I tried to, but to no avail. Sometimes I don't want to scream, not to disturb people but the pain was too strong. Even the clothes with which I try to stifle my cries were useless.
>
> *Case 4, Oumou: interview 2*

Implicit expression

Patient-participants considered that explicit expressions of negative experiences risked them being perceived as being impolite towards Allah and unthankful for their life. Implicit expressions were perceived as a safer option; negative experiences were acknowledged to others, but the severity and impact of such experiences were communicated indirectly. For example, rather than directly communicating the severity of their pain or distress, patient-participants emphasised secondary effects, such as their inability to sleep, loss of appetite, loss of consciousness, or inability to pray.

> I could not even pray because it hurt so much, that I could not bend down
>
> *Case 5, Aissata: interview 1*

> I went to the hospital to change the dressings. During the dressing changes, there were pains, very difficult pains. I fainted because of it, because... I'm tired.
>
> *Case 7, Meimouna: interview 1*

Expression with justification

At times, patient-participants acknowledged their negative experiences and the impact on them. They justified such expressions by arguing that they were a normal response, and that anyone would react this way in the same situation.

> Researcher: Were you worried when you had pains?
>
> Oumou: Of course. I was tired and scared. It's normal, someone who spends a whole night sitting without sleeping, it's difficult.
>
> *Case 4, Oumou: interview 3*

Expression of limited aspects of suffering

Some negative experiences were acknowledged but counterbalanced with thankfulness to Allah for other experiences. For example, evaluation of their condition in contrast to others in worse situations.

> Praise God, my lungs, praise God that the pain in my lungs stopped, but only now these two thighs remain. I can’t stand up, walk or kneel.
>
> *Case 6, Alya: interview 1*

Emphasis of suffering without restraint

Few patient-participants freely acknowledged and stressed their level of suffering. At times, this reinforced their requests for help and to motivate others to have pity and empathy towards them. This approach was furthest removed from the ideal demonstration of Patience & Acceptance. The women accepted that this may lead others to identify them as weak and cowardly. Such expressions were challenging for the women’s families to witness, as discussed below.

> I know that my fear aggravates my situation. There are people who manage to control their illness, but I cannot, I am not brave.
>
> *Case 6, Alya: interview 6*

5.4.2.3 Eternal perspectives of breast cancer

Participants perceived that there were consequences relating to the women's demonstration of Patience & Acceptance in response to their breast cancer. Eternal advantages could be earned by appropriate responses to the experiences of breast cancer. It was considered that those responding to breast cancer with Patience & Acceptance would have their sins removed and improved chances of entering paradise. These eternal rewards were so highly esteemed that some participants extended the analogy of breast cancer as a test, to that of a gift.

> Thus, in this first phase, her misfortunes can become trials she has to endure. In a second phase, if it comes to wash her sins, we can say that it is a gift from Allah [laughs]
>
> *Case 4, cousin: interview 2*

Family members, visitors and health professionals respected those patient-participants who were deemed as earning eternal rewards through their strong faith and their exhibition of Patience & Acceptance. In contrast, family-participants found it challenging when their relative's response did not meet their expectations. They argued that an inadequate demonstration of Patience & Acceptance was a rejection and waste of an opportunity provided by Allah to gain eternal rewards.

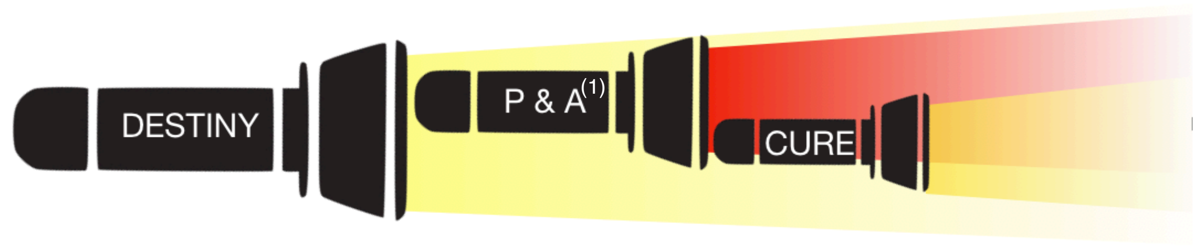
> The patient must endure, to endure is to move towards God, but the fact that they can't endure, then it's possible they could commit suicide […] If they commit suicide, then they go to hell. That's our belief.
>
> *Case 4, cousin: interview 2*

> She will spoil her religion or spoil her level of reward from Allah. The fact that when she has a stomach ache, she says 'I have a stomach ache I must go to the hospital'. It's called fear, as we say, the fear. It's impatience that reduces the number of good points earned from Allah.
>
> *Case 6, daughter: interview 3*

There were clear associations between Patience & Acceptance and eternal rewards in the data. Nonetheless, there were occasions where patient-participants proposed that their experiences of breast cancer were so traumatic that they were worthy of compensation, independent of their responses to it. They hoped that such compensation would include both eternal and earthly rewards, specifically hoping that Allah would cure their breast cancer.

> Do you want to know if it [the mastectomy] bothers me? Of course, it does. If I had two breasts... I'm sorry that I've now only one, but Allah will reward me.
>
> *Case 8, Khadija: interview 2*

5.4.3 Theme 3: Journeying in search of a cure



(1) Patience and Acceptance

Figure 5.18 Hierarchy of themes: torches 1, 2 and 3

Maure women considered they had breast cancer because it was their destiny, given to them by Allah. The best response to this diagnosis was the demonstration of Patience & Acceptance, as discussed above. This acceptance limited the fight against destiny and the cancer but did not contradict or exclude seeking a cure. The third theme, journeying in search of a cure, will be presented under four sub-themes; seeking suitable empty-actions, building knowledge of breast cancer and its cure, negotiating access to the cure, and navigating the journey's diversions.

5.4.3.1 Seeking suitable empty actions

As described above, the patient-participants' understanding and experiences of breast cancer were framed by their belief that Allah was in control when He gave them breast cancer and that He remained in control. This religious paradigm also influenced how they perceived the nature of anti-cancer treatments. As introduced in the first theme, participants considered that Allah synchronously created breast cancer and its cure. A treatment was considered by patient- and family-participants as synonymous with cure. Because a cure was perceived as originating from Allah, it was equally feasible that it would be found in spiritual, natural or scientific domains. Participants employed the term 'sebab' or 'سبب' to refer to any treatment, whether spiritual (for example, amulets), natural (for example, plant- or diet-based therapies) or scientific (for example, chemotherapy or radiotherapy). The curative potential of any of these actions was nil, except when made useful and effective by Allah. To reflect the women's perception that an action's effectiveness was exclusively dependent on Allah, 'sebab' was translated as 'empty-action' in this thesis (see appendix 23 for further details on the translation process).

> It's only Allah who can heal us; the hospital is useless, it's just an '*empty-action'*
>
> *Case 8, Khadija: interview 2*

> We'll try to treat it but it's the good Allah who decides whether it will be treated or not [...] So if a patient is cured, it isn't me who has healed it. I was the '*empty-action'* […] OK, so for me, my belief is that it's not radiotherapy, but the good Allah.
>
> *Healthcare mini-case, H4: interview 2*

Participants experienced uncertainty in deciding which actions had been filled by Allah with a cure, and where these were located. The women's religious paradigm framed how they expressed their experiences of the search. Seeking a cure was portrayed as an appropriate, polite response to the diagnosis of breast cancer because it demonstrated to Allah that His gift of life was appreciated. In addition, they understood that Allah would only choose to heal them if they demonstrated a desire and commitment to be cured. The search was required to be carefully balanced with the ongoing demonstration of Patience & Acceptance of their breast cancer and their destiny, irrespective of whether they were cured or not.

> You must also take care of yourself. Allah has given you the opportunity, you must make every effort to be treated, especially when all your efforts will be rewarded. If you manage to join together the patience and the treatment, then you will be rewarded in any case.
>
> *Case 3, brother: interview 2*

> We must spare no effort to treat the patient and take care of her and do everything in our power and finally to rely on Allah. All we do, the doctor and ourselves, is limited to an 'empty-action' performed under destiny, praise to Allah.
>
> *Case 7, daughter: journal entry 3*

Patient-participants considered that endurance and acceptance of treatment side effects demonstrated to Allah, and health professionals, that they were committed to seeking a cure. Over the course of prolonged, expensive treatments, patient-participants realised that a cure would not be easy to find or to tolerate, despite their reliance on Allah to make their treatments efficacious.

5.4.3.2 Building knowledge of breast cancer and its cure

Patient-participants had limited prior awareness of breast cancer and what they did know made them afraid. As described above, they were confident that Allah was in control of their breast cancer, but they felt uncertain about how to access a cure. In this context, they sought additional information in order to better understand their breast cancer and understand where a cure was most likely to be found. The women's journeys often involved contact with multiple practitioners, both traditional and biomedical. Women compared the effectiveness, costs, and associated dangers of the available empty-actions.

> I have a lot of questions to ask; the first question is, can the disease, with the treatment I take, be healed before five years? Will the treatment be changed before the five years? With my situation of paralysis, is it possible that I can walk again?
>
> *Case 6, Alya: interview 3*

Women questioned the competency, compassion and motivation of those providing the care. They considered that much of the information provided to them along their journey with breast cancer was trivialising and misleading. When confidence was lost, they sought the cure elsewhere.

> She [Oumou] saw a doctor from [anonymised] Hospital who said it's a simple lump and it wasn't serious, and she could leave. He advised her not to have an operation. Then she went to the village where she went to see a traditional practitioner and from there it got worse.
>
> Case 4, cousin: interview 2

> I tried everything. I did the traditional, then I consulted the marabout [spiritual healer], finally I came to the hospital where I finally felt better […] I tried every form of traditional treatment. But it did nothing. The promises of a cure were numerous, but at the end it gave me nothing.
>
> *Case 4, Oumou: interview 2*

Patient-participants continuously constructed their own understanding based on observations and interpretations of their experiences; in addition to information from the television, internet, friends, religious teachers, and care providers. By the time of arrival at the CNO, the women concluded that breast cancer was predominantly a modern disease requiring modern empty-actions; biomedical treatments. For some women, this same process of knowledge construction was employed to work out their own diagnosis, which was not perceived as forthcoming from the health professionals.

> I couldn't find anyone who spoke to me frankly. I brought it [test result] to some doctors and they told me it's nothing, that I just need another test. But when all the breast was removed, I knew that it was cancer [...] I'd heard about it, but I'd never researched it. But at the start of my treatment, at the start of my treatment I entered the internet and started to look up the medicines I was taking.
>
> *Case 3, Binta: interview 1*

Although initially evasive and dismissive, women perceived that health professionals became more open about breast cancer following their mastectomy. During such moments, health professionals counterbalanced the bad news of a breast cancer diagnosis with the idea that the operation had removed all the cancer. Patient-participants were therefore surprised when they later learned that the cancer had spread. As they attempted to understand these events, they blamed the mastectomy, chemotherapy, the evil eye, and wrong treatments for the spread.

> At first, it [the breast cancer] was at the level of the chest. Then when the breast was cut, it went to my thighs. They're trying to fight against this. They'll do an operation, but whether it will be useful or pointless….
>
> *Case 6, Alya: interview 1*

With an increasing knowledge of breast cancer and its treatments, patient-participants became aware that it was easier to treat when it was confined within the breast. Lalla, case two, was afraid that her cancer would spread to her blood, despite already knowing that it was in her bones and lungs. She watched for signs of cancer in her blood and questioned whether there was a relationship between a difficult venesection and the fluid a doctor removed from her chest (figure 4.5).

> The other day I had two blood tests, and at each sample the blood was thick... […] What's that due to? [...] Is it that the veins don't contain any more blood or what is it? [...] It weighs heavy on me, that my blood is reduced or .... the liquid is on the lungs
>
> *Case 2, Lalla: interview 2*

5.4.3.3 Negotiating access to the cure

Patient-participants concluded that breast cancer was predominantly a disease of modern medicine, as introduced above. For it to be cured, they needed to access modern treatments which were controlled by biomedical health professionals, specifically doctors. Access to treatment was hampered because of a lack of access to the doctors. Delays in accessing these doctors, their information and their treatments were frustrating because of their new awareness that breast cancer was easier to cure before it had spread. Women perceived that access was challenging because they were unable to find and access doctors at their work, and secondly because of a cultural gap between them as women and the doctors, who tended to be male.

The women and male doctors were kept apart by a perceived gap of gender, intelligence, sophistication, social status, tribal identity, and language. At times, the male doctors perceived there was a gap of faith between them and the women with breast cancer. Health professionals perceived a need, from their position of strength, to protect the women and their weak faith from spiritual or emotional upset. To help overcome these barriers, patient-participants paid to see doctors in their private clinics, or recruited relatives and friends, such as doctors and nurses, to act as conduits for information. Health-participants appreciated these male external facilitators because they were viewed as sufficiently intelligent and sophisticated to understand some of the medical information (see figure 5.19).

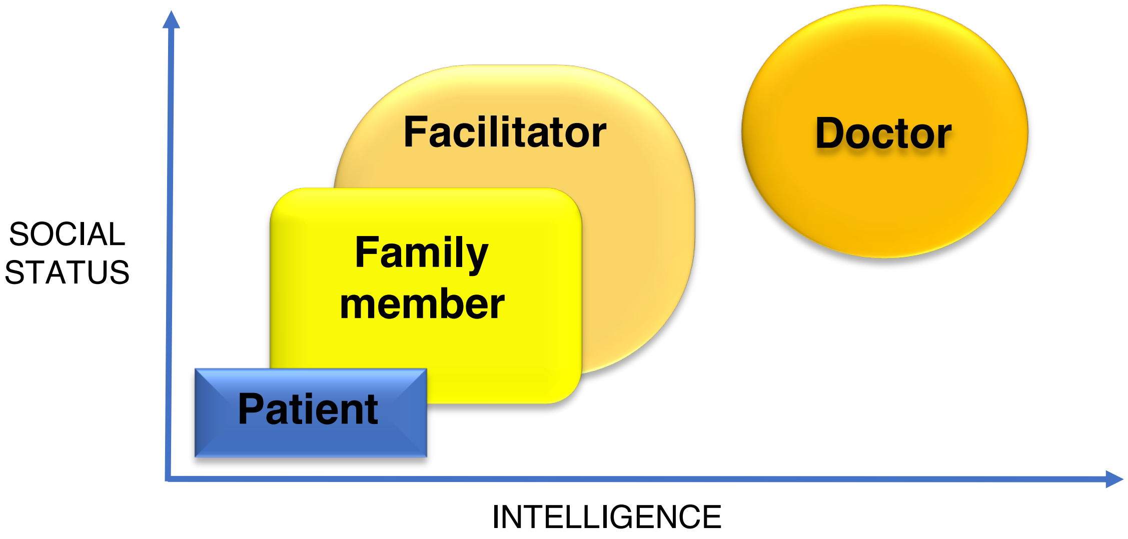


Figure 5.19 The doctor-patient gap

> I think that, for about two weeks, we went trying to find the doctor who would give us the referral letter for the oncology centre [...] In the end he didn't do it. I finally had to resort to another doctor that I know to intervene, to get things moving, otherwise maybe I'd still be there [laughs]
>
> *Case 4, cousin: interview 1*

Patient-participants perceived a need to surrender their preference to be involved in healthcare decisions to gain access to the doctors and their treatments. They tended to accept their identification as ignorant and unsophisticated, and delegated decision-making to others, both health professionals and male family members. Women were often absent from medical consultations, either remaining at home or in the corridor as the doctor communicated with male family members. This is illustrated in a comparison of figures 5.9 and 5.11 above, which show that family-participants were more satisfied with the information they received than the patient-participants.

Women experienced frustration in their lack of access to doctors and information but accepted it because they considered it was necessary to access treatment. For example, they did not express resentment that a mastectomy was performed on them without their consent or against their expressed wishes, because they perceived it was done in their best interest, in search of a cure.

> Researcher: No one told you that your hair will fall out?
>
> Aissata: No, unless the doctors told the men, my companions who understand their language.
>
> *Case 5, Aissata: interview 1*

> They asked me and I told them to take it [the breast] off, that's all. To remove the breast, that's it. She said 'No, don't take it off' but I told the anaesthetist, I'll tell this woman that we'll just remove the lump, it's simple but when she is gently anaesthetised... […] That's how they removed the breast, just like that.
>
> *Case 2, husband: interview 1*

At times, when there was limited response to the prescribed treatments, family- and patient-participants expressed the suspicion that a cure existed but was unobtainable by them. Some suggested that it may be found in more developed countries or that if it did exist at the CNO, they could not access it. For example, Lalla and Alya complained that they were blocked from accessing care for their paralysis and nausea.

> They [staff at the CNO] gave me an appointment, but I couldn't even stand up […] My files were lost there. They told me that they couldn't see a patient without the medical records. For that, they must find the files […] There is a strong negligence with these doctors.
>
> *Case 2, Lalla: interview 2*

> They [the doctors] only fumble. Sometimes they come across the right treatment; but whether it's a good or bad treatment, they give it to me and discharge me. They offer what they have, and they tell me to go even if I'm still vomiting.
>
> *Case 6, Alya: interview 5*

5.4.3.4 Navigating the journey's diversions

At the time of diagnosis, patient-participants expected that once they had accessed a suitable 'empty-action', their breast cancer journey would follow a timely and progressively improving trajectory concluding with a cure. In contrast, journeys were described as full of long and difficult experiences of multiple treatments, many of which were diversions away from cure, with no noticeable benefits. Women learned to question the quality and effectiveness of any treatment received in an attempt to understand whether they were on track towards a cure, or whether this was another diversion, wasting their money and time. When confidence was lost in the local services, and resources permitted, they travelled abroad for care. For example, as described in chapter four: *Within-case findings*, family- and patient-participants experienced shock, confusion and fear when doctors pierced the breast skin with a metal needle during a lump biopsy. This was because they understood that metal caused cancer, or caused it to spread, which stemmed from previous warnings from doctors to avoid the traditional practice of branding, in which skin is burned with a hot metal wire to cure illness.

> I often hear that the part of the body, which is affected by the disease, or when the part is infected, must not be touched by metal. That when the metal touches it, it will facilitate its [cancer's] spread.
>
> *Lalla, case 2: interview 2*

> All I can tell you is that I caught the disease, now if it's because of the syringe or whatever, I don't know […] Only Allah knows. But I suspect it is.
>
> *Case 8, Khadija: interview 1*

Chemotherapy was emphasised by most patient-participants as an especially difficult time in their cancer journeys. It was blamed for causing many symptoms, such as paralysis, fatigue, breathlessness and bone pain. Women felt that these experiences were exacerbated by a lack of warning or communication from health professionals.

> And when we started with the chemo [...] in my opinion... it kills the person and afterwards they try to resurrect them, they try to resurrect them. And it changes... the hardest part of the second injection is that I had no information about it.
>
> C*ase 3, Binta: interview 1*

> I did not understand what these headaches were due to. What caused them? […] It's harder for me when I'm in pain and I don’t know the reason for it.
>
> *Case 8, Khadija: interview 4*

In addition to questioning the different treatments, patient-participants interrogated their own experiences to understand whether their cancer journey was leading towards or away from cure. Experiences which were unexpected and difficult to understand created fear and anxiety that the cancer was spreading; for example, losing their hair or having new pains. In contrast, they felt reassured when they perceived a symptom to be normal and that it had a treatment. Those patient-participants who experienced unexpected hair loss were relieved when they learned from other patients or CNO staff that it was normal following chemotherapy. Other experiences were more difficult to consider as normal; for example, symptoms with no apparent treatment such as paralysis.

> It's difficult, sometimes I think the disease is incurable. I tell myself that it’s not deadly, but perhaps it may not be curable. That's something heavy and thinking about it makes me scared.
>
> *Case 5, Aissata: interview 1*

In response to their experience of a progressive deterioration of well-being, patient-participants began to reframe their understanding of breast cancer and what it meant for them. Doubts were expressed on the possibility of a cure for their symptoms, and their breast cancer. Some expressed acceptance that the breast cancer might never leave them but remained convinced that it would not cause their death, which was exclusively controlled by Allah. At these moments, the patient-participants reemphasised their commitment to accepting their destiny. This involved always being prepared for death; for example, Alya loosened her traditional veil every night to make it easier for her family to prepare her body for burial in case she died in her sleep.

> ‘I want to be a believer of Allah; I prepare myself very well for [death]. Every time [a Muslim] goes to sleep, they prepare for that ... They invoke Allah, prays for the Prophet [Mohamed], peace and blessings on him because they don’t know whether they will wake up or not.’
>
> *Case 6, Alya: interview 5*

5.5 Conclusion

The findings from the within-case analyses illustrated how Maure women’s journeys with advanced breast cancer were associated with negative experiences. This chapter has presented the findings from the cross-case analysis, exploring the quintain. It has shown how Maure women’s experiences of advanced breast cancer and their expressions of these experiences were shaped by their belief in and acceptance of destiny, and their politeness and gratitude towards Allah. Destiny was not fatalistic in nature; rather, women used it to reinforce their innocence for having breast cancer, argue against stigmatisation, and justify their search for a cure. These findings will now be discussed in light of the existing literature and the foreshadowed issues.

Chapter 6: Discussion and conclusion

6.1 Introduction

The two previous chapters described the experiences of women with advanced breast cancer in Mauritania, and the framework in which these are expressed. Chapter four presented experiences particular to the women identified in the within-case analyses, and chapter five described the quintain, identified in the cross-case analysis. This chapter will engage with these findings and discuss their implications and how they fit within the literature on women with breast cancer, including but not limited to Muslim, Arab women and resource-limited settings. It will conclude with reflections on the research process and discussion of the study's strengths and limitations, its contribution to knowledge, and the implications for policy, practice and research.

6.2 The multi-case study

This research set out to understand the experiences of Mauritanian women with advanced breast cancer. The study design allowed rich descriptions of women's experiences, with attention given to their complexity and contextuality (Stake, 1995). The longitudinal data collection from multiple perspectives, women, family and health professionals, provided the opportunity to understand how these experiences changed over time and in response to challenges, such as disease progression. The involvement of family members and health professionals in the research enabled a richer understanding of how culture and religion shape women's experiences and how such experiences are expressed.

The case study was guided by four foreshadowed issues (box 6.1) and a research question, ‘How is the quintain of advanced breast cancer experienced, over time, by Mauritanian women, their families and their healthcare providers?’

1. The belief in an omnipresent being is a comforting influence for the patient and their family as they face challenges to health and well-being
2. Healthcare providers have a sense of ownership and responsibility towards their patients, and this affects the care they provide
3. Mauritanian extended families experience difficulty in adapting to crises and in supporting their members
4. There may be unacknowledged burnout, loss of hope and breakdown in the family cohesiveness.

Box 6.1: Original foreshadowed issues

These foreshadowed issues were reviewed and modified, over the course of data collection and analyses, in response to emerging findings. These modified formulations, known as multi-case assertions (Stake, 2006) are presented in box 6.2, and will be considered along with key findings in the next sections.

1. Maure women and their families are reassured that breast cancer and their destiny are under the control of Allah. They are comforted when they can demonstrate their devotion to Him, despite negative experiences.
2. Healthcare providers have a sense of responsibility towards the spiritual well-being of their patients. This may outweigh other domains of well-being and be used to justify disempowering women, concealing or providing trivialising information.
3. Mauritanian extended families,
    a. cope well with many physical and material difficulties associated with breast cancer
    b. find it challenging to cope with a patient's expressed spiritual or emotional distress
    c. struggle to support a female relative with breast cancer if she is perceived as being responsible for the cancer
4. Families and women with breast cancer prefer not to acknowledge or express certain negative experiences because of cultural and religious beliefs.

Box 6.2: Multi-case assertions

6.3 Allah

My research has found that belief in Allah is important and helpful to Maure women with advanced breast cancer (multi-case assertion 1, box 6.2). This resonates with research from many different contexts, in which women with breast cancer often take comfort from a belief in a higher being (Burke et al., 2011; Balboni et al., 2007; Culver et al., 2002). The ways in which such a belief influences women's experiences of breast cancer relate to their perceptions of the higher being's engagement in their daily life (Schreiber and Edward, 2015; Schreiber and Brockopp, 2011). In my findings, the relationship between Allah and people is described as a master-slave relationship; Allah is unpredictable, distant and formal but remains continuously engaged in His creation. The belief in Allah provides limited comfort by itself in my research. For it to provide comfort, belief must be accompanied with a continuous respect for the sovereignty of Allah and submission to His will, interpreted as their destiny. This is seen from the moment of birth, when new born babies are given diluted goat's milk imbibed with Quranic writings (Kane, 2016a), to death, when Islamic teachings direct the cleansing and burial of the body and the grieving process (Fortier, 2005).

6.3.1 Destiny and fatalism

As described above, Maure women with breast cancer feel reassured that their lives are controlled by destiny; that Allah was, is, and always will be in control of everything. In my findings, destiny is a core and non-negotiable fundamental belief for the participants. This is rooted in the dominant interpretations of Islam in Mauritania, founded on ancient texts with little new theology for centuries (Fortier, 2005). Allah not only has foreknowledge of future events; He actively and purposefully causes these things to happen. My research shows that the inevitable yet unpredictable nature of destiny, and the fragility of the gift of life, motivate Maure women with breast cancer to be careful in how they express their views of cancer treatments and destiny.

I propose that destiny can be at times viewed as synonymous for Allah in Mauritania. Although there is clarity that it is Allah who causes breast cancer, the role of destiny is prominent in the narratives of causation. This nuance helps

Maure women to avoid attributing bad things to Allah; remaining polite and thankful towards Allah despite enduring negative experiences. Combative terminology, such as fighting the cancer, tend to be avoided. The women fear that such vocabulary could be conceived as a rejection of destiny, and hostility towards Allah. This is in contrast to North America and Europe where terms such as 'fighting' or 'battling' cancer are widely used (Semino et al., 2017; Davis, 2006; Ashing-Giwa et al., 2004; Lerner, 2003), and to a lesser extent in other Arab countries (Hammoudeh et al., 2017; Doumit 2010a).

At times, destiny is viewed as synonymous to fatalism; 'a belief that the outcome of their health is controlled by fate or by a god or gods' (Harandy et al., 2009 p.90). Such a perception has been criticised as a comfort mechanism to placate those who lack access to reliable healthcare (Hamdy, 2009). Harandy et al. (2009) associate fatalism of Arab women with feelings of helplessness and a lack of engagement in healthcare. In contrast, my findings emphasise the positive reframing of breast cancer and coping strategies related to belief in destiny; these are consistent with research on experiences of breast cancer in other contexts (Assaf et al., 2017; Hammoudeh et al., 2017; Pahria, 2017; Al-Azri et al., 2014a; Umezawa et al., 2012; Banning et al., 2010).

6.3.2 Empowered by destiny

My findings demonstrate that Maure women feel empowered by the concept of destiny. They perceive that the external control of destiny gives them hope that the world is ordered and not random, and that their breast cancer is a normal illness. Normal because it was created and given to them by Allah, who also created a cure (Fearon et al. 2018b). Firstly, destiny empowers women against stigmatisation, a common experience for women with breast cancer (Assaf et al., 2017; Daher, A.M. et al., 2017; Banning et al., 2010). Maure women attempt to reduce the experience of stigmatisation by emphasising the importance of destiny, and dismissing alternative theories of causation; such as, suppressed anger or immoral behaviours. The view that breast cancer is exclusively under the control of destiny reinforces the women's innocence; that they are not responsible for having breast cancer and to suggest otherwise would be in contradiction to Allah's will.

Secondly, destiny can empower the women's search for treatment. Belief in destiny strengthens the hope that a cure exists, because of its premise that Allah created a cure at the same time as he created breast cancer (Sachedina, 2005). This helps justify Maure women's and their families' seeking of a cure to the best of their ability; including expensive and aggressive treatments up until the moment of death (Fearon et al. 2018b). I propose that such an approach has several implications for the women and their families. Firstly, it demonstrates to Allah, and others, that the gift of life is valued and cherished. Secondly, the family's expenditure of time and money in seeking treatment communicates to the wider family and community that the woman is loved and valued. Finally, it can be used by the woman and family to deny or postpone the acknowledgement of a poor prognosis; that a cure remains a possibility irrespective of how unwell they are or how far the cancer has spread (multi-case 4, box 6.2).

6.4 Empty-actions

Aggressively seeking treatment can appear contradictory to an acceptance of destiny. Maure women are careful in how they describe treatments to minimise this risk. They refer to any treatment as an ‘empty-action’, a term introduced and defined in chapter five. In summary, an empty-action is any activity which becomes useful and effective exclusively when made so by Allah. My findings illustrate how this term equally refers to spiritual, traditional and biomedical treatments. This view that a cure, or comfort, may be found outside of the biomedical sphere is supported by the widespread use of complementary and alternative medicine (CAM) by women with breast cancer (Ali-Shtayeh et al., 2016; Naja et al., 2015; Sawadogo et al., 2012). Maure women with breast cancer take a pragmatic approach to what they hope may help them; they do not distinguish between the epistemic paradigms of the spiritual, traditional or biomedical (Brosnan, 2016). Instead, they emphasise that the effectiveness of any treatment originates from a single, shared source, Allah. The concept of empty-actions and their significance for Maure women with advanced breast cancer will now be discussed in light of the socio-medical, religious, and cultural contexts.

6.4.1 The socio-medical context

My research shows that empty-actions are congruent with the resource limited socio-medical context experienced by Maure women with advanced breast cancer. Health services in Mauritania lack personnel and infrastructure (Yusuf, 2015; Abdel-Wahab et al., 2013; Taleb et al., 2006). Such resource-limited settings are associated with challenges for patients, families and health professionals (Carruth, 2014; Jaffré & Olivier de Sardan, 1999); for example, women with breast cancer experience more powerlessness, fear and uncertainty than in well-resourced settings (Obeidat et al., 2013; Alqaissi and Dickerson, 2010; McEwan et al., 2014). Diagnoses are often ambiguous, results are doubted, multiple treatments are tried, and unwell patients recover to live a long life while the fit and well die suddenly with no explanation found (Fearon et al., 2018b; Carruth, 2014; Tocco, 2010). In these contexts, it is difficult to identify any relationship between treatment and effect. Belief in the unpredictable will of Allah, or destiny, fits with the practical experience and makes sense of the perceived disorder. Life, illness, treatment and death are accepted as unpredictable, of which only death is certain, as described in my findings. The concept of empty-actions is congruent with these perceptions in that they are unpredictable and offer no guarantee of success. Rather, they are options identified and considered by others, such as health professionals or other women with breast cancer, as valid, but unreliable, attempts to facilitate healing from Allah.

6.4.2 The religious and cultural contexts

The foundations of empty-actions can be seen in the history of Islam in Mauritania. Local interpretations and practices have changed little since Sunni Islam arrived in the 11th century, with an emphasis on the sovereignty of Allah (Fortier, 2005; Hames, 1994). Consideration of an Islamic philosophy of causation, occasionalism, can help illuminate the concept of empty-actions. This view proposes that there are no universal laws of science; but that 'God is directly, immediately, and solely responsible for bringing about all phenomena' (Nadler, 1995: p626). There are illusions of patterns because Allah frequently causes events to happen in similar ways. For example, the impact of a bat hitting a ball serves as an occasion or pretext for Allah to cause the ball to move. Burrell (1998) suggests that this high regard for the sovereignty of Allah does not naturally allow for, or explain, the role of human choices and actions. The concept of empty-actions serves to bridge these seemingly contradictory positions of human agency and the sovereignty of Allah; humans are free to seek treatment but any effect remains under the control of Allah.

Maure women perceive that they are not just free to seek treatment, they are obligated to do so. They consider that an action is required of them in order for Allah to cure them; the seeking or hope of supernatural miracles does not feature in my findings. The perception that treatments are necessary help Maure women to cope with the side effects from breast cancer treatments, despite any effect being considered as an illusion (Schmaltz, 1998). In contrast, there is an increase in anxiety when there is no noticeable benefit from the treatments available to them.

6.5 Breast cancer as an opportunity

My research shows that breast cancer can be viewed as an opportunity for Maure women. It is often described as being sent or allowed by God as a test of faith, with potential rewards for the individual (Hammoudeh et al., 2017; Al-Azri et al., 2014a; Obeidat et al., 2013). My findings demonstrate that breast cancer is frequently considered as a test, and less commonly as a gift. These analogies accentuate either of two outcomes from breast cancer; the challenges associated with enduring breast cancer or its potential advantages experienced in the next life (Alqaissi and Dickerson, 2010; Hammoudeh et al., 2017; Obeidat et al., 2013; Saati, 2013). Given that these outcomes coexist in the perspectives of Maure women with breast cancer, I propose that the term ‘opportunity’ is more useful for understanding the quintain. It better reflects the women’s hope for eternal rewards while recognising their challenging experiences of advanced breast cancer.

Maure women undersand their breast cancer in ways congruent with their personal belief system and that of their community. It is common for other groups of women to similarily accept breast cancer as a test from a higher being and find comfort in their faith (Volery et al., 2018; Rapport et al., 2017; Umezawa et al., 2012). Schreiber and Brockopp (2011) suggest that women in North America and Europe who accept their breast cancer as coming from God and do not stuggle against their cultural religious norms experience higher levels of well-being, irrespective of what their beliefs are.

6.5.1 Suffering as capital

The value of breast cancer as an opportunity is dependent upon how Maure women respond to it. This can be understood through the concept of suffering as capital, in which suffering is considered as a finite resource which can be either invested for rewards in the afterlife, through stoic acceptance, or expended in this world, through expressed suffering. The highest eternal rewards are most clearly associated with the silent endurance of negative experiences, with no expression of suffering. Maure women with advanced breast cancer find such stoicism impossible; and so, any rewards in the afterlife appear to be related to the proportion of their total suffering which is expressed (see figure 6.1). Maure women are required to express negative experiences, expending some of their suffering capital, in order to access help and relief. Given the eternal value of this capital resource, it is frustrating for women who spend it on expressing symptoms but fail to have them relieved.

$$S_r = S_t - S_e$$

S_r, rewarded suffering; S_t, total suffering;
S_e, expressed suffering

Figure 6.1: Suffering as a calculation

6.5.2 Stoicism

A stoical response to pain and suffering is idealised in my findings, with the allowed concessions described above. This finding is consistent with the literature demonstrating an idealisation of non-expression of pain in multiple ethnic groups and contexts, such as in cancer pain, childbirth, circumcision and female genital mutilation (Kane, 2016a; Luckett et al., 2013; Willig, 2011; Finnström and Söderhamn, 2006). In these situations, an individual's silent endurance of pain is often motivated by an avoidance of shame for themselves, their family and their ethnic group. It is rewarded by their community through the building of legends about the individual and their response to pain (Sargent, 1984). This legend construction was evident in my findings. Certain women were considered as having a strong faith or being martyrs, and stories were recounted of bereaved families who showed no emotion on learning of the death of a wife and mother.

Maure women feel pressure, from friends, family, and health professionals, to be stoical when enduring negative experiences (Majaj et al., 2013). They may face coercion to deny their suffering. There were occasions in my research, where Maure women with breast cancer endured physical and emotional abuse while undergoing medical interventions such as dressing changes or pleural aspirations, as described in chapters four and five. Such experiences illustrate the experience of powerlessness that Maure women with advanced breast cancer, consistent with the literature documenting the global problem of violence against women in healthcare settings (Bradley et al., 2016; Bohren et al., 2015). In addition to the challenges for the women, these situations are also difficult for the family, who either struggle to support the woman within the boundaries of personal and cultural expectations or are implicated in their coercion and abuse.

6.6 Challenges for the family of women with breast cancer

This multi-case study shows that the diagnosis of breast cancer has a large impact upon families and marital relationships, consistent with a range of literature (Lopes et al., 2018; Hilton et al., 2000). The challenges described by families include their experiences of witnessing women suffering, the financial burden of breast cancer care, moving home and divorce.

6.6.1 The family's response to pain

My research illustrates that families in Mauritania struggle when women with breast cancer overtly express their suffering (multi-case assertion 3b, box 6.2). As discussed above, suffering is a valuable commodity which should be expended only in exchange for concrete earthly benefits, such as relief of severe pain. Families feel awkward and uncertain of how to respond when negative feelings are expressed; such as, anger, sadness and fear. They see limited purpose in such expressions; and instead fear that the woman risks appearing impolite to Allah.

There are parallels between the family's view of Maure women with breast cancer and the literature exploring catastrophising responses to pain. Catastrophising pain is defined as a person's negative responses to actual or anticipated pain, characterised by rumination, magnification and helplessness (Sullivan et al., 2001). This construct is congruent with how families perceive Maure women's responses to their negative experiences of breast cancer. They criticise the women's responses as catastrophising, wasteful and unhelpful.

Catastrophising pain has been shown to be associated with more severe pain for the patient and reduced well-being for the spouse (Leung, 2012; Bishop and Warr, 2003). While such associations have been postulated for cancer and chronic non-cancer pain (Badr and Shen, 2014; Bishop and Warr, 2003), the supporting research is limited to well-resourced contexts in which patients and families have adequate access to information and analgesia (Leung, 2012; Zaza and Baine, 2002). This does not reflect the Mauritanian context which is characterised by limited resources and poor access to analgesia (Fearon et al., 2018b). It finally raises the question of whether the family's labelling of women's responses to pain as catastrophising more closely reflects their difficulty in accepting the expression of negative experiences, rather than the women's inappropriate response to pain.

6.6.2 Financial burden

Health-related costs are challenging for many families globally, increasing with the seriousness and chronicity of the illness (Akala and El-Saharty, 2006; Xu et al., 2003). Breast cancer-related costs can be direct, such as for treatments, or indirect, such as the loss of earnings due to the patient and family members' absence from work. In high-income countries, cancer-related financial hardship is common and can lead to poverty and cessation of cancer treatment, with those in poverty pre-diagnosis being the most vulnerable (Azzani et al., 2015; Ashing-Giwa et al., 2004). Families of patients with metastatic breast cancer face up to 40 percent higher indirect costs than those facing early breast cancer (Cardoso et al., 2018; Koch et al., 2012). In low-income regions such as Africa, where health insurance or free provision of care is more rare, cancer-related healthcare costs may decimate a family's financial reserves (Gysels et al., 2011). My research shows that families pay large sums of money for both modern and traditional remedies including prolonged periods of treatment in other countries, and at times going into debt. Much of these expenses are covered with aid from the tribal network of support, which unites to support its members in need. Ballet and Hamzetta (2003) argue that the Mauritanian tribal support network is not as egalitarian as proposed, and that the richer the person is, the more power and influence they possess and the easier it is for them to access the necessary funds.

6.6.3 Travel for cancer care

Specialist cancer care, along with the major medical specialities, is limited to the capital in Mauritania and so many patients have long distances to travel for care (Taleb et al., 2006; Ballet and Jiddou, 2005). In my findings, it was accepted that a serious illness requires the care only available in the capital, and that certain conditions are best treated abroad (Fearon et al., 2018b; Kane, 2016b). Travelling abroad for several months or moving home to better access breast cancer care are common experiences. I suggest that Maure women's acceptance of such experiences relate to the nomadic heritage in Mauritania, where many people continue to live in tents, including in the capital (Kane, 2016b, Boulay, 2007). Cancer-related travel is consistent with breast cancer care experiences in other resource limited settings (Soliman et al., 2018). In high-income regions, many breast cancer patients face disadvantages from the centralisation of cancer services. Women with breast cancer living in rural communities experience more limited local care options and poorer outcomes than those in urban areas, and either have to accept these restricted options or regularly travel long distances (Obeng-Gyasi et al., 2020; Haggstrom et al., 2005).

6.6.4 Marital relationships

A diagnosis of breast cancer impacts marital relationships. Breast cancer can bring couples closer together (Hammoudeh et al., 2017; Al-Azri et al., 2014a) or lead to relationship difficulties including divorce (Assaf et al., 2017; Elobaid et al., 2016; Jassim and Whitford, 2014; Nizamli et al., 2011). The literature review, presented in chapter two, demonstrated that Arab women with breast cancer perceived divorce as traumatic. My findings, in contrast, suggest that divorce is trivialised as a common social occurrence and is socially accepted. Fortier (2003a) suggests that this is due to blood ties to the family and tribe overriding the legal marital contracts. While this research did not identify situations where Maure women underwent divorce because of their breast cancer; it did describe family members who gave up relationships or activities to better care for their relative with breast cancer. For example, daughters may divorce their husbands to be able to be more available to care for a mother. This suggests that the experiences of Maure women with breast cancer are distinct from those in other Arab countries.

6.7 Seeking and providing breast cancer information

This case study found that Maure women with advanced breast cancer want, and actively seek, reliable and understandable information in order for them to make sense of their experiences. Health professionals and families try to limit women's access to breast cancer information, because they perceive it as dangerous.

6.7.1 Information and experiences

Women with breast cancer frequently seek information on their cancer; and the provision of timely, understandable and appropriate information has been shown to improve their quality of life, coping strategies, and psychological well-being (Albarghouthi and Klempe, 2018; Tiezzi et al., 2017 Obeidat & Khrais, 2014). For example, women's psychological and social well-being are improved when they learn that breast cancer is not contagious, as shown in my findings. They are comforted to know they are not a risk to others and use this knowledge to strengthen their rejection of the process of 'othering', in which they risk being ostracised by society for having a terrible disease (Joffe, 1998).

My findings demonstrate that many experiences of Maure women with advanced breast cancer are linked to the information available to them. Access to appropriate information can improve their experience of breast cancer, and a lack of information can worsen it. My findings show that Maure women tend to receive trivialising and misleading information, or none at all. This has negative implications for them. For example, medical interventions, such as chemotherapy, provoke prolonged fear and distress because the women receive no warning or explanation on the likely side effects. They question the normality of their experiences. They feel frustrated with their healthcare providers and the lack of communication, and often remain uncertain of their situation. Such experiences are not limited to breast cancer, but are evident in general healthcare interactions in Mauritania and West Africa where consultations are frequently brief and perfunctory, irrespective of the seriousness of the illness (Fearon et al., 2018b; Gobatto and Traore, 2011; De Bruijn and Van Dijk, 1995).

6.7.2 Restricted access to information

Maure women with breast cancer are excluded from decision making with limited access to reliable breast cancer information. My findings demonstrate that this imbalance of power is, in part, due to health professionals' perception that Maure women are ignorant and unsophisticated. Health professionals conceal information from the women, because they consider it impossible to simplify the highly complex scientific data surrounding breast cancer to the women's level of comprehension. This is partially supported by Jaffré and Oliver de Sardan's (1999) suggestion that health professionals in West Africa lack the necessary vocabulary to communicate effectively with their patients, despite a shared first language. They explain that this language barrier exists because health professionals' schooling, medical studies, and collaboration with colleagues are conducted predominantly in the colonial language, French. While this may play a role in the limited communication evidenced in my findings, I suggest that the non-disclosure of information reflects the health professionals' preferences to conceal negative information. They trivialise or mislead Maure women about their breast cancer to avoid causing them emotional or spiritual distress, consistent with the principle of non-maleficence (Khalil, 2012; Mystakidou et al., 2004). Such an approach is encouraged by the women's family.

Health professionals feel burdened by guarding breast cancer information because it is so incendiary and dangerous. Open disclosure is avoided because they assume that a woman would lose all hope and stop treatment if she understood breast cancer as they do, equivalent to a death sentence. They fear that they would be held responsible by the family, society, and perhaps by Allah, if their over-disclosure resulted in negative emotional or spiritual consequences for the woman (Fearon et al., 2018b). There is, however, an apparent contradiction in my findings; that although health professionals view women as ignorant, they simultaneously credit them with sufficient intelligence to work out their own diagnosis from hidden clues and overhearing foreign medical terminology. This way of learning a diagnosis protects the health professional from being held accountable by the family for causing upset.

Health professionals often experience a sense of failure when Maure women fail to comply with the breast cancer treatments. They, therefore, wield information as a malleable tool; modified and titrated as necessary to maintain a woman's hope and spiritual well-being while ensuring ongoing compliance to the prescribed empty-actions. Too much information is dangerous to the women's psychological and spiritual well-being whereas too little may lead them to abandoning treatment. Such paternalistic titration of information is not limited to Arab or resource-limited settings. For example, UK health professionals have been shown to be unsure of, or against, informing patients with bone metastases of the relatively small risk of spinal cord compression to avoid their distress, despite it being recommended practice (National Institute for Health and Care Excellence, 2014; Hutchison et al., 2012).

6.8 Maure women and power

Maure women's experiences of powerlessness, in relation to their breast cancer, is a thread which runs through my findings and much of this chapter, as described above. Allah, health professionals, families, and society hold power over them. They experience limited, or no, power over their destiny, healthcare decisions, access to treatment, expression of their suffering, and access to information. Aspects of these experiences are evident in the findings of the literature review, presented in chapter two, and the broader experiences of many women with breast cancer (Broom, 2001). For example, Arab women may require to obtain a husband's permission to seek medical care, or their husbands may make decisions for them irrespective of their wishes; such as, undergoing mastectomy (Jassim and Whitford, 2014; Majaj et al., 2013). To better understand the particular experiences of Maure women with power, as described in my findings, it is helpful to discuss the power of women in Islam, Mauritanian society, and the male-dominated healthcare.

6.8.1 Maure women's power in Islam

My findings establish that Maure women's identification as Muslims influences much of their experiences of advanced breast cancer and how these experiences are expressed, as discussed above (multi-case assertion 1, box 6.2). To be a Muslim means to submit to the power of Allah (Sachedina, 2005). Traditional Islamic teaching positions power at the centre of male-female relationships, with women either ignored or considered as subservient to the relatively more powerful men, as illustrated in my findings (Gemmeke, 2009; Mir Hosseini, 2006; Badran, 2001).

The distinctions between culture and religion are blurred by the portrayal of culture, faith and organized religion as united in a single monolithic Islam (Bramadat et al., 2013; Mir Hosseini, 2006). While the central tenets of Islam, outlined in chapter 1: *Introduction*, are widely accepted; there is no single, universal interpretation of Islam. The imbalance of power experienced by Maure women with breast cancer stems from one cultural tradition which has been influenced by patriarchal formulations of Islam; it is not synonymous with Islam. These different approaches to Islam are illustrated in the differing beliefs and practices at the individual and societal levels; for example, conflicting attitudes towards traditional medicine, women's initiation of divorce and women's reproductive rights (Karam, 2017; Kane, 2016b; Fortier, 2010; Hessini, 2007). Feminist Islam rejects traditional negative views of women as remnants of patriarchally-inflected Islamic interpretations of law, and replaces them with Quran-based principles of gender equality (Mir Hosseini, 2006; Miller and Petro-Nustas, 2002). Such newer interpretations of Islam propose that the foundations of Maure women's experiences of relative powerlessness to men are cultural rather than religious.

6.8.2 Maure women's power in healthcare

> 'All claims to knowledge are inevitably claims to power'
>
> (Weinberg, 2007: p33)

In my findings, Maure women perceive male doctors to be gatekeepers of knowledge and, therefore, holders of power. Subsequently, power is at the centre of the women-doctor relationship. This is consistent with Lupton's (2003) suggestion that there is an imbalance of power in any healthcare interaction; the holder of scientific knowledge credited with power by the person seeking help, the legal system in which they work and the social context. This case study illustrates that, at times, such an imbalance of power can be unconstructive, ranging from paternalistic to corruptive and abusive (Bradley et al., 2016; Salmon and Hall, 2003).

Maure women with breast cancer tend to be passive in their face-to-face interactions with health professionals, accepting the power imbalance in the relationship. The women's submissive expressions of politeness and gratitude towards health professionals resonates with their attitudes towards Allah. Health professionals and Allah are perceived as powerful, unpredictable and possibly easily offended. In contrast to the avoidance of criticising Allah, as described above, Maure women are willing to express dissatisfaction with their healthcare.

My research illustrates that Maure women with advanced breast cancer are careful in their interactions with health professionals, especially those women with limited viable alternatives. They fear that trying to exercise power over treatment choices or asking too many questions may threaten the health professional's sense of authority and risk treatment being stopped. Instead, they endure disrespect and neglect in healthcare, with limited attempts at recourse; consistent with the limited literature describing healthcare interactions in Mauritania (Fearon et al., 2018b; Kane and Fearon, 2018).

6.8.3 Maure women's autonomy

As described above, Maure women experience limited power in their healthcare interactions. The promotion of shared decision-making and person-centred care has been shown to help redress these imbalances of power (Pulvirenti et al., 2012). Such approaches tend to be controversial in paternalistic contexts, as seen in Mauritania, because they promote an individual's autonomy alongside the ethical principles of non-maleficence, beneficence and justice (Beauchamp and Childress, 2013). Firstly, in congruence with my findings, Rathor et al. (2011) suggests that autonomy is incongruent with Islamic theology because of its underpinning secular idea of 'self-rule', the assumption that people have control over their own destiny rather than it being under the power of Allah. Secondly, autonomy and empowerment are feared because they are associated with hedonism and sinful personal gratification (Mustafa, 2014; Albishi, 2004). I suggest that this latter argument is expressed, in my findings, through the family's and health professionals' perception of women as weak and vulnerable who need protection from harmful thoughts and actions; such as, anger towards Allah (multi-case assertion 2, box 6.2). Male health professionals and family members fear that Maure women with advanced breast cancer would react inappropriately to bad news and so conceal information or lie to them.

6.9 Reflections on the research process

6.9.1 The constructivist paradigm

This thesis employed a constructivist approach, as described in chapter three: Methodology and methods, which recognises that new knowledge is constructed by individuals and groups through their experiences, observations and interpretations. This approach helped to better understand the presence of multiple constructions of breast cancer in Mauritania. Maure women's knowledge creation has been shaped by their experiences of powerlessness in relation to Allah, health professionals and their families. Women are aware of these imbalances of power, and in turn recognise that their understanding of breast cancer is flawed and incomplete. They, therefore, seek information to construct more reliable understandings of their situations. The constructivist approach facilitated this context for several reasons. Firstly, the view that knowledge is constructed rather than uncovered helps to avoid a binary view of true or false (Atkinson and Gregory, 2007). Secondly, it accepts that everyone has flawed and limited knowledge and does not contradict the participants' view that perfect knowledge is accessible only by Allah (Kukla, 2000). Thirdly, the approach affirms the validity of the experiences of the women, but without the need to accept all constructions as equally valid, as in extreme relativism (Järvensivu and Törnroos, 2010). Knowledge is constructed in a social context and I propose that women should have a more prominent place in its construction. Finally, it is acknowledged within the constructivist approach that the researcher plays a role in any construction of knowledge. I am not a neutral conduit through whom the women's voices can be heard unaltered or in their entirety. This is elaborated below.

6.9.2 The researcher

It is important to reflect on how my identity as a male, foreign, Christian, UK-trained doctor has impacted this multi-case study from design to analysis. Whittemore et al. (2001) suggest that all data arising from qualitative research are influenced by what participants desire to control and what researchers desire to find out. As discussed in chapters one: *Introduction*, and two: *Methodology and methods,* this thesis supports that experiences are shaped by the act of a person entering into their experience in order to describe it to a researcher (Luft and Overgaard, 2012). At its essence, this thesis is an exploration and interpretation of what Maure, Muslim, Arabic-speaking women with advanced breast cancer described to me. The women's choice of experiences to report and how they were verbalised were partly shaped by their perception of me and my role. Fortier (2003b) argues that researchers from Western contexts, as inheritors of a Christian culture, are ill equipped to perceive the spiritual dimensions of Islam beyond what they consider prosaic. I suggest that this argument is flawed because of two presumptions; firstly, that there is a single, orthodox Islamic theology in Mauritania, a concept challenged in this thesis; and secondly, that Christians in high-income regions routinely neglect the spiritual realm of life. I accept that my identity has influenced this research and there are gendered power imbalances throughout the thesis (Mauthner and Doucet, 2003). While a female Muslim researcher would construct different meanings to those that I have described, there would be differences between any two researchers (Finlay and Gough, 2003).

Reflexive research is not limited to appreciating how the researcher influences the research process, it is also about how the research changes the researcher (Finlay and Gough, 2003). The iterative questioning and reflecting on my presumptions, experiences and learning, including the prolonged engagement with the existing literature and my data, resulted in several changes I could identify. One change was the further development of my epistemological paradigm, which has been in a process of change since starting the PhD programme, moving away from an Evidence Based Medicine influenced positivism to a more interpretive paradigm. My views on people's spirituality also changed, with a deeper appreciation that many fears and hopes, my own included, are shared experiences irrespective of any religious adherence.

6.10 Limitations of this study

This thesis has described the quintain of advanced breast cancer in Mauritania. The scope of the findings is limited to women over 40 years of age with metastatic breast cancer, who speak Hassaniya, are aware of their diagnosis, and have accessed care at the CNO.

The CNO, the research setting, is a study limitation. The active involvement of participants at the biomedical cancer centre resulted in the collection of narratives attentive to that stage of their cancer journey. Many of the most challenging experiences described by participants had occurred several years previously, such as receiving the diagnosis and undergoing mastectomy. Furthermore, the seeking of treatment in different approaches, such as the traditional, tended to have occurred prior to attendance at the CNO. As described in my findings, the retrospective accounts of the traditional tended to be negative and critical. By the time of recruitment, the majority of participants had concluded that traditional remedies were not appropriate for breast cancer.

This may reflect the participants desire to appease their health care professionals and their concurrent commitment to the CNO's approach. Given that no traditional practitioners were nominated, the study's exploration of their role in the quintain was limited to the perspectives of others.

The case study was further limited by the duration and frequency of the collection of quantitative data. The APCA African POS and PPSv2 detected slow deteriorations in the participants' well-being, but sudden or larger changes often occurred between data collections. A longer duration of data collection, with more frequent data collection points, may have helped to record and better understand the patterns of changing performance status and well-being. In addition, the controversy of questioning the quality of life, in my findings, suggests that the APCA African POS may not be an appropriate scale for use in Arab Muslim women with breast cancer.

This thesis involved the collection of a large quantity of rich data, useful to answer the research question. Data from the health professionals held less utility than expected because there were fewer occasions where the health professionals accounts of experiences overlapped with those of the women and their families. This was perhaps due to the lack of consideration I paid to the style of healthcare interactions at the CNO in the planning stages. This limitation was mitigated to some degree through the creation of the healthcare mini-case.

Finally, there were limitations related to the cross-cultural and cross-language nature of this multi-case study research. As outlined above, my identity influenced the case study from conceptualisation to writing up. My findings are limited by what Arab-speaking Muslim women chose to divulge to a non-Arabic speaking Christian man and a male interpreter. Despite these limitations, I propose that my findings hold utility for understanding the experiences of advanced breast cancer in Mauritania. As a Christian, I was positioned by participants somewhere between being an infidel and a Muslim. I was pitied for not being a Muslim and yet considered closer to their view of truth than an atheist or polytheist. This positioning meant that I was not bound by the same cultural norms and expectations. Most participants were happy to patiently explain their answers to my questions, despite suggesting that no Muslim researcher would pose such questions. In some ways, it seemed I was considered as a young, wayward child with limited understanding of what was normal, and who needed to be instructed in Islamic truth. Others politely refused to answer certain questions, pitying me for my ignorance of spiritual matters. In regard to the gender imbalance within the interviews, I would recommend any future non-Arabic speaking researcher undertaking research with Maure women to consider employing a female Mauritanian translator.

My identity influenced how participants viewed me and interacted with me, as described above. My otherness in this case study also influenced how I, as a researcher, interacted with them. It is feasible that a fear of causing offence or appearing prejudiced may have restrained my questioning of the genuineness of participants' acceptance of destiny and the concept of empty-actions. For example, Adib (2004) suggests that Islamic approaches towards medicine are restricted to an exterior posture,

> 'Islamic medicine can be metaphorically described as a pious garment which Muslim doctors and patients are expected to don as they approach an otherwise Western medical model' (Adib, 2004 p701)

This limitation was partly addressed by the case-study's constructivist focus on the experiences of the women. The aim of this thesis is to provide an image of the quintain which is congruent with the women's accounts. Much of these descriptions underwent translation prior to analysis, a further limitation of the study. Techniques were employed to maintain validity, as presented above in chapter three: *Methodogy and methods*, but it remains inevitable that some of the nuance and vibrancy of the women's voices were not captured and communicated in this thesis.

6.11 Strengths of this study

This multi-case study has several strengths, including the novelty of being the first research to explore the experiences of Maure women with advanced breast cancer. The focus of the research has enabled an in-depth exploration of these experiences, both in the uniqueness of individual women's narratives and the broader concept of the quintain as experienced across the sample of women, family members and health professionals. This has enabled the comparison of these experiences with those described in high-income regions and other

African and Arab contexts. Experiences in common include the impact of physical and psycholigcal suffering and the importance of access to reliable information. The study allowed a deeper understanding of some of these areas; for example, the role and meaning of destiny, which tends to be dealt with superficially in the literature from the Arab region. Other experiences described in the thesis appear to be more contextual to Maure women and feature less prominently in the broader literature; for example, the perception of suffering as capital and the interpretation of treatments as empty-actions.

There are several methodological strengths to the study. Stake's multi-case study approach facilitated the exploration and description of these experiences. The individual level within-case analyses priviledged the women's voices and journeys, while the quintain level cross-case analysis identified broader ideas and concepts of advanced breast cancer in Mauritania. Other strengths of this thesis include the approach to data collection and analysis. Firstly, the inclusion of perspectives of multiple women with breast cancer, family members and relevant health professionals encouraged both the construction of multi-layered descriptions of several different journeys, and a richer understanding of the quintain, in recognition that experiences are not constructed in isolation (Abma and Stake, 2014). Secondly, the longitudinal collection of data allowed the synchronous exploration of experiences, not a retrospective recounting. For example, rich data were collected on experiences and perspectives which evolved over time and in response to concurrent life events; such as, pleural aspirations, family weddings and changing family dynamics. In several cases, such changes were due to a gradual deterioration in their well-being which resulted, at times, in their death during study participation. Finally, the use of innovative mixed methods allowed experiences to be explored from different researcher-based perspectives, an approach which values data for their utility in understanding the quintain and the contextuality of the cases (Stake, 2006). The qualitative data from interviews and journals held most utility in understanding experiences and were prioritised in this thesis. Quantitative data played a role in describing and measuring experiences, for example the reduction of several experiences to a numerical figure enabled a pictorial description of experiences aiding recognition of patterns over time and their comparison across cases. In addition, the APCA African POS provided an alternative way in which participants could express negative experiences. The act of quantifying an experience on a six-point scale allowed a sense of detachment and lower emotional investment.

6.12 Implications for future research

This thesis is the first research on experiences of breast cancer in Mauritania. It is hoped that its findings will form the foundation for further palliative care research. Due to the previously uncharted nature of breast cancer journeys in Mauritania, there are many directions for further research. These include the comparison of Maure women's experiences of advanced breast cancer with the experiences of earlier stages of breast cancer or with other forms of advanced cancer. Given the novelty of this thesis, and its gendered imbalances as described above, it would be interesting to compare its findings with similar research undertaken by a female researcher or team of researchers.

Responding to a diagnosis of breast cancer with patience and acceptance is important for Maure women. A similar response has been suggested as important for both Muslim and Christian populations elsewhere (Asad, 2003). It would be interesting to explore how the expression of experiences within these two groups have been labelled and described in popular and academic literature. For example, are Muslims more likely to be negatively labelled as fatalistic, whereas Christians positively as long-suffering and stoical.

Stoicism has been identified as an expectation and trait amongst certain ethnic groups, often associated with rites of passage including childbirth, circumcision and female genital mutilation (Finnström and Söderhamn, 2006). It would be interesting to consider breast cancer as a socially constructed rite of passage in Mauritania, through which a women's social status could be strengthened through their demonstration of faith and acceptance along their cancer journey.

6.13 Implications for practice

This research has demonstrated how Maure women seek information and knowledge on their breast cancer. They are in a constant process of observation and interpretation trying to make sense of their experiences. They respect the knowledge of health professionals but are frustrated that access to it is lacking.

Health professionals should be aware that women have an understanding of breast cancer, and that they will continue to construct this understanding using any information or observations available to them. This knowledge construction should be encouraged and facilitated.

Bad news is associated with emotional upset, but the extremes of distress tend to be short-lived especially when given in appropriately sized and understandable blocks (Abazari et al., 2016). In contrast, the women's sense of unknowing and uncertainty increases their fear and psychological distress on a larger scale and over a longer period of time (Obeidat and Lally, 2013; Alqaissi and Dickerson, 2010). More details on breast cancer and its treatments should be provided to the women, through culturally appropriate ways. Volunteer organisations may have a role in this, if health professionals remain resistant.

The analysis and description of individual cancer journeys and the broader exploration of the quintain have served to make the experiences of advanced breast cancer in Mauritania accessible to much of the palliative care community who are unlikely to visit the region. Maure women with advanced breast cancer experience physical, social, emotional and spiritual suffering but may prefer not to express it. Any expression of negative experiences comes at a perceived cost to the women and should be taken seriously. Culturally appropriate approaches to providing care while enabling women to maintain their preferred external demeanour or stoicism are feasible and should be sought. In healthcare interactions in any context, a women's passivity should not be misinterpreted as agreement or consent, nor that they are symptom-free. In addition,

6.14 Contribution to knowledge

This multi-case study presents original, empirical research on the experiences of advanced breast cancer in Mauritania, at the level of the case and the quintain. It offers unique insights into how experiences of Maure women change in response to contemporaneous events, and how these experiences are expressed. Maure women's journeys with advanced breast cancer have been shown to be influenced by their lack of power, in relation to Allah who causes their cancer and holds their cure, to health professionals who control access to information and treatment, and to families who influence how they express negative experiences of breast cancer and its treatments. The thesis allows broad comparisons of its findings with experiences described and measured in other Arab countries. My findings explore in depth how women with advanced breast cancer perceive and employ destiny. This understanding encourages a nuanced approach to women with such beliefs, shaping the physical, psychological, social and spiritual care provided for them. Destiny is not equivalent to fatalism and we must be on guard against superficial explanations and simplifications. We should treat Muslim women as individuals with beliefs and interpretations unique to them. This research contributes to case study discourse by providing an example of a constructivist Stakian multi-case study employing embedded mini-cases and incorporating mixed methods of data collection, including the use of audio-journals. Its cross-cultural and cross-language context offers a novel contribution to the limited palliative care research in Africa, specifically in non-Anglophone Africa.

6.15 Conclusion

The aim of this study was to understand how women experience advanced breast cancer in Mauritania, and what influences these experiences. This is an important and novel area of research relevant to cancer and palliative care in resource limited contexts. In chapter one: *Introduction*, the research background was presented, with an overview of breast cancer and the study's geographical location, the Islamic Republic of Mauritania in North-West Africa. In chapter two: *Literature review*, a systematic review of the qualitative and quantitative research on the experiences of Arab women with breast cancer was presented. The review found diversity in cancer journeys, but with some common features; such as, respect for Allah, fear and depression at the time of diagnosis, uncertainty of the future, and adaptation to new identities as breast cancer survivors. The review identified little literature from resource limited contexts, with no literature from Mauritania.

In chapter three: *Methodology and methods*, Stakian multi-case study research was introduced. Its constructivist paradigm and the working methods of the thesis were described. The multi-case study was guided by four foreshadowed issues (box 6.1, page 189). The findings of this thesis were presented in two chapters; the particular and unique narratives of the eight cases were described in chapter four: *Within-case findings.* The quintain, the phenomena of advanced breast cancer as experienced across the cases was presented in chapter five: *Cross-case findings*.

In this final chapter, my findings have been discussed with reference to the wider literature. This multi-case study describes experiences which feature in a Maure woman's journey with advanced breast cancer. Many of these experiences, both positive and negative, are framed within nuanced balances of power. Firstly, women experience a feeling of powerlessness in their Islamic faith. They attribute Allah with complete power over their destiny. Allah was, is and will always be in control of breast cancer. Rather than a negative fatalistic experience, Maure women feel reassured that life and cure remain possible because of His sustenance; but are aware that the gift of life is fragile.

Secondly, the cultural dominance of local interpretations of Islam impacts on how Maure women express negative experiences. The women and their families accept that the gift of life should be valued and cherished, irrespective of its quality. Maure women fear that complaining about their experiences of breast cancer and its treatment may offend Allah, who could punish them in this life and/or the next. Families encourage stoicism out of a concern for the women's spiritual well-being. Such silent endurance in the face of suffering is idealised because it most clearly demonstrates to Allah, family, and society that they are good Muslims with a strong faith.

Thirdly, Maure women with breast cancer experience limited power in their interactions with health professionals. Maure women view health professionals as unpredictable and unreliable. Through their experiences, they conclude that information and treatment are withheld from them, through negligence or disregard. Women remain passive in healthcare interactions in order to avoid causing offence to the health professionals, which they feel could further restrict access to treatment options. Health professionals, meanwhile, prefer to communicate with family members or facilitators because they are considered to be more intelligent, sophisticated and emotionally stable than the women.

Maure women perceive breast cancer and its associated suffering as temporary. The imbalances of power, described above, are accepted as either reflecting the true nature of reality or are unchangeable by them. They were chosen by Allah to have breast cancer. Maure women seek a cure in the hope that one will feature in their destiny, while they simultaneously, and to the best of their ability, use their experiences of breast cancer as an opportunity to earn eternal rewards in the afterlife. Life, breast cancer, and death are unpredictable, but only death is certain.

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Appendices

Appendix 1: Experiences of breast cancer in Arab countries. A thematic synthesis

Quality of Life Research
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REVIEW

Experiences of breast cancer in Arab countries. A thematic synthesis

D. Fearon[1,2] · **S. Hughes**[1] · **S. G. Brearley**[1]

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Abstract

Background Breast cancer is the most common cancer in women globally. Its negative effects on a woman's quality of life are related to the individual and socio-cultural factors. This review aimed to identify and synthesise the reported experiences and quality of life of women with breast cancer in Arab countries.

Methods PubMed, Embase, Web of Science, SCOPUS, PsychInfo, CINAHL, Allied and Complementary Medicine Database, and Index Medicus for the Eastern Mediterranean Region were searched for articles published from start to March 2019 using PRISMA guidelines. These searches were complimented by citation tracking and hand searching of relevant journals. A thematic synthesis was carried out on the 'findings/results' sections from the identified papers.

Results Of 5228 records identified, 19 were included in the review which represented 401 women from 11 Arab countries. All used qualitative methods of data collection to produce rich descriptions of experiences. Thematic synthesis of the extracted data identified three major themes, Perceptions and reactions, Coping or enduring and Changing roles.

Conclusions This review provides a rich description of the reported quality of life and experiences of women with breast cancer in Arab countries. These are influenced by the women's and society's views of cancer, the women's role in society and family, religious faith and the healthcare context and access to treatment choices and information.

Keywords Quality of life · Breast cancer · Arab · Muslim · Qualitative · Thematic synthesis

Background

Breast cancer is the most common cancer diagnosed in women globally [1]. High-income regions, such as North America and Europe, experience the highest rates of incidence, considered to be due to screening and earlier detection, and genetic differences [1, 2]. Inversely, its incidence is lowest but mortality highest in low- and middle-income regions, due to the limited diagnostic and treatment capacities [1, 3, 4]. In the Arab world, breast cancer ranks as the most frequently diagnosed cancer overall, representing an estimated 17.7 to 19% of all new cancers in 2018 [5, 6]. Its prognosis is relatively better than in much of sub-Saharan Africa. There is, however, much variation across the region, with worse outcomes seen in lower to middle-income countries; for example, the 5-year survival rates for breast cancer are 43.1% in Jordan compared with 85.3% in Qatar [7].

Research exploring the impact of breast cancer on women's health-related quality of life (HRQOL) and experiences has explored how experiences change over time. The time of diagnosis is associated with shock and fear, feelings which fluctuate over the course of treatment and as the women face either progression or survivorship [8–10]. These experiences and the journeys are influenced by cultural and societal values. Much of this cultural understanding comes from research with ethnic minority groups in higher income regions; however, there is an increasing body of research from different regions, such as Arab contexts. Two recent reviews [11, 12] of HRQOL of women with breast cancer in the Arab region identified two common measurement scales, the European Organization for Research and Treatment in Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the EORTC breast cancer specific quality of life

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✉ D. Fearon
d.fearon@lancaster.ac.uk

[1] International Observatory on End of Life Care, Faculty of Health and Medicine, Lancaster University, Lancaster, UK

[2] Cairdeas International Palliative Care Trust, Nouakchott, Mauritania

questionnaire (EORTC QLQ-BR23). These scales provide a measurement of global HRQOL, symptom burden, role functioning and breast-specific aspects of HRQOL. Haddou Rahou et al. [11] found much heterogeneity in the limited data originating from Arab countries, with a mean global HRQOL score ranging from 45.3, in Kuwait, to 74.6, in Bahrain, on a scale of 0 to 100, with 100 representing the best well-being. They subsequently performed a narrative analysis of the data rather than a meta-analysis concluding that Arab women have low quality of emotional well-being but higher levels of social well-being, which they suggest is due to the strong family links and support available. Hashemi et al. [12] more recently explored experiences in the Eastern Mediterranean region and found a similar broad range of global HRQOL scores, ranging from 31.1 in Saudi Arabia to 75.6 in Qatar. They also found lower scores for emotional well-being and higher scores for social functioning; however, their meta-analysis has limited utility for the Arab context because 19 out of the identified 36 articles originated from Iran or Pakistan, neither of which are Arab countries. These reviews, and the use of scales, are helpful to understand, measure and compare reported experiences and HRQOL of women with breast cancer. Such understanding can be enriched with data originating from qualitative methods of data collection, which provide deeper, richer understanding of individuals' experiences of a phenomenon such as breast cancer [13]. Consequently, this review aimed to identify and synthesise the available literature exploring Arab women's experiences of breast cancer from such a qualitative perspective. This was guided by the review question, 'What is the experience of Arab women with breast cancer?'

Methods

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [14]. Data extraction, analysis and synthesis followed Thomas and Harden's thematic synthesis approach, which translates the concept of thematic analysis of primary data to secondary data [15–17]. This approach aims to go beyond thestudies authors' original findings to produce new, higher-level understanding of the phenomenon of interest.

Search strategy

The following electronic databases were searched from the earliest available date to March 2019, PubMed, Embase, Web of Science, SCOPUS, PsychInfo, CINAHL, Allied and Complementary Medicine Database, and Index Medicus for the Eastern Mediterranean Region. Search terms were truncated where appropriate (Table 1). The search strategy for PubMed can be found in the Supplementary Information. This broad range of terms was selected due to their relevance to the subject area and the relative difficulty of finding qualitative research [15]. The electronic database search was complemented with

- tracking of citations found in the identified articles and reviews;
- hand searching of the indexes of the following regional journals: The Middle East Journal of Family Medicine, Oman Medical Journal, Journal Medical Libanais, La Tunisie Médicale, the Arab Journal of Psychiatry and the Pan African Journal of Oncology;
- experts in the region were personally contacted for suggestions on eligible articles.

Selection criteria

Articles were included in the review if they met the inclusion and exclusion criteria in Table 2.

Selection procedure

Identified items were imported into Papers for Mac version 3 [18] and duplicates were removed. Titles and abstracts were screened against the inclusion criteria by the author DF. Full-text articles were retrieved and assessed for articles meeting the inclusion criteria or when in doubt.

Table 1 Search terms used with electronic databases

Participant	Experience	Location
(Breast OR Mammary) AND (Cancer OR Tumour OR Tumor OR Malignancy OR Neoplasm)	Adaptation, attitudes, anxiety, barrier, belief, believe, coping, culture, depression, enduring, expectation, experience, health knowledge, idea, lived experience, motivation, narrative, perception, perspective, psychological, quality of life, social support, survivor, view	Arab, Algeria, Bahrain, Comoros, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, United Arab Emirates, Yemen

Table 2 Inclusion and exclusion criteria

	Inclusion	Exclusion
Study design	Original research with qualitative design published in peer-reviewed journals	Review articles, books, conference articles, posters, letters to editor and opinion pieces
Language	Published in English or French	Non-English, non-French language
Focus	Experiences of breast cancer	Other cancers or impossible to disaggregate data relating to breast cancer from other cancers
	Experiences of women with breast cancer	Experiences of relatives, healthcare professionals, or men with breast cancer
Context	Arab women in an Arab country	Immigrant Arab women in a non-Arab country

Quality assessment

Quality assessment of included studies was not performed. Many established quality-assessment tools have limited utility in research from non-Anglophone countries, especially those with less established research platforms [19, 20]. Such tools tend to measure the quality of report writing rather than the identification of interesting and novel findings [21]. Finally, there is no established cut-off of quality below which the exclusion of papers would be justified or beneficial [16].

Data extraction and synthesis

All papers were read and re-read before and during the analysis. Study characteristics, such as research aims, study design, sample size, participant demographics and main findings were extracted and tabulated. All data found under the headings 'findings' and/or 'results', including participant's quotations, were exported verbatim into N-Vivo for Mac v.10.2.2. Analysis and synthesis of these data followed Thomas and Harden's guidelines [15]. Extracts were read and re-read, and then coded line by line. Codes were then linked into clusters and subsequently into themes. Themes were examined for interconnectedness across the sample with the development of superordinate theme.

Results

A total of 5228 citations were identified, of which 262 papers were selected for full-text review after the removal of duplicates and the screening of titles and abstracts (Fig. 1).

Study characteristics

The characteristics and main findings of the 19 included studies are displayed in Table 3. Sample size ranges from 2 to 60, with a total of 401 women with breast cancer from 11 Arab countries; Bahrain ($n=1$), Egypt ($n=1$), Jordan ($n=3$), Lebanon ($n=4$), Morocco ($n=1$) Oman ($n=2$), Palestine ($n=1$), Syria ($n=1$), Saudi Arabia ($n=2$), Tunisia ($n=1$) and United Arab Emirates ($n=2$). Participants' ages range from 24 to 71 years old. All disease stages are represented, and time since diagnosis ranges from 3 months to 9 years. Research aims include the impact of diagnosis, issues around late diagnosis, the challenges of active treatment, survivorship, familial and social support networks, sexuality, and access to information.

Synthesis results

Based on Arab women's experiences of all stages of breast cancer three major themes were identified, 'Perceptions and reactions', 'Coping or enduring', and 'Changing roles', and seven sub-themes (Table 4).

Theme 1. Perceptions and reactions

1a The diagnosis The majority of diagnoses within the identified literature arose from women presenting with symptoms rather than through screening; however, many experienced a delay between first symptoms and receiving a diagnosis. This period was characterised by uncertainty and multiple visits to modern and traditional healthcare providers [23, 30, 39, 40]. The moment of receiving a diagnosis of breast cancer resulted in much fear and anxiety for Arab women [22–25, 31, 38, 40]. Nevertheless, they felt unable to openly express these concerns with their healthcare professionals. Instead, they passively followed the recommended investigations and treatments, or alternatively they sought second opinions and treatment elsewhere, including travelling abroad [23, 24, 34, 38, 39].

The subsequent trajectory of these reactions following the diagnosis diverged according to the healthcare setting. Women cared for in specialist centres felt well informed of their diagnosis and empowered in their treatment choices [24, 37]. In contrast, women who were cared for in local non-specialist hospitals often perceived that the healthcare professionals lied to them and provided incorrect management and advice [24, 30, 34, 37]. These experiences increased fear

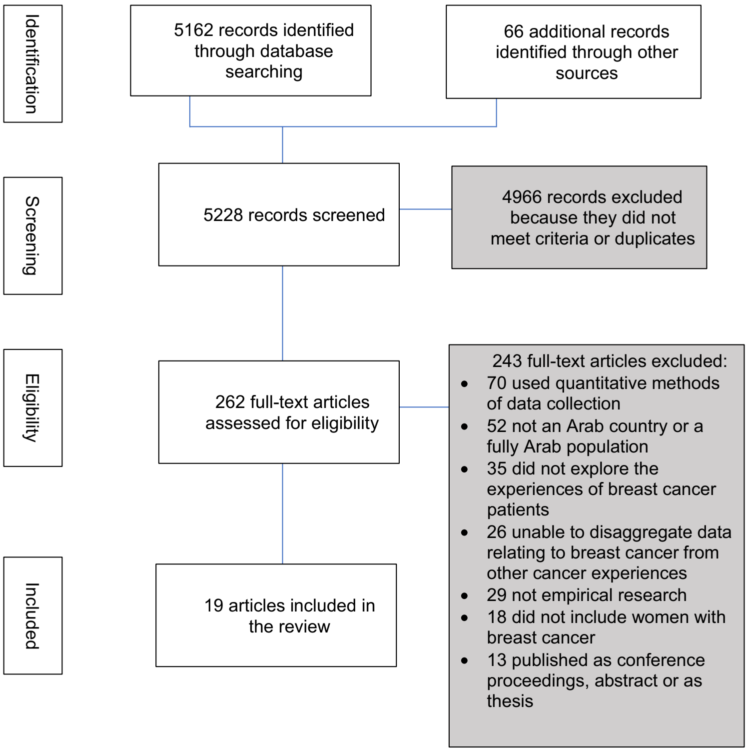

Fig. 1 Flow diagram to show literature search process in accordance with PRISMA

and mistrust which, at times, resulted in uncertainty of their diagnosis and a persistent perception of breast cancer as a death sentence [22, 24, 31, 32, 36–38, 40].

1b Perceptions of treatment The identified literature described Arab women's experiences of a variety of cancer treatments such as radiotherapy, chemotherapy, mastectomy and lumpectomy. Women often perceived themselves as periphery to any treatment decisions, and occasionally underwent treatment against their expressed wishes [27, 32, 34, 37, 38]. Several authors labelled the described breast cancer treatments as losses. For example, women described losing their hair, a breast, a normal life, fertility, independence, autonomy, physical attractiveness and arm function [23, 24, 28–32, 36–38]. These losses, especially hair loss and mastectomy, were emphasised by respondents as negatively influencing their quality of life, physical well-being, body image and relationship with their husbands, if married [28, 32]. For some women, losing a breast was as equally shocking as learning of their diagnosis [36, 38]. However, over time, most came to accept their treatment-associated losses as minor in comparison to their diagnosis and their hope of a cure.

1c Changing perceptions Women's perceptions of breast cancer changed as they progressed along their journeys with it. For many women, the early dominant view of breast cancer as a death sentence was replaced by the new concept of breast cancer being a curable illness or a chronic condition [29, 31, 32]. This process was described more often for those respondents who were several years post diagnosis; however, it also was evident in the experiences of women who had received options for treatment, and who had accessed information from the internet or from breast cancer survivors [23, 24, 28, 29, 31, 32, 34, 37, 38]. Nevertheless, breast cancer continued to be considered as a death sentence by women who remained uncertain of their diagnosis, feared recurrence or were anxious about passing the disease on to others in their family [23, 24, 28, 29, 32–34, 37, 38].

Table 3 Characteristics of the included studies

First author	Year	Country	Research focus	Methods	*n*	Demographics	Main findings
Al-Azri [22]	2014	Oman	Coping strategies after diagnosis	Semi-structured interviews (single). Framework analysis	19	Aged 24 to 54 years old All stages of disease and treatment Time since diagnosis: 3 months to 3 years (mean 12.2 months)	Six themes: (a) denial, (b) optimism, (c) withdrawal, (d) religious beliefs and practices, (e) support of family members and healthcare providers
Al-Azri [23]	2014	Oman	Psychosocial impact of diagnosis	Semi-structured interviews (single). Framework analysis	19	Aged 24 to 54 years old. Attending outpatients or hospitalised. All stages of disease and treatment Time since diagnosis: 3 months to 3 years (mean 12.2 months)	Four themes: (a) psychological distress of the disease and uncertainty, (b) reactions of family members, (c) views of society and (d) worries and threats about the future
Alqaissi [24]	2010	Jordan	Meanings of social support through the cancer journey	Semi-structured interviews (single). Heideggerian hermeneutical analysis	20	Aged 24 to 72 years old. All stages of disease. Late stage or post treatment Time since diagnosis: 6 to 24 months (mean 12.7 months)	Six themes: (a) stigmatised disease, (b) social support, (c) being strong for self and others, (d) resources, (e) controlling information for protection and (f) spiritual meaning as support One constitutive pattern: culture influencing the meaning of social support
Almegewly [25]	2019	Saudi Arabia	Perspectives of survivorship following treatment	Interviews (single). Interpretative phenomenological analysis	18	Aged 30 to 50 years old with stage I or II. 6 to 47 months post treatment	Three themes: (a) the meaning of cancer, (b) hidden survival and concealing the diagnosis and (c) cultural meanings of survival
Assaf [26]	2017	United Arab Emirates	Experiences following diagnosis and treatment	Semi-structured interviews (single)	20	Aged 30 to 65 years old. All disease stages. Undergoing active treatment. Time since diagnosis: 8 to 24 months	Three themes: (a) protecting oneself from stigma, (b) facing uncertainties and (c) getting on with life
Doumit [27]	2007	Lebanon	Lived experiences of oncology patients receiving palliative care	Semi-structured interviews (single). Phenomenological analysis (Utrecht School)	3	Age NR Palliative stages of disease Time since diagnosis: NR	Eight themes: (a) distress at being dependent, (b) dislike for pity, (c) worry for the family, (d) reliance on God, (e) dislike of hospitals, (f) fear of pain and (g) need to communicate

Table 3 (continued)

First author	Year	Country	Research focus	Methods	*n*	Demographics	Main findings
Doumit [28]	2010	Lebanon	Coping strategies	Semi-structured interviews (longitudinal). Seven-stage hermeneutical analysis (Diekelmann and Ironside)	10	Aged 36 to 63 years old. All disease and treatment stages. Time since diagnosis: 4 months to 9 years	Seven themes: (a) cancer is from God, (b) cancer is similar to any other disease, (c) positive support from others, (d) sharing the experience, (e) changed body image, (f) fear of reoccurrence and (g) pity Constitutive pattern: cancer is a cut in our lives that we have to fight
Doumit [29]	2010	Lebanon	Lived experiences of BC	Semi-structured interviews (multiple). Phenomenological analysis (Utrecht School)	10	Aged 36 to 63 years old. All disease and treatment stages. Time since diagnosis: 4 months to 9 years	Four themes: (a) living with losses, (b) living with guilt feeling, (c) living with fears and uncertainty and (d) living with a need to know
Elobaid [30]	2016	United Arab Emirates	Delayed presentation and health seeking behaviour	Semi-structured interviews (single). Thematic framework analysis	19	Aged 35 to 68 years old. Advanced stages of disease. Time since diagnosis: < 2 years	Three themes: (a) symptom recognition and appraisal, (b) role of community and social network and (c) healthcare delivery system
Hammoudeh [31]	2017	Palestine	Experiences of BC and its impact on families and social relationships	Semi-structured interviews (single) and focus group discussions. Thematic analysis	35	Aged 25 to 71 years old. All stages of disease and treatment. Time since diagnosis: < 1 year to several years	Three themes: (a) the transition from shock to the daily struggles, (b) the role of social support in helping women cope and (c) faith and reliance on God
Jassim [32]	2014	Bahrain	Experiences, beliefs, perceptions and attitudes relating to QOL in BC	Semi-structured interviews (single). Constant comparative analysis	12	Aged 39 to 68 years old. All stages of disease and treatment. Time since diagnosis: 1 to 8 years (mean 2.6 years)	Five themes: (a) meaning of cancer and QOL, (b) spirituality and beliefs about causes of breast cancer, (c) coping mechanisms, (d) impact of illness and (e) change in relationships
Kobeissi [33]	2014	Lebanon	Translation and validation of FACT-B into Arabic	Focus group discussions	41	Aged 20 to 71 years old. All stages of disease and treatment. Time since diagnosis: NR	Five themes: (a) physical well-being, (b) social/family well-being, (c) emotional well-being, (d) functional well-being and (e) additional concerns
McEwan [34]	2014	Egypt	Experiences of diagnosis and treatment delays	Semi-structured interviews (single). Thematic content analysis (social ecological model)	15	Aged 29 to 60 years old. All stages of treatment. Staging of disease: NR. Time since diagnosis: NR	Four themes: (a) intrapersonal factors, (b) interpersonal relationships, (c) institutional factors and (d) public policy factors

Table 3 (continued)

First author	Year	Country	Research focus	Methods	*n*	Demographics	Main findings
Masmoudi [35]	2016	Tunisia	Issues of sexuality	NR	2	Aged 44 to 48 years old. Post mastectomy. Time since diagnosis: NR	Five themes: (a) difficulties of communicating with the doctor, (b) erroneous beliefs, (c) reactive depression, (d) changing body image and (e) trouble communicating within the couple
Nizamli [36]	2011	Syria	Experiences of chemotherapy	Semi-structured interviews (single). Content analysis	17	Aged 30 to 45 years old. All stages of disease. Undergoing active chemotherapy. Time since diagnosis: NR	Four themes: (a) psychological discomfort, (b) physical problems, (c) social dysfunction and (d) failure in the family role
Obeidat [37]	2013	Jordan	Experiences of information exchange following diagnosis of early stage BC	Semi-structured interviews (single). Content analysis	28	Aged 29 to 70 years old. All stages of disease. Mastectomy or lumpectomy < 6 months. Time since diagnosis: NR	Three themes: (a) knowledge about BC and its treatment, (b) communication of cancer diagnosis and treatment and (c) education on treatment side effects
Obeidat [38]	2013	Jordan	Personal meanings of diagnosis and surgical treatment for early stage BC	Semi-structured interviews (single). Heideggerian interpretive phenomenological analysis	28	Aged 29 to 70 years old. All stages of disease. Mastectomy or lumpectomy < 6 months. Time since diagnosis: NR	Four themes: (a) fearing BC, (b) trusting as coping, (c) surrendering to and suffering through treatment and (d) embodied self as changed One constitutive pattern: controlling fear
Saati [39]	2013	Saudi Arabia	Experiences of diagnosis and treatment	Semi-structured interviews (single) and focus groups. Grounded theory analysis	60	Mean age: 46 years old. Stage of disease: NR. All stages of treatment. Time since diagnosis: NR	Five themes: (a) communication, (b) acceptance, (c) knowledge and understanding, (d) limitations imposed by culture and (e) positive dimensions of culture
Soliman [40]	2018	Morocco	Experiences and perspectives of barriers to diagnosis and treatment of BC	Semi-structured interviews (single). Grounded theory analysis	25	Age: NR. Stage of disease: II to IV. All stages of treatment. Time since diagnosis: NR	Six themes: (a) treatment-associated costs, (b) burden of transportation and distance, (c) healthcare choice, (d) identity and femininity, (e) community influence and (f) spirituality and conception of death

BC breast cancer, *NR* not reported, *QOL* quality of life

Table 4 Themes and sub-themes

Theme	Sub-theme
(1) Perceptions and reactions	(1a) The diagnosis
	(1b) Perceptions of treatment
	(1c) Changing perceptions
(2) Coping or enduring	(2a) Challenges to coping
	(2b) Strategies for coping
(3) Changing roles	(3a) Care-provider versus care-receiver
	(3b) Positive new roles

Theme 2. Coping with breast cancer

Arab women described coping with breast cancer as a continuous battle [29, 31]. They battled not just against cancer, but also against the stigmatisation they experienced.

2a Challenges to coping Arab women considered that their ability to cope with breast cancer was hindered by the cancer itself and by their family and society's perception of the condition. Cancer- and care-related challenges included the financial burden of treatment, distressing symptoms such as pain, the fear of cancer recurrence, infertility, losing their independence and dying alone [23, 27, 29, 30, 33, 38, 40].

The responses of husbands and families were sometimes challenging for the respondents. Although husbands tended to be valued as sources of emotional and financial support, there were occasions where married Arab women were afraid that their husbands may divorce them or take a second wife, because they were no longer fertile or sexually attractive [25, 30, 32, 36]. There were infrequent examples in the literature where these fears were realised, with the rupture of sexual relationships, separation, divorce, and physical or emotional spousal abuse being experienced [24, 26, 30, 32, 35, 36].

Arab women found it difficult to cope with society's negative reactions to their illness. These were characterised as being pitied, shunned and blamed for having breast cancer [25, 26, 29, 31, 33, 36, 38]. Respondents felt that many people, including friends and work colleagues, feared them and avoided them because of a fear that breast cancer was contagious. At times, a distrust of those around them was developed because of their experiences of being blamed for having breast cancer, a sign of punishment for undisclosed past sins or uncontrolled anger, or social humiliation and ridicule [22, 23, 26, 30, 32, 34]. Various strategies were therefore employed to cope with, or avoid, such distressing experiences.

2b Strategies for coping To avoid being viewed as a sick person, Arab women with breast cancer attempted to maintain their pre-diagnosis persona [25, 29, 31, 33, 38]. Several strategies were employed to either achieve this image, or to help when it was no longer possible for the women to maintain the portrayal as a well person. These were the non-disclosure of diagnosis, faith in Allah, receiving support from friends and family, and relationships with others with breast cancer.

2bi Non-disclosure of diagnosis Arab women preferred to conceal their diagnosis from others, at least initially. They managed this by not disclosing the diagnosis, hiding signs of illness or treatment side effects, and explicitly denying any problems; for example, wearing a wig or a traditional head covering (hijab) to hide hair loss [22, 24, 28, 30, 32, 33, 36, 38]. However, these attempts to conceal were often insufficient, such as during chemotherapy when the signs of illness were more visible. At these times, many women chose to isolate themselves from others [22, 23, 30, 36, 38]. While such responses tended to be temporary and treatment related, there were examples where prolonged isolation appeared to lead to low mood and depression for the women [22, 36, 38].

2bii Faith in Allah The Muslim faith played an important role in how Arab women coped with breast cancer. The belief and acceptance that life and death are predestined was a comfort to the women, because it meant that cancer, its treatment and its cure were controlled by Allah [23, 26, 27, 31, 38]. This acceptance of destiny was not fatalistic in nature and in contrast, women considered that they were equally obliged by religion to seek medical advice and comply with treatment.

Breast cancer was viewed as a test of faith, sent by Allah [22, 31, 39]. To pass this test, women perceived the need to respond to it with patience, endurance and acceptance [24, 31, 38, 39]. Exhibition of such responses would be eternally rewarded through the reduction of sins. Several older participants described their diagnosis as a gift because it had inspired a re-evaluation of what was important in life and the afterlife. However, the advantages of faith were not limited to the afterlife, as women considered that their faith in Allah helped them to remain hopeful for a cure and to endure the side effects of treatment [22, 23, 31, 38].

2biii Receiving support from friends and family The support of friends and family was valued by respondents. The nature of the help provided varied according to the relationship. For example, a husband's role was to be the main provider of emotional and material support [22, 24, 28, 31, 34, 38, 39]. Friends, neighbours and the wider family were expected to visit the women's homes to give moral support [22, 24, 27]. Although the women preferred to avoid the subject of cancer, they took comfort in being told stories of others being cured of cancer [20]. In contrast, female members of the immediate family provided practical support and help, such as helping with the household chores and child care [24, 28, 31, 38]. Financial aid was often received from the wider family, even if there was no great need [24, 34].

2biv Relationships with other women with breast cancer Contact with other women with breast cancer helped the women cope with their own diagnosis. Firstly, participants appreciated knowing that they were not alone in their experiences [22, 26, 32]. Secondly, they made reassuring comparisons between themselves and others who were less fortunate, for example, those with more advanced disease or those who were young and unmarried [24, 28, 34, 38]. Thirdly, there were examples where women, post treatment and in good health, felt empowered and encouraged to support others with breast cancer, especially those more recently diagnosed [24, 28, 29, 32].

Theme 3. Breast cancer and roles

The role of women in the Arab societies was primarily viewed as being a daughter, a wife or a mother. However, a diagnosis of breast cancer threatened these identities and roles [25, 31, 32, 36, 38, 40].

3a Care-provider versus care-receiver The principal priority for many Arab women was to protect and promote their family's well-being. Women initially concealed their diagnosis so as to protect others from distress and sadness, especially their children [32, 38]. They therefore experienced frustration and sadness when breast cancer rendered them care-receivers, in contrast to being self-sufficient care-providers. This switching of roles was especially evident during active treatment or with an increasing disease burden [31, 36, 38].

Arab women's role of care-provider was not limited to practical tasks; they were also partly responsible for the family's social and spiritual well-being. It was therefore distressing for those women who blamed themselves for introducing breast cancer into the family [29, 30, 34]. They considered that they failed at their role because they could no longer provide the best chances for their family, which included the nurturing of marriage opportunities for their unmarried female relatives [29, 30, 34].

3b Positive new roles For many women, a diagnosis of breast cancer stimulated a re-evaluation of what they valued in life, which leads to new post-diagnosis identities and roles [26, 32, 38]. Women challenged society's view of them as sick women waiting for death to take them, by encouraging the view that breast cancer was a curable or chronic illness, equal or even favourable to diabetes [29, 31]. New positive roles included being respected informal advisors to other women with breast cancer, or strong women able to endure and accept their destiny [22, 28, 29, 38]. These new identities strengthened the argument against society's stigmatisation of them [30, 38].

In contrast to seeking a new role in society, there were occasions where Arab women with breast cancer rejected the idea of re-entry into society's roles and normality. Instead, they embraced the idea of breast cancer as a death sentence and were keen to demonstrate their acceptance before Allah and others [22, 24, 31]. They argued that death was the inevitable outcome for all, irrespective of whether they have cancer or not [22, 26].

Discussion

This thematic synthesis of qualitative data has generated an understanding of how breast cancer is experienced by Arab women in Arab countries. The broad range of literature identified and synthesised in this review, representing 401 women in 11 different countries, has illustrated both convergences and divergences of experiences and impact upon their reported HRQOL. This review has illustrated how Arab women's experiences are formed in response to their perceptions of cancer and its evolution within an interplay of individual, social and religious factors.

At the personal level, the identified literature suggests that much of Arab women's negative experiences, such as anxiety, fear, and symptoms, are most problematic around the time of diagnosis and during active treatment. This is consistent with the broader literature, which suggests that breast cancer survivors go on to have a good quality of life [8, 41]. However, Arab women who remain symptomatic and uncertain of their diagnosis with limited access to reliable information may struggle to transition to the ideal new identity as strong breast cancer survivors, even several years post treatment. While many of these fears and worries are consistent with other populations, such as the fear of recurrence [42, 43], other concerns suggest a closer association with the Arab context, such as the avoidance of pity, and the transition from care-provider to care-receiver.

An appreciation of how Arab women perceive their role in their social context is helpful to understand and interpret their experiences. They identify as mothers, wives and daughters, and their role is to provide and protect their family, sacrificially if required. Therefore, many of the experiences of breast cancer are challenging for them because of their impact on their family rather than on themselves. For example, the initial response to a diagnosis is to conceal it and protect others from emotional upset. Arab women were afraid that their diagnosis of breast cancer had damaged and tarnished their family. This was understood as either through hereditary means or infectious contagion. For women with an awareness of breast cancer genetics, many consider that they have introduced breast cancer into their family bloodline and are thereby guilty for reducing the marriage chances for their daughters and grand-daughters. This fear may be intensified and more common in this ethnic group because of the frequent practice of the family vetting potential marriage partners for suitability, fertility and character [29, 30]. In addition, some Arab countries have a mandatory pre-marital genetic testing due to the high rates of consanguineous marriage and the increased transmission rates of autosomal recessive disorders, such as β-thalassemia [44]. In contrast, women with limited access to information perhaps focus more on their fear that breast cancer is contagious, and thus perceive themselves to be a risk to their family's physical well-being. It is pertinent to note that these fears are founded on a shared perception that they and their family risk being stigmatised because of their diagnosis. Consequently, women promote breast cancer as a normal disease with a cure to counter such stigmatisation. Alternatively, some women embrace their mortality and encourage others to do likewise reinforcing the Islamic view that it is Allah who is fully in control of the manner, moment and place of their death, and not breast cancer.

Islam has been a major influence in Arab countries since the eleventh century, although there is currently much blurring of the boundaries between religion and culture in the region [45]. Nevertheless, the practices and interpretations of Islam are perceived as defining much of how health and illness are experienced, for example encouraging adherents to interpret breast cancer as a divine test of faith [46]. Such a view is not unique to the Arab context, and is a common experience for non-Arab Muslims and other religious groups [43, 47, 48]; however, it is important to give credence to the importance that Arab women attribute to their faith and the felt need to demonstrate polite appreciation to Allah in all circumstances. In light of this, they consider that there are potential advantages to having breast cancer, both for this life and the next. For example, in this life, women hold that an appropriate response to breast cancer may lead to a reprioritisation of their life values, improved relationships with husbands, friends and family, and eternal rewards from Allah, in the next life. Errihani et al. [49] recognise a duality of effectiveness in this approach. They suggest that, for Muslim patients, increased religious practices can, firstly, increase chances of a cure because it is Allah who controls the effectiveness of any treatment; and secondly, even if religion does not help them to recover, it may help them enter paradise after their death.

Strengths of the literature review

This review was strengthened by the breadth of the articles identified. Included data in this review represented 11 heterogeneous Arab countries, with much variation in their cancer services. For example, the five-year breast cancer survival in Jordan, with an annual health expenditure of $224 per capita, is 43.1% in contrast to 78.4% in Saudi Arabia which expends $1147 [50]. Such heterogeneity was compounded by the inclusion of rural and urban populations, high- and low-income families, all stages of breast cancer and all stages of treatment, including pre-treatment, active treatment and survivorship.

Limitations of the literature review

There were several limitations of the literature review. Firstly, the heterogeneity of the data while providing rich diverse descriptions of Arab women's experiences may also hinder the understanding of experiences across this geographical and ethnic region and within sub-groups of the population. Secondly, as with any review, it was limited by the available data identified. The 11 countries represented in this review tend to be higher income and therefore the voices of Arab women with breast cancer from middle- and low-income Arab nations feature less in this review. Subsequently, there continues to be a need for further research exploring the experiences and HRQOL of women with breast cancer in Arab region. This should include primary qualitative research in addition to an updated, broader systematic review of the quantitative data exploring HRQOL in women with breast cancer in the Arab region.

Conclusion

The purpose of this literature review was to understand women's experiences of breast cancer in Arab countries, and its impact upon their quality of life. The review concludes that the experiences of Arab women with breast cancer are strongly influenced by their family, social, religious and healthcare contexts. Many of theseexperiences are negative and distressing. Women balance their belief and hope that breast cancer comes from Allah while questioning the veracity of society's assumption that breast cancer is a death sentence. The journeys of women, who are actively implicated in decision making, have access to appropriate information, and receive support from husbands, family and friends, appear to follow similar trajectories towards survivorship as described in higher income settings. In contrast, Arab women tend to remain uncertain and fearful when they have limited access to reliable information or treatment choices. Further research comparing these findings with women elsewhere would be useful. A person-centred approach should therefore be encouraged, in which Arab women are provided with appropriate information in accordance to their understanding and desires.

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Compliance with ethical standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

Informed consent For this secondary analysis of data, formal informed consent was not required.

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Appendix 2: Sample of regional bio-medical journals

Journal	Website	Language of Publication
Middle East Journal of Family Medicine	http://www.mejfm.com	English
Oman Medical Journal	www.omjournal.org	English
Qatar Medical Journal	www.qscience.com/	English (Occasionally Arabic)
Saudi Medical Journal	www.smj.org.sa/	English
Journal of Medicine Liban	www.lebanesemedicaljournal.org	French or English
Kuwait Medical Journal	www.kma.org.kw	English
The Arab Journal of Psychiatry	http://www.arabjpsychiat.com	English and Arabic
The Bathrain Medical Bulletin	www.bahrainmedicalbulletin.com	English
Alexandria Journal of Medicine (Egypt)	http://www.journals.elsevier.com/alexandria-journal-of-medicine/	English
La Tunisie Médicale	www.latunisiemedicale.com	French and English
The Libyan Journal of Medicine	www.libyanjournalofmedicine.net	English
Jordan Medical Journal	http://journals.ju.edu.jo	English

Appendix 3: Qualitative papers included in literature review

Study	Research focus	Methods	Sample size	Demographics	Findings
Al-Azri et al. (2014a), Oman	Coping strategies after diagnosis.	Semi-structured interviewing (single). Framework analysis	19	Age: 24 to 54 years old. All stages of disease and treatment. Time since diagnosis: 3 months to 3 years (mean 12.2 months)	6 main strategies to cope with the diagnosis; (a) denial, (b) optimism, (c) withdrawal, (d) religious beliefs and practices, and (e) support of family members and health-care providers.
Al-Azri et al. (2014b), Oman	Psychosocial impact of diagnosis	Semi-structured interviewing (single). Framework analysis	19	Aged 24 to 54 attending out patients or hospitalised. All stages of disease and treatment. Time since diagnosis: 3 months to 3 years (mean 12.2 months)	4 themes: a) factors related to psychological distress of the disease and uncertainty; b) reactions of family members; c) views of society; and d) worries and threats about the future
Alqaissi & Dickerson (2010), Jordan	Meanings of social support through their diagnosis and treatment trajectories.	Semi-structure interviews (single). Heideggerian hermeneutical analysis	20	Aged 24 to 72. All stages of disease. Late stage or post treatment. Time since diagnosis: 6 to 24 months (mean 12.7 months)	6 themes :(a) breast cancer as a stigmatized disease among Jordanian women with breast cancer, (b) social support from social network members, (c) being strong for self and others, (d) resources influence availability and need for social support, (e) controlling information for protection, and (f) using spiritual meaning as support. 1 constitutive pattern: culture influencing the meaning of social support.

Almegewly et al., (2019), Saudi Arabi	Perspectives of survivorship following treatment	Interviews (single). Interpretative phenomenological analysis	18	Aged 30 to 50 years old with stage I or II. 6-47 months post treatment	3 themes: (a) the meaning of cancer, (b) hidden survival and concealing their diagnosis (c) the cultural meaning of survival and the problems with the idea of 'survivorship'
Assaf et al. (2017), United Arab Emirates	Experiences following diagnosis and treatment.	Semi-structured interviews (single)	20	Aged 30 to 65 years old. All disease stages. Undergoing active treatment. Time since diagnosis: 8 to 24 months	3 themes: (a) Protecting one's self from stigma, (b) Facing uncertainties and prayers, and (c) Getting on with life
Doumit et al. (2007), Lebanon	Lived experience of oncology patients receiving palliative care	Semi-structure interviews (single). Phenomenological analysis (Utrecht school)	3	Aged 21 to 71 years(1) Palliative stages of disease. Time since diagnosis: 2 to 21 months(1)	8 themes (a) their distress from being dependent; (b) their dislike for pity; (c) their worry for the family and the worry about the family's worry; (d) their reliance on God and divinity; (e) their dislike of the hospital stay; their need to be productive; (f) their fear of pain; and (g) their need to communicate.
Doumit et al. (2010a), Lebanon	Coping strategies	Secondary data analysis of data from Doumit et al. (2010b)	10	Aged from 36 to 63 years old. All disease and treatment stages. Time since diagnosis: 4 months to 9 years	7 main themes; facilitating factors: (a) Cancer is something from God; (b) Cancer is similar to any other disease, mainly diabetes; (c) Positive support from work, family and husband; (d) Sharing the experience with people who know; and hindering factors: (e) Changed body image; (f) Fear of reoccurrence; (g) Being pitied by others Constitutive Pattern: Cancer is a cut in our lives that we have to fight

Doumit et al. (2010b), Lebanon	Lived experience of living with BC.	Semi-structure interviews (Two interviews two weeks apart). Phenomenological analysis (Utrecht school)	10	Aged 36 to 63 years old. Inclusion: All disease and treatment stages. Time since diagnosis: 4 months to 9 years	Four themes: (a) Living with losses; (b) Living with guilt feeling; (c) Living with fears and uncertainty; (d) Living with the need to know and to share that knowledge.
Elobaid et al. (2016), United Arab Emirates	Delayed presentation and health seeking behaviour	Semi-structured interviews (single). Thematic framework analysis	19	Aged 35 to 68 years old. Advanced stage of disease. Late stages or post treatment. Time since diagnosis: Less than 2 years, with symptoms occurring 3 to 24 months prior to diagnosis	Three main themes were: (a) symptom recognition and appraisal, (b) role of community and social network and (c) healthcare delivery system.
Hammoudeh et al. (2016), Palestine	Experiences and coping, and the impact of BC on families and social relationships.	Semi-structured interviews (single) and focus group discussions. Thematic analysis.	35	Aged from 25 to 71 years old. All stages of disease and treatment. Time since diagnosis: Less than 1 year (n=13), 1-2 years (n=10) and over 3 years (n=12)	(a) the transition from initial shock to the daily struggles with disruptions caused by illness, (b) the role of social support in helping women cope with the burden of disease, and the importance of (c) faith and reliance on God.
Jassim & Whitford, (2014), Bahrain	Experiences, beliefs, perceptions and attitudes relating to quality of life.	Semi-structured interviews (single). Constant comparative analysis.	12	Aged 39 to 68 years old. All stages of disease and treatment. Time since diagnosis: 1 to 8 years (mean of 2.6 years)	The themes were (a) meaning of cancer and quality of life, (b) spirituality and beliefs about causes of breast cancer, (c) coping mechanisms, (d) impact of illness and (e) change in relationships.
Kobeissi et al. (2014), Lebanon	Translation and validation of FACT-B into Arabic	Focus group discussions.	41	Aged 20 to 71 years old. All stages of disease and treatment. Time since diagnosis not reported.	The themes were (a) Physical well-being; (b) Social/family well-being; (c) Emotional well being; (d) Functional well-being; (e) Additional concerns

McEwan et al. (2014), Egypt	Experiences with, and interpretations of, diagnosis and treatment delays	Semi-structured interviews (single). Thematic content analysis (social ecological model)	15	Aged 29 to 60 years old. All stages of treatment. Staging of disease not reported. Time since diagnosis not reported	4 superordinate themes: (a) Intrapersonal Factors: (i) fears; (ii) Breast cancer awareness; (iii) Symptoms interpretation; (iv) Health literacy: Causation belief; (v) Modesty; (b) Interpersonal relationships; (i) Knowledge networks; (c) Institutional Factors; (d) Public Policy Factors (i) Low economic capacity, inefficiency of the public sector
Masmoudi et al., (2016); Tunisia, French	To describe the sexuality issues in two Tunisian women with breast cancer.	Not described	2	Aged 44 and 48 years old post mastectomy.	Two vignettes with five themes: (a) difficulties of communicating with the doctor; (b) erroneous beliefs; (c) reactive depression; (d) changing body image and (e) trouble communicating within the couple
Nizamli et al. (2011), Syria	Experiences regarding chemotherapy	Semi-structured interviews (single). Content analysis	17	Aged 30 to 45 years old. All stages of disease. Undergoing active chemotherapy (having had four to nine cycles). Time since diagnosis not reported	Four main themes: (a) psychological discomfort (negative emotion, body image, and depressive symptoms), (b) physical problems (acute consequences of chemo- therapy and general aspects of chemotherapy), (c) social dysfunction (social isolation and lack of marriage opportunities), and (d) failure in the family role (mother role and sexual relationship).
Obeidat & Lally (2013), Jordan	Experiences of information exchange following diagnosis of early stage BC.	Secondary data analysis of data from Obeidat et al. (2013). Content analysis.	28	Aged 29 to 70 years old. All stages of disease. Mastectomy or lumpectomy within the last six months. Time since diagnosis not reported	Three themes: (a) knowledge about breast cancer and its treatment, (b) communication of cancer diagnosis and treatment, and (c) educating on treatment side effects.

Obeidat et al. (2013), Jordan	Personal meanings of diagnosis and surgical treatment for early-stage BC	Semi-structured interviews. Heidegger interpretive phenomenological analysis.	28	Aged 29 to 70 years old. All stages of disease. Mastectomy or lumpectomy within the last six months. Time since diagnosis not reported	Four themes and 1 constitutive pattern (a) Fearing breast cancer; (b) Trusting as coping; (c) Surrendering to and suffering through treatment; (d) Embodied self as changed 1 constitutive pattern: Controlling Fear
Saati (2013), Saudi Arabia	Culture and experiences of diagnosis and treatment.	Semi-structured interviews (single) and focus groups. Grounded theory analysis.	60	Mean age was 46 years old. Range not given. Disease stage not reported. All stages of treatment. Time since diagnosis not reported	Five themes: (a) communication, (b) acceptance, (c) knowledge and understanding, (d) limitations imposed by culture and (e) positive dimensions of culture
Soliman et al., (2018); Morocco, English	Personal experiences and perspectives in respect to barriers to diagnosis and treatment of breast cancer.	Semi-structured interviews (single). Grounded theory approach	25	Age not reported. Two participants were stage II, and 23 were either stage III or IV.	Six sub-themes divided in to two major themes (a) Structural Barriers; (i) Treatment-Associated Costs, (ii) Burden of Transportation and Distance, (iii) Choice of Medical Arena, and (b) Sociocultural Barriers; (i) Identity and Femininity, (ii) Community Influence, (iii) Spirituality and Conception of Death

Note: BC, Breast cancer; QOL, Quality of Life

(1) Data refers to sample size before data relating to breast cancer was disaggregated

Appendix 4: Quantitative papers included in literature review

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Abasher (2009); Sudan, English	To find out if there is any decrease in sexual function as a result of BC treatment	Comparative observational study between breast cancer patients and a control group. Data from WSFQ	100	58% of women reported that their diagnosis had a negative impact on their sexual life, of these 60% stopped having sexual intercourse entirely. 9% stated they thought their husbands found them less attractive post mastectomy.	Better sexual function was associated with higher educational levels (p=0.002) and younger age (P = 0.030)
Abasher (2014); Sudan, English	Are educational materials effective in enhancing sexual health of breast cancer women?	Three arm experimental design study comparing educational material, psycho-social sessions and a control group (with randomisation). Data from WSFQ and HADS	89	Mean baseline HADS scores was 9.23 ± 4.79 SD and WSFQ scores was 50.77 ± 4.79 SD.	The provision of printed educational material improved HADS scores (p=0.000) and the WSFQ scores (p=0.000).
Abdel Aziz et al. (1986); Egypt, English	1. To determine the perception of BC patients of the nature and characteristics of support provided to them. 2. To determine the relationship between the level of social support and the psychological reactions for women undergoing mastectomy	Cross-sectional study. Data from Norbeck Social Support Questionnaire, Thomas Psychological Reaction Scale, and Woods and Earp Depression scale	40	22 of the 30 married participants considered their spouses as a source of support	Higher levels of social support were associated with lower levels of depression (p=0.01) Depression reduced post mastectomy (p=0.05)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Abou Kassm, et al. (2017); Lebanon, English	To determine the current and lifetime major depression prevalence rates in Lebanese breast cancer patients, as well as their current religiosity scores.	Cross-sectional study. Data from BDI, Unidentified religiosity questionnaire with 5 items and Mini-International Neuropsychiatric Interview	102	77.4% were highly and 21.5% moderately religious. 71.5% experienced an increase in their religiosity after the diagnosis. 30.3% were currently suffering from a major depressive episode	Being divorced and widowed was associated with higher rates of depression (p=0.003) No associations were found between religiosity score and current (p=0.123) or post diagnosis depression (p=0.055). No association was found between treatment at the Ministry of Health hospital and depression (p=0.015) There were no association between depression and educational attainment (p=0.37) and economic status (p=0.41)
Abu Farha et al., (2017); Palestine, English	To examine cancer-related post-treatment pain and its impact on HRQOL for women with breast cancer	Cross-sectional study. Data from Brief Pain Inventory (BPI) and the EuroQol five-dimensional instrument (EQ-5D)	170	BPI: Median pain severity score was 14.50 (interquartile range: 8.00–21.25) on a scale of 0 for no pain to 40 for worst pain. Median pain interference score was 17.00 (interquartile range: 9.00–30.00) on a scale of 0 (no interference) to 70 (worst). EQ-5D: Median score was 0.67 (interquartile range: 0.51–0.84) on a scale of 0 (worst status) to 1 (best status)	QoL was negatively associated with the presence of post-treatment pain, cancer recurrence or ongoing treatment (p<0.05)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Abu-Helalah et al. (2014); Jordan, English	1. To assess the quality of life and psychological well-being of women with BC. 2. To measure the proportion of patients with undiagnosed depression or anxiety and to identify the predictors of the quality of life and psychological well-being scores.	Cross-sectional study. Data from EORTC QLQ-C30, EORTC QLQ-BR23, and HADS	236	Mean Global Health score for the QLQ-C30 was 63.7± 20.2 SD. Social functioning scored high whereas emotional scoring was low. Mean HADS scores was 18 ± 9.0 SD. 53% scored abnormal (8% severe) on the anxiety scale and 45% (14% severe) on the depression scale. Br23: Lowest scores: body image (mean: 52.1 ± 36.8 SD), and 'future perspective' (mean=52.9 ± 38.5 SD) Worst symptom was 'upset by hair loss' mean: 69.8 ± 43.0 SD Other scores not reported.	Lower overall QOL score was associated with a positive family history of cancer (p=0.044). Higher overall QOL score was associated with lumpectomy as opposed to mastectomy (p=0.044) and post diagnosis counselling (p=0.02) Total HADS score and current social problems were predictors for lower overall QOL (r-squared= 0.209)
Ahmed et al. (2005); Sudan, English	To study the efficacy of different palliative procedures used for symptoms control, degree of patient satisfaction with treatment and quality of life.	Cross-sectional study. Data from Unidentified scale based on EORTC scale	90	50% of participants did not know their diagnosis. Sisters or daughters were the major source of support for 50% and spouses for 12%. Depression was diagnosed in 34%, anxiety in 26% and psychosis in 2.2% participants	Awareness of the diagnosis was associated with higher levels of mood disturbance (p<0.0007)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Ahmed et al. (2017); Saudi Arabia, English	To assess the QOL of Saudi women with breast cancer when compared with socio-demographic factors.	Cross-sectional study. Data from MOS Health Survey 36-Item Short Form (SF-36)	145		Regular exercise was a positive predictor of increased general health (P=0.01). Physical functioning was negatively associated with multiple tumours (p=0.001), aged over 60 years old (p=0.002), immunotherapy (p=0.001) and the presence of metastases (p=0.001). It was positively associated with university level education (p=0.001) Emotional well-being was negatively associated with multiple tumours (p=0.001), metastases (p=0.001) and fever (p= 0.003).
Ahmed et al., (2018); Saudi Arabia, English	To estimate the prevalence of anxiety, depression, and stress and their contributing factors among cancer survivors in Saudi Arabia.	Cross-sectional study. Data from the Depression Anxiety Stress Scale (DASS-21)	125 (with breast cancer)	49.6% of women had depression, 60.8% had anxiety and 47.2% had stress	

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Akel et al., (2017); Lebanon, English	To determine the prevalence and severity of anxiety and depression among women with breast cancer in Lebanon and assess their quality of life	Cross-sectional study. Data from HADS and FACT-B	150	The median total HADS score was 10.0 ± 8.0 SD. 41.3% were anxious and 24.7% depressed (scores ≥ 8) Overall QOL mean 108.72 ± 18.77 SD (possible range: 0-148) Physical 22.62 ± 4.65 Social/family 21.71 ± 4.79 Emotional 18.92 ± 4.08 Functional 21.49 ± 4.72 Breast specific 23.98 ± 6.15	Higher education (secondary or above) was associated with lower levels of depression and anxiety (p=0.001) Lower financial income, stage IV cancer and chemotherapy were associated with reduced QOL
Al-Bahri et al., (2019); Oman, English	To identify the roles of the women and family members in the treatment decision making process among Omani women with breast cancer	Cross-sectional study. Data from a modified Cancer Care Outcomes Research and Surveillance (CanCORS) questionnaire	79	21.5% of women reported little or no input from the family, 54.4% reported joint decision making and 24.1% reported families made decisions with little or no input from them.	Family controlled decision making was more common in advanced cancer stages (p=0.029) and when communication with the oncologist was mainly with a family member (p=0.036)
Al-Maskati et al.(2003); Bahrain, English	To establish the acceptability of the HADS and the utility of this scale in assessment of psychological status of cancer patients	Cross-sectional pilot study. Data from HADS	11	18% were depressed (HADS-D scores over 9) 18% were anxious (HADS-A scores over 9)	

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Al-Naggar et al. (2011); Yemen, English	To evaluate the QOL and affecting factors on it among BC patients	Cross-sectional study. Data from FACT-B	106		Overall QOL was negatively associated with being underweight (p=0.001) and lower family monthly income (p=0.001) Social wellbeing was positively associated with university level education (p=0.003) and negatively associated with time since diagnosis (p=0.008).
Al-Natour et al. (2017); Jordan, English	To investigate the relationship between spirituality and QOL of Jordanian women diagnosed with breast cancer.	Cross-sectional study. Data from FACIT-Sp	150	Mean total score for QOL was 79.86 ±18.07 SD. Women scored social/family well-being the highest (mean 23.21± 5.37SD) and psychological well-being the lowest (mean 18.57± 6.93SD)	There were positive correlations between spiritual well-being and all QOL domains (p=0.000). The strongest correlation was with functional well-being (r = 0.63 (df) = 148, p < 0.01, two-tailed)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Al-Sulaiman et al., (2018); Qater, English	To test the hypothesis that crisis counselling and/or psychoeducation confer more advantage to breast cancer patients than the standard of care alone in terms of improving their psychological well-being, quality of life and treatment compliance.	Longitudinal RCT with three arms crisis counselling, psychoeducation and normal standard of care. Three points of data collection using Depression, Anxiety and Stress Scale (DASS-21) and EORTC QLQ-C30	201	77% of all participants exhibited mild-to-moderate psychological distress on The DASS-21 Baseline EORTC QLQ C-30 scores for the control group: Mean global: 67.23 Physical: 84.48 Role: 64.93 Emotional: 60.32 Cognitive: 85.32 Social: 43.5	The control group experienced worsening quality of life and more psychological distress over time (p<0.05) Both intervention groups showed statistically significant less psychological distress post intervention (p<0.001) on the DASS-21, and better emotional functioning on the EORTC-QLQ C-30.
Alawadhi & Ohaeri (2009); Kuwait, English	1) to determine the QOL scores for women with BC 2) to compare QOL. 3) to assess the variables that predict the global health status/ QOL scale and the five functional scales of the QLQ – C30	Psychometric validation study. Data from EORTC QLQ-C30 and EORTC QLQ- BR-23	348	Mean total score for QOL was 45.3 ± 15.3 SD Physical: 52.6 ± 18.8 SD Role: 55.1± 21.4 SD Emotional: 60.3 ± 22.5 SD Cognitive: 59.9 ± 23.9 SD Social: 61.2 ± 22.7 BR-23: Body image 61.8 ± 1.4 SD Sexual functioning 70.2 ± 1.3 SD Sexual enjoyment 61.8 ± 1.6 SD Future perspective 59.7 ± 1.8 SD Worst symptoms was ‘upset by hair loss’ mean: 44.4 ± 1.6 SD	Increasing age was positively associated with functional wellbeing, sexual functioning and body image (p<0.02). It was associated with lower levels of systemic side effects, breast symptoms, arm symptoms, upset by hair loss (p<0.01). Financial difficulty was a negative predictor for overall QOL (P < 0.007) and social functioning (P < 0.001).

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Albabtain, (2018), Saudi Arabia	To identify the association between the use of Complementary and Alternative Medicine and QoL	Survey. Structure CAM questionnaire, EORTC QLQ-C30 and EORTC QLQ-BR-23	95	81.1% of study participants used CAM; spiritual therapy most frequent: 70.5% Mean total score for QOL was 73.16 ± 20.26 SD (CAM); 64.82 ± 32.79 SD (non CAM) Physical: 68.05 ± 21.72 SD (CAM); 63.33 ± 28.02 SD (non CAM) Role: 78.14 ± 29.28 SD (CAM); 62.96 ± 42.23 SD (non CAM) Emotional: 70.78 ± 29.54 SD; 67.14 ± 32.39 SD (non-CAM) Cognitive: 79.22 ± 24.05 SD (CAM); 83.33 ± 25.56 SD (non CAM) Social: 83.33 ± 26.35 SD (CAM); 72.22 ± 33.82 SD (non CAM) BR-23: Body image: 80.63 ± 23.40 SD (CAM); 66.67 ± 34.78 (non-CAM) Sexual Functioning: 19.26 ± 25.23 SD (CAM); 25.93 ± 31.43 SD (non-CAM) Sexual enjoyment: 21.33 ± 28.81 (CAM); 24.08 ± 33.94 (non-CAM) Future Perspective: 64.07 ± 38.53 (CAM); 55.55 ± 41.23 (non-CAM)	Difference between CAM user and non CAM users were statistically significant (P-value <0.005) for total EORTC QoL score, role functioning, and social functioning, and body image on the Br-23. The authors concluded that CAM use was associated with higher overall global QoL, better role and social functions and were more concerned about their body images as compared to non-CAM users.
Algamdi & Hanneman (2009); Saudi Arabia, English	To test the psychometric performance of the FACT-B in the Arabic speaking population in Saudi Arabia	Cross-sectional study. Data from the FACT-B and the Cancer Behaviour Inventory - Brief	167	Mean score 99.7 ± 21 SD (range 33 to 140)	

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Ali & Khalil (1991); Egypt, English	To identify stressors, level of stress, coping strategies, and coping effectiveness in female mastectomy patients	Cross-sectional study. Data from McNett's Coping Effectiveness Questionnaire	64	There were high levels of stress across the sample: mean level of stress of all stressors was 4.56 (range of 1-5) The most commonly identified stressors were hope for cure (39.2%), treatment effectiveness (23.4%), fear of the unknown (20.3%), pain (9.3%) and progression of disease (7.8%). Faith, compliance with medical regimen and seeking information and social support were all frequently cited as coping strategies. There was limited use of self-distraction as a strategy.	
Alkhyatt et al. (2012); Iraq, English	To examine whether the diagnosis and treatment of breast cancer produced PTSD	Cross-sectional study. Data from BSI, IES, SIE, THQ and Structured psychiatric interviews	100	With liberal criteria, the PTSD rate was 5% at any time post cancer diagnosis (up to 20 months) or post treatment (up to 1 year). The rate was 3% with more stringent criteria.	

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Almutairi et al. (2016); Saudi Arabia, English	To assess the quality of life of Saudi female breast cancer patients and determine the effect of the sociodemographic and clinical characteristics on the quality of life of those patients’	Cross-sectional study. Data from EORTC QLQ-C30 and EORTC QLQ-BR-23	145	Overall QOL mean score: 31.2 ± 20.5 SD Physical: 62.9 ± 24.6 SD Role: 67.6 ± 29.2 SD Emotional: 83.3 ± 22.7 SD Cognitive: 68.3 ± 27.3 SD Social: 65.0 ± 35.7 SD Among functional scales, emotional functioning scored the highest (83.25 [95% CI 79.53-86.98]). The most distressing symptom on the symptom scale was insomnia (mean 84.14 [95% CI 79.95-88.32]), followed by appetite loss (mean 80.92 [95% CI 76.51-85.33]) and dyspnoea (mean 80.00 [95% CI 75.51-84.49]). Poor functioning was found in sexual enjoyment (mean 22.52 [95% CI 17.97-27.08]) while future perspective scored the highest (mean 76.32 [95% CI 70.52-82.12]).	Advanced stage of BC was associated with lower global QOL and functional scores ($p<0.005$). The educational level and employment status affected the physical functioning of patients ($p<0.005$). Emotional functioning of patients was affected by employment status ($p=0.019$). Patients diagnosed earlier had a higher future perspective score compared to patients diagnosed later ($p<0.005$).
Aloulou et al. (2015); Morocco, French	Identification of factors which lead to patients consulting at a late stage of breast cancer	Cross-sectional study. Data from unidentified questionnaire exploring reasons for delay in diagnosis	130		A long delay was associated with lack of financial resources (40%), geographical distance (23%), prior consultations with traditional medicine (20%), inadequate initial healthcare (7%), diagnostic errors (6%) and fear (4%).

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Awad et al. (2008); United Arab Emirates, English	To assess the validity and reliability of the standard Arabic version of the general (QLQ-C30) and breast-specific (QLQBR23) questionnaires in an Arab breast cancer population.	Psychometric validation study. Data from EORTC QLQ-C30, EORTC QLQ-BR23 and HADS	87	Global QOL was 74.6 ± 18.0 SD Physical: 73.8 ± 22.6 SD Role: 82.5 ± 27.6 SD Cognitive: 74.0 ± 30.7 SD Emotional: 65.8 ± 32.8 SD Social: 85.1 ± 26.0 SD 26% had moderate or severe anxiety. 30% had moderate or severe depression. Br23: Future perspectives scored the lowest, body image the best, and the worst symptom was breast related.	Mastectomy was associated with lower levels of emotional and cognitive functioning compared with lumpectomy (p<0.01). Mastectomy patients also reported more side effects of treatment (nausea and vomiting symptoms) and arm symptoms (p<0.01). Lower levels of body image were significantly associated with higher levels of depression (p<0.001). Anxiety and depression was associated with lower functional scores and higher symptom burden (p<0.001).
Awadalla et al. (2007); Sudan, English	To compare the subjective QOL of women living in stable condition with breast, cervical and ovarian cancer and those of their family caregivers	Comparative observational study between breast, cervical and ovarian cancer patients and their carers. Data from WHOQOL-Bref	117	Physical health: 31.2 ± 3.4 SD (possible range: 7-35) Psychological health 25.9 ± 3.1 SD (possible range: 6-30) Social relations 12.3 ± 2.9 SD (possible range: 3-15) Environment 30.6 ± 5.1 SD (possible range 8-40) General QOL 8.4 ± 1.8 SD (possible range 2-10)	

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Awan et al. (2015); Saudi Arabia, English	To study the demographic and socioeconomic factors influencing the desire to utilize post-mastectomy breast reconstruction and to evaluate the barriers to post-mastectomy breast reconstruction	Cross-sectional study. Data from unidentified questionnaire including 10 question on the perceived barriers to breast reconstruction	91	43% felt that breast reconstruction was not important physically and psychologically. 63% did not feel they had sufficient information. 33% did not have sufficient family support. 28% felt their cancer was too advanced to consider reconstruction.	
Ba-Khubaira & Al-Kahiry (2012); Yemen, English	To determine the QOL after treatment of early stage breast cancer, and to compare those less than 50 years old with those over 50 years old.	Cross-sectional study. Data from FACT-B	58	Overall QOL mean 77.6 ± 12.1SD (possible range: 0-144) Physical 21.3 ± 3.2 Social/family 17.2 ± 6.3 Emotional 18.2 ± 2.1 Functional 7.8 ± 2.7 Breast specific 21.2 ± 5.4	Younger women experience worse QOL (p=0.006). Women over 50 are more worried about passing BC onto their family than those less than 50 (p=0.019)
Bani Mohammad, (2019); Jordan, English	To compare virtual reality and morphine against morphine for pain and anxiety	RCT. Data from visual analogue scale for pain and State Anxiety Inventory	80	Pain scales were 7.32 and 7.33 (out of 10) for both groups prior to intervention Anxiety was 64.98 and 63.30 (on a scale of 20 to 80 with 80 is worst).	Pain reduced in both groups (to 4.84 in control and to 0.33 in intervention) p<0.001 Anxiety reduced in both groups (to 50.13 in control and to 37.68 in intervention). p <0.00.1
Bener et al. (2017a); Qatar, English	To assess the psychometric properties of the Arabic version of the EORTC QLQ-C30 for breast cancer patients in Qatar.	Observational cohort study. Data from the EORTC QLQ-C30	678	Global QOL was 75.6 ± 22.71 SD Physical: 79.3 ± 17.9 SD Role: 65.2 ± 25.5 SD Cognitive: 86.2 ± 20.2 SD Emotional: 62.5 ± 27.5 SD Social: 51.3 ± 28.8 SD	Physical functioning was negatively associated with more advanced cancer (p=0.022)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Bener et al. (2017b); Qatar, English	To assess the relationship between socio-demographic variables and hopelessness, depression and social support of breast cancer patients	Observational cohort study. Data from BDI, Beck Hopelessness Scale (BHS) and the Multidimensional Scale of Perceived Social Support (MSPSS)	678	27.7% of patients had moderate depression and 19.5% had severe depression (mean score of the BDI was 25.1±7.7 SD)	Having consanguineous parents was associated with higher rates of depression (p=0.001).
Berhili et al. (2017); Morocco, English	To estimate the prevalence of psychological distress in Moroccan breast cancer patients, and to determine associated clinical and social demographic factors	Cross-sectional study. Data from DT and HADS	446	46.6% women were defined as having psychological distress. 26.9% women had HADS global scores greater than or equal to 15. HAD-A and HAD-D sub-scores were greater than or equal to 11 in 5.6% and 6.7% women, respectively.	Older patients had lower HADS and DT scores (p=0.001) Higher HADS and DT scores were associated with metastases (p<0,001), current chemotherapy (p<0,001), lower levels of social and family support (p<0,001), and 'lived difficult situations' (p<0,001)
Berhili et al., (2019); Morocco, English	To determine the factors associated with psychological distress in a sample of Moroccan breast cancer patients (<45 yrs) in the postoperative setting	Cross-sectional study. Data from HADS	122	33.6% had a HADS global score > 15 HAD-A and HAD-D sub-scores were greater than or equal to 11 in 8.2% and 6.6% women, respectively	Higher HADS scores were associated with difficult emotional and financial situations, a lack of family support and radical as opposed to conservative surgery (p<0.005)

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Daher et al., (2017); Iraq, English	To assess the impact of BC on QOL among sample of Iraqi patients.	Cross-sectional study. Data from Breast cancer impact scale (BCIS)	247	13.6% of women described BC having a high negative impact on them and 25.2% reported having a poor quality of life The following were most commonly negatively impacts: Happiness 74.49% of patients Ability to focus on daily tasks 63.97% Affects sleep 57.89% Least common were: Appearance, physical shape 14.17% Family relationships (husband, children) 20.65% Feelings of being stigmatised 23.08%	
Daldoul et al. (2018); Tunisia, English	To evaluate the QoL of women with breast cancer and its correlation with anxiety, depression and socio demographic, anatomo-clinical and therapeutic parameters	Cross-sectional study. Data from HADS and SF-36	70	SF-36 (0 – worst, 100 – best) Mean total score: 53.95 ± 22.66 SD. Lowest mean score was for physical role functioning: 25.71 ± 41.91 SD and highest mean score was for mental health 67.64 ± 34.96 SD HADS: 12.9% had depression (mean score was 6.24 ± 3.88 SD) and 21.4% had anxiety (mean score was 6.91 ± 4.72 SD)	QOL was significantly associated with chemotherapy and the presence of depression or anxiety ($p<0.05$) There was no significant association between QOL and surgery type or age.

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Denewar et al. (2011); Egypt, English	To investigate the relations between social support and hope, and to determine whether they vary according to socio-demographic variables.	Cross-sectional study. Data from the Hope Measurement Questionnaire and Social Support Measurement Questionnaire	301		Patients with higher levels of social support expressed higher levels of hope (p=0.01). There were no correlations between age, marital status and educational levels; and the participants' levels of hope and social support.
Denewer & Farouk (2007); Egypt, English	To evaluate the application of nipple-sparing mastectomy with immediate breast reconstruction and its effect of quality of life.	Descriptive clinical case-study. Data from 5 yes/no questions of their post operation result	41	95.1% were happy with the nipple-areolar complex. 7.3% regretted having the operation done. 68.2% felt the sensation was the same as the other side. 87.8% felt that symmetry was achieved.	
Denewer et al. (2012); Egypt, English	To evaluate quality of life, body image, and patient satisfaction comparing different surgical procedures	Comparative observational study between patients undergoing traditional or sparing mastectomy (non-randomised). Data from BITS and BSS	200	All groups showed moderate distress of body image according to the BITS post operation. Scores, group 1: mean 30.14 ± 8.92 SD; group 2: mean 30.63 ± 9.83 SD (possible range: 13–65) BSS scores group 1: 31.94 ± 6.54 SD, group 2: 29.08 ± 7.08 (possible range: 11–55)	
El Fakir et al. (2014); Morocco, English	To translate and adapt the the EORTC QLQ-BR23 from the English to the Moroccan Arabic language	Psychometric validation study. Data from EORTC QLQ-BR23	105	Body image and breast symptoms scored the highest, most distressing. Hair loss, future perspectives, and sexual enjoyment were the least distressing.	

Paper	Research Aims	Study design	Size	Summary of findings	Associations
El Fakir et al., (2016); Morocco, English	To describe self- reported HRQOL in patients with breast cancer and to investigate its associations with sociodemographic and clinical variables.	Cross-sectional study. Data from EORTC QLQ-C30 and EORTC QLQ-BR23	1463	Global QOL was 68.5 ± 18.5 SD Physical: 78.1 ± 21.5 SD Role: 74.1 ± 28.6 SD Cognitive: 83.2 ± 23.2 SD Emotional: 62.5 ± 28.5 SD Social: 86.2 ± 22.7 SD	Younger women experienced better physical well-being but worse body image and sexual enjoyment than older women
El-Hadidy et al. (2012); Egypt, English	To assess psychiatric morbidity in recently diagnosed breast cancer patients and their partners, in comparison to healthy couples from the same population.	Comparative observational study between patients, their partners and a control group. Data from BDI, HAM-A, Rosenberg Self-Esteem Scale and Structured Clinical Interview for DSM-IV	54	38.8% had a major depressive disorder. 29.6%had a generalized anxiety disorder. 9.2% had a panic disorder.	Duration of marital relation was positively associated with BDI (r=0.576), HAM-A (r=0.404) and Rosenburg scale (r=-0.410) with p<0.01 (two-tailed). The husbands' scores on HAM-A, BDI and Rosenburg scale were directly correlated across all scales scores on of the other partner (all correlations over r=0.566 or under r=-0.536) with p<0.01 (two-tailed). Depression and anxiety scores were higher among educated patients than among less-educated patients (p< 0.05). There were no correlations between tumour size, stage, and age and scores on BDI, HAM-A or Rosenburg scale.

Paper	Research Aims	Study design	Size	Summary of findings	Associations
El-Sayed (2011); Egypt, English	To evaluate the effect of counselling post mastectomy for women undergoing adjuvant chemotherapy on their QOL.	Quasi experimental design incorporating assessment, planning, implementation, and evaluation stages. No division into groups. Data from EORTC CLQ-C30 (modified), EORTC QLQ-BR23 (modified) and unidentified questionnaire consisting of 35 true\false questions	42		Counselling was associated with reduction of total physical impairment symptoms (p= 0.000), improved global health status (p= 0.000), and improved total functional impairment and body symptoms on BR23 (p= 0.000).
El-Sharkawi et al. (1997); Egypt, English	To determine the effects of the different modalities of treatment on the QOL of women with early breast cancer	Prospective comparative observational study between different treatment modalities (non-randomised). Data from unidentified questionnaire.	272	60% of all participants had severe depression and 86.8% had severe anxiety. 67.6% experienced severe body image distress, 86.8% severe sexual dysfunction, 58.8% severe loneliness, and 52.9% felt desperate about the future.	Higher levels of overall QOL was associated with increasing age (p<0.01). Triple therapy (mastectomy, chemotherapy and radiotherapy) was associated with the worst scores for all QOL domains (p=0.000).
El-Shinawi et al. (2013); Egypt, English	To assess breast cancer awareness among recently diagnosed breast cancer patients.	Cross-sectional study. Data from unidentified questionnaire. Possible responses were ‘yes’, ‘no’ and ‘don’t know’.	45	68.9% of women agreed that a good quality of life could be maintained after treatment of cancer. 75% agreed that breast cancer is a potentially curable disease. 60% agreed that medical care could be provided regardless of age at initial presentation. 68.9% of patients were previously unaware of breast reconstruction options.	56.82 % thought that family history is a risk factor. 15.56 % thought that stress was a risk factor

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Ellouz et al., (2019); Tunisia, French	To evaluate the impact of breast cancer on the sexuality of Tunisian women	Cross-sectional study Data from HADS, BIS and FSFI	100	HADS: depression was present in 37% (mean 8.26 ± 8.63 SD); anxiety in 48% (mean 10.1 ± 8 SD). BIS: alteration in body image in 45% (mean score 11.5 ± 11.2 SD) FSFI: sexual dysfunction was 75% (mean score 15.1 ± 11.7 SD). Pain was most problematic.	Sexual dysfunction is associated with negative reactions from the husband, relationship problems, poor body image, depression and anxiety (all $p<0.005$).
Elmoez and Ebraheim, (2016); Egypt, English	To assess predictors of depression and anxiety in a sample of Egyptian women with breast cancer >1 year post treatment	A case control study comparing women with breast cancer with a control sample. Data from BDI and HAM-A	37 women with BC	BDI: mean score 19.14 ± 9.93 SD HAM-A: mean score 21.35 ± 11.26	There was a statistically significant increase in anxiety for women with BC compared with the control ($p=0.038$). There was no difference in depression in the two groups.
Elsheshtawy et al. (2014); Egypt, English	To determine the different coping strategies employed by female patients diagnosed as having breast cancer and to estimate the presence of anxiety and depression among them.	Cross-sectional study. Data from Brief COPE scale and HADS	56	The most commonly used coping strategies were religion (mean 4.55 ± 1.6 SD), acceptance (mean 4.14 ± 1.3 SD), and emotional support (mean 4.04 ± 1.4 SD) followed by self distraction (mean 3.62 ± 1.3 SD). Self-blame (mean 2.5 ± 1 SD) was infrequently seen. HADS results showed that about 70% of patients had mild to moderate depression, none had severe depression. 73% had mild to moderate anxiety, with 2% having severe anxiety	Presence of metastases was found to be positively correlated with venting ($p< 0.05$) and denial ($p<0.01$).

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Elsheshtawy et al. (2015); Egypt, English	To study the psychosocial, clinical or biological factors which predict the development of depression and anxiety in female patients diagnosed with breast cancer.	Cross-sectional study. Data from HADS, MOS Social support scale, Mini International Neuropsychiatry Interview, and Rotter's Internal and External Locus of control, Social Readjustment rating scale	104	43.3% of women had adjustment disorders. 28.8% had major depressive disorders. 28.8% had mild anxiety symptoms. 23.1% had generalized anxiety disorders. 1.9% had panic disorder.	Locus of control was correlated (r= 0.350 at p<0.01) with depression while social interaction was negatively correlated (r=-0.215 at p<0.01). Predictors for depression were external locus of control, high educational attainment, lymph node (LN) status and tumour grading (beta= 0.346, 0.498, 0.256, 0.186 respectively), while predictors for anxiety were high educational attainment, tumour size and HER2 receptors (beta=0.233, 0.271, -0.260 respectively)
Enien et al., (2018); Egypt, English	To study the QOL of breast cancer patients and its association with the type of surgery	Cross-sectional study. Data from EORTC QLQ-C30 and EORTC QLQ-BR23	172	QLQ-C30 Global: 28.38 ± 11.7 Physical: 83.37±12.54 Role: 62.45 ± 21.16 Emotional: 59.61 ± 24.96 Cognitive: 65.56 ± 22.05 Social: 87.91 ± 17.92 QLQ- BR23 Body image: 74.51 ± 13.21 Sexual functioning: 74.45 ± 14.89 Sexual enjoyment: 32.23 ± 19.53 Future perspective: 41.75 ± 20.088	Increasing age was associated with better global QOL.

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Ermiah et al. (2012); Libya, English	To learn more about the extent and reasons behind diagnosis delay of breast cancer	Cross-sectional study. Data from structured interviews	200	Reasons for delays included: 27% of women did not consider their symptoms serious, 13.0% were delayed due to initially seeking alternative therapy. Fear (10%) and shame (4.5%) also delayed diagnosis. 15.5% of women were inappropriately reassured at the first medical visit that the lump was benign.	
Fido et al. (1992); Kuwait, English	To explore the nature of affective reactions in patients with BC, particularly in a clinical setting where patients do not share management decisions.	Comparative observational study between breast cancer patients and a control group. Data from Clinical Interviews and GHQ-28	40	30% had a depressive-type reaction and 57.5% had generalised anxiety reactions	A higher level of education was associated with higher levels of depressive type reactions ($p<0.05$) and higher levels of overall QOL ($p<0.05$).

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Huijer & Abboud (2012); Lebanon, English	To evaluate the QOL, symptom prevalence and management, functional ability, and quality of care provided to Lebanese women with BC at a tertiary healthcare facility.	Cross-sectional study. Data from Barthel Index, EORTC-QLQ C-30, MSAS and NEST	89	EORTC-QLQ C-30 mean 59.64 ± 29.09 SD. Physical 79.10 ± 21.08 SD; Role functioning: 73.41 ± 30.43 SD; Emotional functioning: 65.91 ± 28.46 SD; Cognitive functioning: 84.45 ± 22.16 SD; Social functioning 60.29 ± 28.76 SD. The most common symptoms were feeling nervous (66.3%), feeling sad (60.7%), lack of energy (59.6%), pain (55.2%), and dry mouth (44.9%).	Paying less than $450 a month on healthcare was associated with better physical functioning ($p < 0.00$), role functioning ($p < 0.00$), emotional functioning ($p=0.04$), and social functioning ($p=0.01$). Time since diagnosis was associated with lower physical functioning ($p=0.03$) and role functioning ($p=0.03$), and more financial difficulties ($p=0.01$). The presence of metastases was negatively associated with physical functioning ($p=0.05$) and role functioning ($p=0.05$).

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Jassim & Whitford (2013); Bahrain, English	To describe the quality of life of Bahraini women with breast cancer and to identify factors that may facilitate improvements in healthcare for breast cancer survivors in Bahrain.	Cross-sectional study. Data from EORTC QLQ-C30 and EORTC QLQ-BR23	239	Participants had a mean score for global health of 63.9 (95% CI 61.21-66.66). Among functional scales, social functioning scored the highest (Mean 77.5 [95% CI 73.65-81.38]) whereas emotional functioning scored the lowest (63.4 [95% CI 59.12-67.71]). The most distressing symptom on the symptom scales was fatigability (Mean 35.2 [95% CI 31.38-39.18]). EORTC QLQ-BR23 results showed that sexual functioning scored the lowest (Mean 25.9 [95% CI 70.23-77.90]). On the symptom scale, upset due to hair loss scored the highest (Mean 46.3 [95% CI 37.82-54.84]).	
Kobeissi et al. (2014); Lebanon, English	To translate, adapt and face-validate FACT-B into formal Arabic in the Lebanese context	Face validity study (translation process). Data from FACT-B	41	Overall QOL: mean 57.6 ± 15.7 SD (possible range 0-148); Physical wellbeing: mean 8.7 ± 4.5 SD (0-28); Social wellbeing: 9.3 ± 4.7 SD (0-28); Emotional wellbeing: 7.2±4.5 (0-24); Functional welling-being: 12 ± 4.6 SD (0-28) and Additional concerns: 23.3 ± 6.2 SD (0-40)	No associations reached statistical significance.

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Lazenby & Khatib (2012); Jordan, English	To investigate (1) whether spiritual well-being is associated with different aspects of Health related QOL and (2) whether participants' age, sex, marital status, and site and stage of disease are related to spiritual well-being among Arab Muslims in treatment for cancer.	Cross-sectional study. Data from FACIT-Sp and FACT-G	59	Total FACIT-Sp score 32.9 ± 6.6 SD (possible range 0-48); Peace score 9.1 ± 2.7 SD (0-16); Meaning 9.8 ± 2.7 SD (0-16); Faith 13.8 ± 6.5 SD (0-16)	Social welling (R= 0.494) and functioning well-being (R=0.633) were positively correlated with the FACIT-Sp in BC patients (at p<0.000).
Leila et al. (2016); Tunisia, English	To evaluate the changes in sexual life after treatment of breast cancer in Tunisian women and to identify the influence of demographic and clinical factors on sexuality.	Cross-sectional study. Data from EORTC QLQ-BR23 and HADS	50	Body image score mean: 47.6 ± 26.4 SD Sexual functioning score mean: 45.3 ± 22.1 SD Sexual satisfaction score mean: 43.9 ± 25.1 SD 80.9% reported diminished sense of sexual attractiveness. Women reported decreased frequency of sexual intercourse (53.2% of those sexually active). 38.3% also reported their partners had sexual problems such as decreased libido or erectile dysfunction. 56.3 % reported a strengthening of their spousal relationship whereas 21.8% reported either a deterioration or separation. 42% of women had anxiety and 44% had depression.	Negative changes in body image were associated with increased levels of depression and anxiety. They were not associated with sexual functioning. Sexual satisfaction scores were negatively associated with post menopausal status (p=0.018) and the partner having a sexual problem (p=0.014) There were associations between anxiety and lower body image scores (p=0.002) and sexual satisfaction (p=0.0003). Depression was association with lower body image score (p=0.0002)

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Masmoudi et al. (2009); Tunisia, English	To assess the feasibility of QOL assessment in a cohort of Tunisian cancer patients	Feasibility study, incorporating data from a cross-sectional study. Data from EORTC QLQ-C30 taken prior to starting adjuvant chemotherapy and during the 3rd cycle of chemotherapy.	23	Baseline mean scores (SD or CI not reported): overall QOL: 72.5; Physical functioning: 82.3; Role functioning: 63.7; Emotional functioning: 69.5; Cognitive functioning: 85.5; Social functioning: 89.1	There was a deterioration in physical (P = 0.004), cognitive (P = 0.007) and social functioning (P = 0.012) between the pre-treatment and on-treatment assessments.
Melam et al. (2016); Saudi Arabia, English	To evaluate the effect of adding an exercise component and a home program to Complete Decongestive Therapy (CDT) on Health related quality of life in post- mastectomy lymphoedema patients.	Two arm experimental design study comparing two CDT with conventional lymphoedema therapy. Limited evidence of randomisation. Data from EORTC QLQ C30, EORTC QLQ BR23 and Visual Analogue Scale for pain	60	Baseline pain mean scores were 6.87 ± 0.94 SD (95% CI 6.52–7.22). Baseline C-30 global scores : 39.63 ± 4.71 SD (95% CI 37.81–41.39); Functional scale 79.93 ± 1.41 (95% CI 79.41–80.46); Symptoms scale 40.93 ± 3.26 (95% CI 39.72–42.15) Baseline BR23 scores: Functional scale 32.20 ± 2.11 (95% CI 31.41–32.99); Symptoms scale 58.67 ± 2.34 (95% CI 57.79–59.54)	CDT and conventional therapy was associated with improvements in overall QOL scores and reduced pain scores over time ($p < 0.05$). Changes in CDT were larger ($p<0.01$).

El Missiry et al. (2011); Egypt, English	To assess psychiatric morbidity, pattern of coping and degree of social support in a sample of Egyptian women with early and recurrent breast cancer	Cross-sectional study. Data from BDI, Dealing with Illness Coping Inventory, MOS Social Support Survey, MTAS, and Structured Clinical Interview for DSM Axis-I	100	31% of all women had moderate, and 6% had severe depression. 47% had moderate, and 3% had severe anxiety.	The most frequently used coping methods were active cognitive and behavioural methods, and were equally used in both group (p=0.11). 'Active reliance on other' was the most used specific coping strategy across both groups. The recurrent group preferentially used Avoidance coping (p=0.016), Active Positive Involvement (p=0.04) and Passive Resignation (p=0.005) strategies as compared to the early BC group. DSM-IV psychiatric interviews: early BC was associated with higher levels of anxiety and recurrent BC was associated with higher levels of depression (p=0.015) BDI: Recurrence was associated with higher levels of depression (p=0.019). MTAS: There was no statistically significant association with anxiety (p=0.425)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Mortada et al., (2018); Egypt, English	to measure the QOL of BC Egyptian females then to compare scores according to different treatments	Cross-sectional study. Data from EORTC QLQ-C30 and EORTC QLQ-BR23	142	Baseline C-30: Global score: 35.44 ± 8.4 Physical: 54.46 ± 14.9 Role 68.30 ± 20.3 Emotional 29.22 ± 8.1 Cognitive 64.31 ± 19.9 Social 46.71 ± 14.4 QLQ-BC23: Body image: 40.61 ± 7.5 Sexual functioning: 78.87 ± 11.6 Sexual enjoyment: 81.22 ± 16.6 Future perspectives: 19.71 ± 4.9	Participants with hormone therapy had the highest global QOL (p = 0.008) Global QOL was negatively associated with the presence of chronic disease, stage of cancer and chemotherapy
Mostafa et al. (2010); Egypt, English	1. Assessment of quality of life of female breast cancer patients 2. Evaluation of the physical, emotional and social status of female breast cancer patients 3. Evaluation of the relation between quality of life and different variables related to breast cancer 4.Trial to improve the QOL of patients and their families through multi-disciplinary interventions e.g. counselling, social and medical support	An experimental design study with pre and post intervention measurements of QOL. Intervention was provided to those with initial low levels of QOL. No randomisation. Data from EORTC QLQ-C30 and EORTC QLQ-BR23	180	38.3% had overall QOL scores 0-40. 52.8% had overall QOL scores over 65. Mean overall QOL scores not reported. Baseline C-30 results: Physical score: mean 38.8 ± 25.8 SD; Role 23.8 ± 27.9 SD; Emotional 20.2 ± 31.1 SD; Cognitive 37.7 ± 24.7 SD; Social 28.2 ± 37 SD.	Intervention was associated with improvements in physical, role, emotional, cognitive and social functioning (p <0.0001). Women undergoing chemotherapy had worse physical functioning compared to other treatment modalities (p=0.02). More advanced BC was associated with worse QOL score (p=0.0001)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Naja et al. (2015); Lebanon, English	To investigate CAM use among breast cancer patients in Lebanon and whether its use was associated with QOL	Cross-sectional study. Data from FACT-B and an unidentified questionnaire covering CAM	180	40.6 % of participants used CAM (95 % CI: 35-48 %) 72.6% of CAM users did not disclose this to their doctors The most commonly used CAM was 'special food', followed by 'herbal teas', 'diet supplements', 'spiritual healing', and 'folk medicine'. Spiritual healing was in the form of religion-specific practices such as saying prayers, lighting candles, pledging specific vows, consuming foods deemed holy such as 'Zamzam water' (a type of holy water for Muslims, brought from Mecca), and fasting.	There was no statistically significant association between CAM use and QOL
Nejmi et al. (2010); Morocco, English	To create and validate an Arabic version of the M. D. Anderson Symptom Inventory	Psychometric validation study. Data from MDASI and ECOG PS	32	Mean (SD) symptom severity: 4.53 ± 1.60 SD Mean symptom interference 5.87 ± 2.52 SD Interference with walking, activity, and work scored high at 7.78 ± 3.48 SD Interference with relationships with other people, enjoyment of life, and mood had a mean score of 3.96 ± 1.90 SD	

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Obeidat & Khrais (2014); Jordan, English	To determine Jordanian women's attitudes toward disclosure of breast cancer information and their information need	Cross-sectional study. Data from INQ	156	92 % of patients wanted to know whether the diagnosis was breast cancer 78 % wanted to know about the stage of the disease.	Women treated at the public hospital were more likely to have lower levels of education ($p<0.05$) Older age was associated with a preference of not knowing the diagnosis ($p < 0.05$). Higher levels of education was associated with a preference for knowing the diagnosis ($p<0.05$).
Rostom et al. (2012); Egypt, English	To evaluate the efficacy of scalp cooling in prevention or reduction of anthracycline induced hair loss and its psychological impact in female breast cancer patients.	Randomised controlled trial: scalp cooling versus no cooling. Data from EORTC QLQ-C30 and EORTC QLQ-BR23	120	Mean scores not reported. Overall QOL (not defined): 68.3% of all women had moderate disturbance and 12.5% severe. Physical: 33.3 % had moderate disturbance and 0% severe. Role: 40 % had moderate disturbance and 50.8 % severe. Cognitive: 14.2 % had moderate disturbance and 0% severe Social: 32.5 % had moderate Disturbance and 22.5% severe	Scalp cooling was associated with less hair loss ($p=0.007$), improved emotional functioning ($p=0.0001$) and body image ($p=0.00001$)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Sbitti et al. (2011); Morocco, English	To evaluate the body image scale, and the impact of breast cancer therapy on women's sexuality from Morocco.	Cross-sectional study. Data from BIS and FSFI.	120	BIS overall score not reported. Women rated the following as 'very much': self consciousness (62.5%), dissatisfied with appearance (66%), Difficult to see self naked (66.5%) and dissatisfied with body (66.5%). 81.5% of women reported no change to their femininity FSFI score: 17.7 ± 12 SD (possible range 2-36). The most frequent sexual dysfunctions were dyspareunia (65%) followed by lubrication difficulties (54%) and the absence (48%) or reduction (64%) of sexual desire.	
Shoma et al. (2009); Egypt, English	To examine the relationship between body image and two surgical options in Egyptian postmenopausal breast cancer patients	A randomised controlled trial : conservative breast surgery versus mastectomy. Data from BITS, BSS, IES and SDS	100		There was no statistical change between pre and post operation levels of body image distress associated with radical mastectomy. BCT was associated with lower levels of cognitive distress ($p=0.041$), affective distress ($p=0.020$) and behavioural distress ($p=0.05$)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Shouman et al. (2016); Egypt, English	To measure Health Related QOL among women with early stage BC under curative treatment; and identify factors affecting their quality QOL	Cross-sectional study. Data from FACT-B, FACT-G and unidentified questionnaire	64		Higher QOL was associated with having children (p<0.05), sufficient family income (p<0.05), older women p<0.01), and higher educational attainment p<0.01) Lower QOL was associated with difficulties in obtaining medication (p<0.01)
Soltan et al. (2012); Egypt, English	To study the clinical variables and life stresses associated with the coping patterns used by Egyptian female patients with breast cancer.	Cross-sectional study. Data from BDI, Dealing with Illness Coping Inventory, MOS Social Readjustment Rating Questionnaire, MTAS and Structured Clinical Interview for DSM-IV	100		Higher levels of depressions were associated with avoidance coping method (p=0.03) and less affectionate social support (p=0.05). Higher levels of anxiety were associated with passive resignation (P = 0.01) Lower levels of anxiety were associated with higher levels of total support (p=0.02) Higher levels of life stresses were associated with more active coping strategies (0.001)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Stapleton et al. (2011); Egypt, English	To identify patient-mediated factors associated with initial diagnosis of late-stage breast cancer in Egypt.	Cross-sectional study. Data from unidentified questionnaire	343		Having no pain was associated with diagnosis at a later stage (p=0.018) Women presenting at an early stage were more likely to be sure about breast cancer not being contagious (p=0.0001). Women who sought a second opinion at the study cancer centres were more likely to present at early stages (p=0.035).
Thabet et al. (2007); Egypt, English	1. Assess the nature and scope of depressive phenomena, and physical symptom distress in women after breast cancer diagnosis. 2. Determine the relationship between depressive symptoms and physical symptom distress among breast cancer women. 3. Determine the relation of depression as well as physical symptoms distress to patient's quality of life	Cross-sectional study. Data from BDI and van Holten-Verzantvoort Symptom Distress Scale (modified)	50	28% had moderate depression, 12% severe 76% of women had moderate or severe fatigue and 52% had moderate or severe mobility impairment. 46% of women classed their symptoms as severe	There was a strong correlation between symptom distress and depression (p=0.001). Quality of life was negatively associated with surgery and chemotherapy in comparison to surgery and radiotherapy (p=<0.001)

Paper	Research Aims	Study design	Size	Summary of findings	Associations
Traore et al., (2018); Morocco, English	To evaluate the evolution of quality of life of Moroccan patient with breast cancer during the first year of follow-up.	Longitudinal cross-sectional study. Data collected at month 1 and 12 using EORTC QLQ-C30 and EORTC QLQ-BR23	1463	Month 1 C-30: Global score: 66.67 ± 17.76 Physical: 80.88 ± 19.31 Role 75.65 ± 27.58 Emotional 63.01 ± 28.59 Cognitive 84.83 ± 22.77 Social 87.85 ± 21.76 Month 12 C-30: Global score: 76.02 ± 17.74 Physical: 84.69 ± 18.64 Role 83.69 ± 23.28 Emotional 73.06 ± 25.10 Cognitive 88.36 ± 20.47 Social 88.53 ± 19.40 Month 1 QLQ-BC23: Body image: 81.88 ± 23.32 Sexual functioning: 76.69 ± 23.68 Sexual enjoyment: 55.60 ± 29.64 Future perspectives: 39.78 ± 37.23 Month 12 QLQ-BC23: Body image: 85.52 ± 20.50 Sexual functioning: 69.84 ± 22.19 Sexual enjoyment: 53.14 ± 30.30 Future perspectives: 46.48 ± 38.13	There were statistically significant improvements in QOL over the 12 months as measured by the EORTC QLQ-C30 ($p<0.001$), expect for the improvement in social functioning ($p=0.473$). The EORTC QLQ-BR23 data showed a statistically significant improvement in body image and future perspective ($p<0.001$) but a deterioration in sexual function and enjoyment ($p<0.001$).

Notes: BC, Breast Cancer; BDI, Beck Depression Inventory; BIS, Body Image Scale; BITS, Breast Impact of Treatment Scale; BSI, Brief Symptom Inventory; BSS, Body Satisfaction Scale; CAM, Complementary and Alternative Medicine; CI, Confidence Intervals; DSM, Diagnostic and Statistical Manual of Mental Disorders; DT, Distress Thermometer; ECOG PS, Eastern Cooperative Oncology Group Performance Status; EORTC QLQ C-30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Cancer Specific; EORTC QLQ Br23, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Breast Cancer Specific; FACT-B, Functional Assessment in Cancer Therapy–Breast; FACT-G, Functional Assessment in Cancer Therapy–General; FACIT-Sp, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being; FSFI, Female Sexual Function Index; GHQ, General Health Questionnaire; HAM-A, Hamilton Anxiety Scale; HADS, Hospital anxiety and depression scale; IES, Impact of Event Scale; INQ, Information Needs Questionnaire; MSAS, Memorial Symptom Assessment Scale; MTAS, Taylor Manifest Anxiety Scale; MOS, Medical Outcome Study; NEST, Needs at End of life Screening Tool; PTSD, Post Traumatic Stress Disorder; QOL, Quality of life; SD, Standard Deviation; SIE, Stressful Illness Experiences; SDS, Situational Discomfort Scale; THQ, Trauma History Questionnaire; WHOQOL, World Health Organisation Quality of Life; WSFQ, Watts Sexual Function Questionnaire

Appendix 5: Domains of experience covered by the quantitative papers

Experiential Domain / Author	Global health	Social	Psychological	Physical	Role function	Cognitive	Spiritual	Sexual	Body Image	Spousal relation	Financial
Abasher (2014)			+					+			
Abasher (2009)								+	+	+	
Abdel Aziz et al. (1986)		+	+							+	
Abou Kassm, et al. (2017)			+				+				
Abu Farha et al., (2017)	+	+	+	+	+						
Abu-Helalah et al. (2014)	+	+	+	+	+	+		+	+		+
Ahmed et al. (2018)			+								
Ahmed et al. (2017)	+	+	+	+	+	+		+	+		+
Ahmed et al. (2005)	+	+	+	+	+						
Akel et al., (2017)	+	+	+	+	+			+	+		
Al Maskati et al.(2003)			+								
Al Naggar et al. (2011)	+	+	+	+	+			+	+		
Al Natour et al. (2017)	+	+	+	+	+		+				
Al-Bahri et al., (2019);	+	+	+	+	+	+	+			+	+
Al-Sulaiman et al., (2018)	+	+	+	+	+	+	+				+
Alawadhi & Ohaeri (2009)	+	+	+	+	+	+	+	+	+		+
Albabtain, (2018)	+	+	+	+	+	+	+	+	+		+
Algamdi & Hanneman (2009)	+	+	+	+	+	+		+	+		
Ali & Khalil (1991)			+	+			+				
Alkhyatt et al. (2012)			+								
Almutairi et al. (2016)	+	+	+	+	+	+	+	+	+		+
Aloulou et al. (2015)			+								+
Awad et al. (2008)	+	+	+	+	+	+		+	+	+	+
Awadalla et al. (2007)	+	+	+	+			+				
Awan et al. (2015)			+						+		
Ba Khubaira & Al Kahiry (2012)	+	+	+	+	+			+	+		
Bani Mohammad, (2019)			+	+							
Bener et al. (2017a)	+	+	+	+	+	+	+				+
Bener et al. (2017b)	+	+	+		+						
Berhili et al. (2019)			+								
Berhili et al. (2017)		+	+								+
Daher et al., (2017)	+	+	+		+				+	+	

Experiential Domain Author	Global health	Social	Psychological	Physical	Role function	Cognitive	Spiritual	Sexual	Body Image	Spousal relation	Financial
Daldoul et al. (2018)	+	+	+	+	+	+	+				+
Denewer et al. (2012)			+	+					+		
Denewar et al. (2011)		+	+	+	+		+		+		+
Denewer & Farouk (2007)				+					+		
El Fakir et al., (2016)	+	+	+	+	+	+	+	+	+		+
El Fakir et al. (2014)	+	+	+	+	+	+		+	+		+
El Hadidy et al. (2012)			+						+	+	
El Missiry et al. (2011)		+	+								
El Sayed et al. (2011)	+	+	+	+	+	+		+	+		+
El Sharkawi et al. (1997)	+	+	+	+	+			+	+		
El Shinawi et al. (2013)	+			+							
Ellouz et al., (2019)			+					+	+		
Elmoez and Ebraheim, (2016)			+								
Elsheshtawy et al. (2015)		+	+				+				
Elsheshtawy et al. (2014)		+	+								
Enien et al., (2018)	+	+	+	+	+	+	+	+	+		+
Ermiah et al. (2012)			+								
Fido et al. (1992)			+								
Huijer & Abboud (2012)	+	+	+	+	+	+	+				+
Jassim & Whitford (2013)	+	+	+	+	+	+	+	+	+		+
Kobeissi et al. (2014)	+	+	+	+	+			+	+		
Lazenby & Khatib (2012)	+	+	+	+	+		+				
Leila et al. (2016)	+	+	+	+	+	+	+	+	+		
Masmoudi et al. (2009)	+	+	+	+	+	+					+
Melam et al. (2016)	+	+	+	+	+	+		+	+		+
Mortada et al., (2018);	+	+	+	+	+	+	+	+	+		+
Mostafa et al. (2010)	+	+	+	+	+	+	+	+	+		+
Naja et al. (2015)	+	+	+	+	+			+	+		
Nejmi et al. (2010)	+	+	+	+	+						
Obeidat & Khrais (2014)			+	+							
Rostom et al. (2012)	+	+	+	+	+	+		+	+		+
Sbitti et al. (2011)								+	+		
Shoma et al. (2009)			+						+		
Shouman et al. (2016)	+	+	+	+	+			+	+		+

Experiential Domain Author	Global health	Social	Psychological	Physical	Role function	Cognitive	Spiritual	Sexual	Body Image	Spousal relation	Financial
Soltan et al. (2012)		+	+		+						
Stapleton et al. (2011)		+	+								
Thabet et al. (2007)		+	+	+	+						
Traore et al., (2018);	+	+	+	+	+	+	+	+	+		+

Note: +, domain covered by employed scale(s), not necessarily the author's focus of enquiry

Appendix 6: EORTC QLQ-C30 data

Author	n	Age		EORTC QLQ-C30																													
				Global		Physical		Role		Emotional		Cognitive		Social		Fatigue		Nausea		Pain		Dyspnoea		Insomnia		Appetite		Constipa		Diarrhoea		Finance	
		μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD
Abu-Helalah, 2014	236	50.7	10.7	63.7	20.2	-	-	-	-	59	33.5	-	-	78.1	28.6	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Al-Sulaiman, 2018	201	-	-	67.23	-	84.48	-	64.93	-	60.32	-	85.32	-	43.5	-	45.43	-	23.13	-	40.79	-	14.42	-	53.73	-	34.32	-	14.42	-	10.94	-	63.18	-
Alawadhi, 2009	348	48.3	10.3	45.3	15.3	52.6	18.8	55.1	21.4	60.3	22.5	59.9	23.9	61.2	22.7	38.9	21.3	30.2	24.5	43.8	21.7	42.4	27.8	42.7	28.2	37.5	28	27.8	28.2	22.1	27.5	31.2	25.2
Albatain (CAM use), 2018	77	-	-	73.16	20.26	68.05	21.72	78.14	29.28	70.78	29.54	79.22	24.05	83.33	26.35	33.62	29.13	19.7	30.55	33.99	31.46	25.11	30.19	48.06	41.01	31.6	34.59	29.01	39.13	12.99	28.69	13.42	29.25
Albatain (non CAM use), 2018	18	-	-	64.82	32.79	63.33	28.02	62.96	42.23	67.14	32.39	83.33	25.56	72.22	33.82	41.97	30.39	12.04	26.07	50.92	28.85	24.07	29.83	40.74	46.52	29.63	41.05	14.81	28.52	18.52	38.3	20.37	34.56
Almutairi, 2016	145	-	-	31.2	20.5	62.9	24.6	67.6	29.2	83.3	22.7	68.3	27.3	65	35.7	76.2	22.9	68.9	76.2	76.2	24	80	27.3	84.1	25.5	80.9	26.9	59.3	31	41.2	32.4	52	39.3
Awad, 2008	87	48.6	9.9	74.6	18	73.8	22.6	82.5	27.6	65.8	32.8	74	30.7	85.1	26	35.8	30.5	21.8	33.4	85	26.9	21.1	30.1	44.7	42.7	31.8	39.3	25.2	37.9	11.24	27.8	10.47	26.7
Bener, 2017a	678	47.7	10.2	75.6	22.71	79.3	17.9	65.2	25.5	62.5	27.5	86.2	20.2	51.3	28.8	35.5	28.5	25.3	26.4	31.5	27.5	15.7	22.4	42.8	30.2	29.3	26.3	22.1	26.8	16.2	21.2	50.7	39.7
El Fakir, 2014	105	48	16	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
El Fakir, 2016	1463	55.6	11.2	68.5	18.5	78.1	21.5	74.1	28.6	62.5	28.5	83.2	23.2	86.2	22.7	29.2	24.5	9.3	19.8	23.8	26.8	15.5	24.8	21.1	29.2	21.7	29.6	10.9	23	4.4	14.1	63.2	38.2
Enien, 2018	172	-	-	28.38	11.7	83.37	12.54	62.45	21.16	59.61	24.96	65.56	22.05	87.91	17.92	39.43	17.7	5.86	10.93	36.44	18.07	17.58	24.01	21.24	26.53	13.18	22.15	21.24	26.53	5.86	13.69	57.87	20.98
Huijer, 2012	89	49.2	11	59.64	29.09	79.1	21.08	73.41	30.43	65.91	28.46	84.45	22.16	60.29	28.76	34.58	28.3	9.5	17.92	32.4	34.57	7.86	19.48	33.71	40.36	24.34	38.85	10.86	25.51	9.74	25.72	37.45	39.83
Jassim, 2013	239	-	-	63.93	21.34	74.92	21.69	68.84	35.96	63.41	33.46	73.38	29.87	77.52	30.27	35.28	30.62	10.29	30.77	29.97	31.23	20.22	30.32	30.12	39.29	13.38	27.62	17.99	30.66	6.83	18.95	34.58	42.26
Masmoudi, 2009	23	48	-	72.5	-	82.3	-	63.7	-	69.5	-	85.5	-	89.1	-	25.4	-	8	-	26.8	-	17.3	-	27.5	-	18.7	-	13	-	0	-	27.5	-
Melam, 2016	30	56.3	3.3	39.63	4.71	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Mortada, 2018	142	-	-	35.44	8.4	54.46	14.9	68.3	20.3	29.22	8.1	64.31	19.9	46.71	14.4	53.2	14.4	53.28	13	40.14	10.7	32.86	9.8	24.41	6.1	69.48	15.6	49.76	7.7	51.17	13.6	76.99	20.7
Moustafa, 2010	180	45.9	10.6	-	-	38.8	25.8	23.8	27.9	20.2	31.1	37.7	24.7	28.2	37	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Traore, 2018	1463	50.5	10.9	66.67	17.76	80.88	19.31	75.65	27.58	63.01	28.59	84.83	22.77	87.85	21.76	26.83	22.69	8.04	18.29	21.85	25.47	13.04	23.01	21.1	27.62	21.7	27.63	9.08	20.97	4.41	11.88	66.67	37.62

Appendix 7: EORTC QLQ-Br23 data

Author	n	Age		EORTC QLQ-Br23															
				Body image		Sexual function		Sexual enjoyment		Future perspectiv		Systemic effects		Breast symptoms		Arm symptoms		Distress at hair loss	
		μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD	μ	SD
Abu-Helalah, 2014	236	50.7	10.7	52.01	36.8	-	-	-	-	52.9	38.5	-	-	-	-	-	-	69.8	43
Alawadhi, 2009	348	48.3	10.3	61.8	23.3	69.9	23.6	61.5	23	59.5	31.9	40.1	17.5	35.6	25.4	38.2	23.4	44.8	29.6
Albatain (CAM use), 2018	77	-	-	80.63	23.4	19.26	25.23	21.33	28.81	64.07	38.53	25.98	19.67	22.73	21.62	37.36	28.39	34.85	41.89
Albatain (non CAM use), 2018	18	-	-	66.67	34.78	25.93	31.43	24.08	33.94	55.55	41.23	26.14	27.41	23.15	23.33	36.42	29.97	51.86	44.45
Almutairi, 2016	145	-	-	64.7	35.7	52.3	23.7	22.5	27.7	76.3	35.3	64.4	27.6	65.1	26.1	62.9	24.1	64.4	33
Awad, 2008	87	48.6	9.9	69.4	26.5	62.6	28.7	59	31.8	47.3	39.4	38.4	22.6	21.4	18.5	32	31.1	63.2	43.5
Bener, 2017a	678	47.7	10.2	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
El Fakir, 2014	105	48	16	77.54	25.82	61.11	29.83	58.49	29.17	46.98	41.27	59.86	22.98	77.86	19.94	-	-	34	41.23
El Fakir, 2016	1463	55.6	11.2	79.8	24.6	-	-	57.5	30.3	40.5	37.3	18.7	18.1	21.3	21.7	23.6	21.8	19.5	28.5
Enien, 2018	172	-	-	74.51	13.21	74.45	14.89	32.23	19.53	41.75	20.09	28.41	14.76	11.53	14.36	32.35	23.22	15.75	24.01
Jassim, 2013	239	-	-	75.64	29.86	25.92	29.77	48.56	32.12	61.29	39.37	19.27	17.76	13.66	18.06	36.58	31.76	46.33	42.87
Leila, 2016	50	52.1	10.1	47.6	26.4	45.3	22.1	43.9	25.1	-	-	-	-	-	-	-	-	-	-
Mortada, 2018	142	-	-	40.61	7.5	78.87	11.6	81.22	16.6	19.71	4.9	46.14	11	53.99	10.3	57.12	12.2	89.67	15.5
Traore, 2018	1463	50.5	10.9	81.88	23.32	76.69	23.68	55.6	29.64	39.78	37.23	16.86	17.04	18.71	19.97	22.52	21.16	20.97	27.65

Appendix 8: Participation Information Sheet (patient-participant)

Study Title:

Life journeys with breast cancer in Mauritania: A mixed methods case study

My name is David Fearon and I am conducting this research study as a student on the PhD programme at Lancaster University, Lancaster, United Kingdom.

You are invited to be involved in this study and this information sheet explains what it is about. If there are words or paragraphs that you do not understand, please ask the researcher to explain it.

What is the study about?

The purpose of this study is to gain a better understanding of how breast cancer affects women in Mauritania. It is interested in how you cope with breast cancer over a six to nine-month period and also how it affects your family, your doctors, nurses and traditional healers. This information will help us to make improvements to how we care for women with breast cancer in the future.

Why have I been approached?

You have been approached because this study needs information from women with breast cancer and you are living with this illness.

Do I have to take part in the study?

No. It is completely up to you to decide whether or not to take part and you can withdraw from the study at any time you choose without giving a reason for your decision. If you decide not to take part or to leave the study, there will be no negative repercussion on your current or future care and treatment.

What will I be asked to do if I take part in the study?

If you decide you would like to take part, you will be asked to:

- Sign a consent form which states that you consent to take part in the study. Both you and the researcher will keep a copy of this signed form.
- Identify two of your family members, two of your medical team (for example a nurse and a doctor) and a traditional healer, if you visit one – who we can invite to also take part in the study.
    - We will ask you to contact your family members to check whether they would be happy to take part in the study.

- Take part in an interview with the researcher each month (7 times) in which the researcher will talk to you about your illness, what has happened since the previous interview and how these events have affected you and your family.
    - The first interview will last between 60 and 90 minutes. The following interviews will probably be shorter.
    - The interviews will be audio recorded.
    - A Mauritanian translator will help with this if necessary.
- Answer a short questionnaire (seven questions) each month (7 times), which ask about your illness and how you are feeling

Will someone be able to identify me through my information?

The information you provide is confidential.

Any information which may identify you will be removed, such as your name or names of your family. You will be asked to choose a different name for yourself to protect your identity. The data (information) collected for this study will be stored securely and only the researcher conducting this study and his supervisors will be able to see it.

In addition:

- The researcher will collect and record your information in a file. This will include your name, date of birth and ethnic origin. All this personal information will be confidential and kept separately from your interview transcripts and questionnaires.
- Data will be collected from your healthcare records held at the National Cancer Centre.
- Interviews will be transcribed (typed) and this writing will then be translated into English and made anonymous by removing any information that could identify you, including your name.
- All translators and transcribers have experience in this type of research and will maintain your confidentiality.
- The audio recordings will be destroyed when the study has been completed and examined.
- Any files kept on the computer will be encrypted which means that only the researcher will be able to access them. The computer will be password protected. Computer files will be kept securely by Lancaster University for ten years after the study is finished and then destroyed.
- The researcher may write some notes during the interview, which are to help them remember things from the interview.
- Anything published from this study in reports or articles may include quotes of what you said during an interview, but your name and anything else that could identify you will be removed.
- All information collected during the research will be kept strictly confidential to the extent permitted by the law.

- Information, which does not identify you, will be stored in an official databank for similar research, either at www.ukdataservice.ac.uk or at Lancaster University. For official and legal purposes, persons with permission from the Research Ethics Committee, or a government agency may access your file. All these individuals and organizations are guided by a privacy policy.

There are some limits to confidentiality: if what is said in an interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to an appropriate person about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The researcher will use the information you provide for research purposes in order to meet the scientific standards of their PhD thesis at the University of Lancaster. It may also be published in scientific journals and shared with others in scientific discussions. No publication or scientific communication will contain information that identifies you.

Are there any risks?

You may find talking about your illness and how it affects you, upsetting. In that case the interview will be paused or stopped. If you experience any upset during the interview please let the researcher know. If you feel upset after the interview, the Mauritanian association 'Mieux vivre avec les cancers gynaecologiques' can offer support to patients and families affected by breast cancer, they can be contacted on 46 55 76 22.

Are there any benefits to taking part?

It is not expected that taking part in this study will bring any real benefits to you, although some people do find it helpful; to talk about their experiences to someone outside of their family and healthcare team. We expect that this study will help give better care for other persons with cancer in the future, especially in Mauritania.

What happens if I decide to leave the study?

Taking part in this study is voluntary and you are free, at any time, to stop your participation, without having to explain your decision. This will not affect the medical care you receive now, or in the future. If you withdraw from the study there would be no further interviews with you, your family or healthcare providers. If you wish, any information you provided within the previous two weeks would be destroyed; however information older than that would remain in the study.

Will I be paid for participating?

There is no payment for taking part in the study. If you need to travel for an interview, your transport costs will be reimbursed to a maximum of 1000 Ouguiyas for each interview.

Where will the results of the study be published?

The results will be published at www.facebook.com/CairdeasSahara. They may also be presented at scientific conferences and meetings and will be written in articles for publishing in scientific magazines.

Who has reviewed this study?

The Ethics Committee at the Faculty of Health and Medicine at the University of Lancaster has approved this study. (Ref no….. *when received*)

Where can I get further information about the study if I need it?

If you have any questions about the study please contact the researcher Dr David Fearon, on 48 35 48 10 or d.fearon@lancaster.ac.uk; or one of the translators on 41 11 13 13 or 41 11 14 14.

Where can I find further support?

The two Mauritanian associations, 'Mieux vivre avec les cancers gynécologiques' and 'Association Mauritanienne de Lutte Contre le Cancer' can offer advice and support to patients and families affected by cancer; they can be contacted on 46 55 76 22 and 44 47 62 22 respectively.

Who can I contact if I want to complain about the study?

If you wish to make a compliant or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Mohammed Salem, Head of Personnel at the National Cancer Centre.

You could also contact;

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine
Lancaster University
Lancaster, LA1 4YD. United Kingdom.

Tel: +44 1524 593746
Email: p.bates@lancaster.ac.uk

Researcher contact details:

David Fearon
115 Ilot K
Tevragh Zeina
Nouakchott
d.fearon@lancaster.ac.uk
00222 48 35 48 10

Thank you for taking the time to read this information sheet.

Appendix 9: Brief Participation Information Sheet (Patient-Participant)

Overview of study

This study is interested in how breast cancer affects people in Mauritania, including women with it, their families and their healthcare workers. To best know this, we would like to invite you to join this six- to nine-month study.

Do I have to?

This is completely voluntary and will not affect your present or future care, either whether you join or not. If you decide to join, you are free to leave whenever you wish.

What would I do?

We would like to have several conversations with you, during which we would ask questions about your experiences with breast cancer. These interviews would occur every four weeks over the six- to nine-months, and occur at a location and time which suits everyone. The first interview is likely to take 60 to 90 minutes and the later interviews will probably be shorter. We would also like to access your healthcare records held at the National Cancer Centre.

If willing, we will ask you to sign a consent form and to nominate two family members, two healthcare professionals and a traditional health practitioner, if you regularly see one. We would also like to speak with these people, over the six months.

Why?

Each interview will be recorded, and will be typed out. This information will be used by the researcher as part of their PhD with the University of Lancaster in England. Your name will not be mentioned in any publication and no-one will be able to identify you or your comments.

Benefits/harms?

It is not expected to bring you any benefits, however some people feel it helpful to speak about their experiences. However, sometimes speaking about these things may upset people, and we will be able to provide support if this was to happen.

Interested?

If you are interested please ask the researcher for further information and the accompanying information sheet with more details. The researcher is David Fearon, tel: 48 35 48 10 or 41 11 13 13.

Appendix 10: Interview topic guide: patient-participant

Context:

Could you tell me about your illness and what do you understand about it?

Do you think your understanding is different to that of your family, or doctor?

What does cancer mean to you?

What does breast cancer mean to you?

Causation:

When did you first notice something was wrong with your body?

What did you think was happening with your body before you diagnosed?

How did you find out you had cancer?

What do you think caused this problem?

Significant events:

As the rapport builds, ask for examples of ‘crisis points’ or when the participants felt they coped well or not so well

Can you describe what happened?

Why do you think these happened?

Who was involved?

What made these situations different to other events?

Contact with healthcare:

What contact have you had with both conventional and traditional healthcare?

What do you think of this care?

Why have you been given this advice or care?

How would you describe their relationship with you?

Did you follow the advice from the care provider? If not, why not?

What do you think of their motivation in providing care?

Exploring what helps participants to manage.

Do you feel you have coping skills? If so, how did you develop these?

Who has been helpful?

How do you manage difficult thoughts and feelings?

Probe: The role of their faith

Family dynamics.

Has your role in the family changed?

Have there been any changes of roles of family members?

Do you require help to maintain your roles ? If so who in the family helps you ?

Who makes decisions regarding your health?

Can you describe the support you receive from the family?

What support do you provide for your family?

How did you expect your wider family to support you?

Were your expectations met?

If not why not

Probe: Areas of conflict or burnout.

The role of the extended family

Future events and planned coping strategies.

If you had any concerns now about your health or the care you are receiving, where would you go first for help/advice?

Probe: Different problems needing different providers

Thank you for your time.

Do you have any questions that you would like to ask of me?

Appendix 11. Instructions for keeping of journal

Dear participant,

Thank you for agreeing to take part in this research project. You have agreed to keep a journal, which can either be recorded using a provided paper journal or an audio journal using a provided digital voice recorder or WhatsApp, this can be in French, English or a local language. Please spend 15 to 30 minutes recording your diary at least twice a week, commenting on anything you think will help the researcher understand what it is like for someone to live with breast cancer in Mauritania. The questions below are only suggestions, and please write freely. A reminder card with these suggestions will be given to you. On the reverse of this reminder card is a short questionnaire with three questions. Please answer these three questions each time you record the diary. The researcher or translator will phone you now and again to check how you are finding keeping a diary. The researcher will collect and replace the diary every four to six weeks.

Overall, we would like you to freely describe your day and how the illness of your relative affects you. You may find these suggested questions helpful in the early stages of keeping a diary:

What daily activities do you carry out which are related to their health?

What role do you play in decisions made regarding their health?

How has your role in the family changed?

What events do you feel have been significant for you?

How did these events influence how you felt?

The short questionnaire

These three questions require a response from 0 to 5, as explained below.

1. How much information have you and your family been given?

Please answer according to the scale:

0 = None
1 = Very little
2 = Some
3 = Quite a lot
4 = A great deal
5 = As much as wanted

2. How confident does the family feel caring for your relative?

Please answer according to the scale:

0 = Not at all
1 = Not confident about many things
2 = Confident about a few things
3 = Confident about some things
4 = Confident about most things
5 = Very confident

3. Has the family been feeling worried about the patient over the last 3 days?

Please answer according to the scale:

0 = Not at all worried
1 = Worried very occasionally
2 = Worried some of time
3 = Worried a lot of the time
4 = Worried most of the time
5 = Worried all of the time

Should you have any questions or comments please contact the researcher Dr David Fearon, on 48 35 48 10 or d.fearon@lancaster.ac.uk; or one of the translators on 41 11 13 13 or 41 11 14 14.

Appendix 12: Laminated journal aide-memoire

Side A:

Please describe your day....

What activities did you carry out today that are related to the health of your relative?

What role did you play in any decisions made regarding their health, who else played a role in these decisions?

What events do you feel have been significant today?

Please describe how these events make you feel?

Questions?

David Fearon 48 35 48 10 or Research assistant 41 11 13 13

Side B:

1. **How much information have you and your family been given?**

   Please answer from 0 'None' to 5 'As much as wanted'

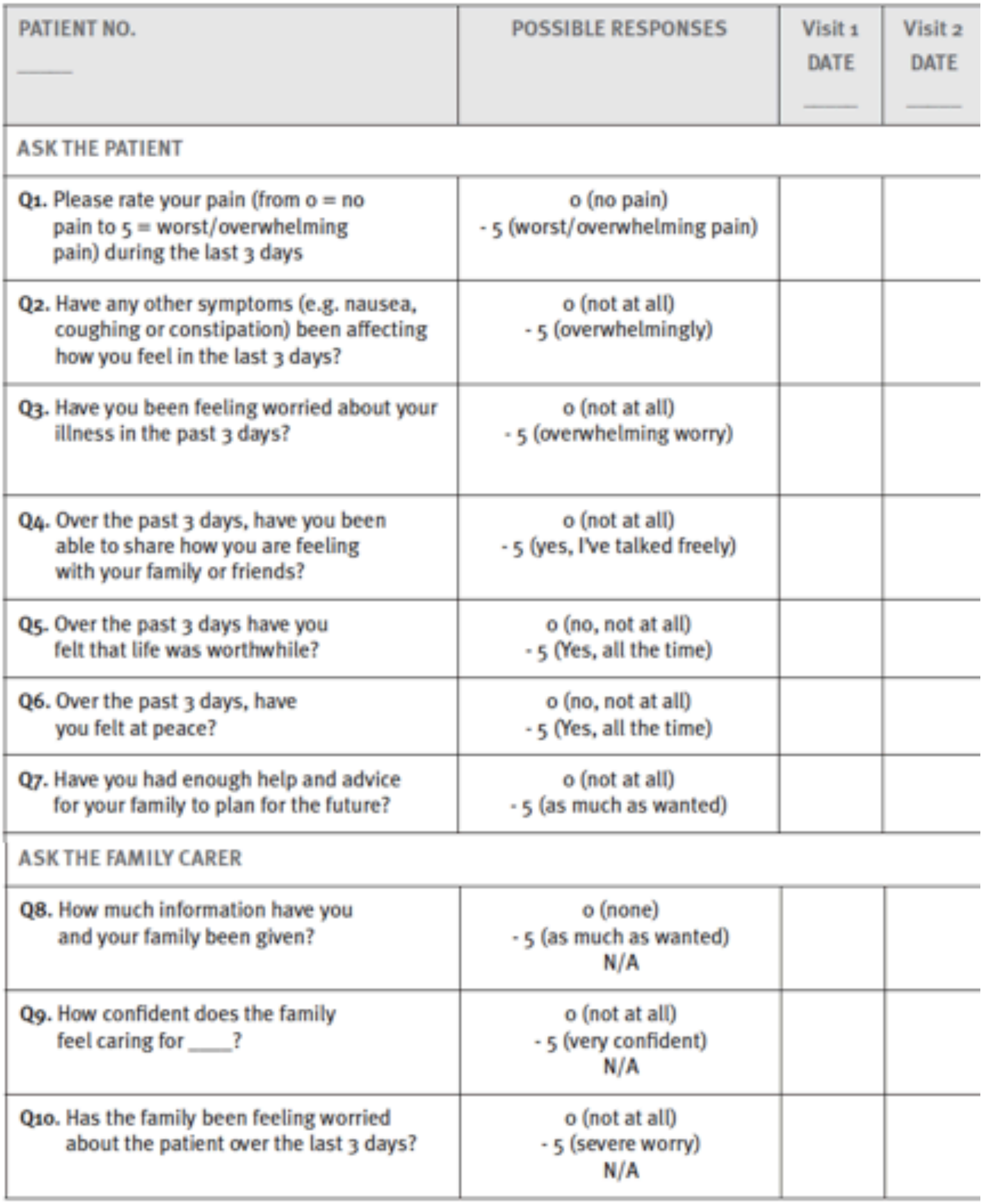
2. **How confident does the family feel caring for your relative?**

   Please answer from 0 'Not at all' to 5 'Very confident'

3. **Has the family been feeling worried about the patient over the last 3 days?**

   Please answer from 0 'Not at all worried' to 5 'Very confident'

Appendix 13: APCA African POS



PATIENT NO. ____	POSSIBLE RESPONSES	Visit 1 DATE ____	Visit 2 DATE ____
ASK THE PATIENT			
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (no pain) - 5 (worst/overwhelming pain)		
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all) - 5 (overwhelmingly)		
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all) - 5 (overwhelming worry)		
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) - 5 (yes, I've talked freely)		
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all) - 5 (Yes, all the time)		
Q6. Over the past 3 days, have you felt at peace?	0 (no, not at all) - 5 (Yes, all the time)		
Q7. Have you had enough help and advice for your family to plan for the future?	0 (not at all) - 5 (as much as wanted)		
ASK THE FAMILY CARER			
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A		
Q9. How confident does the family feel caring for ____?	0 (not at all) - 5 (very confident) N/A		
Q10. Has the family been feeling worried about the patient over the last 3 days?	0 (not at all) - 5 (severe worry) N/A		

Appendix 14: Palliative Performance Scale (PPSv2)

A Circle Of Care
Victoria Hospice
SOCIETY

Palliative Performance Scale (PPSv2)

version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Appendix 15: Transcription and translation procedure

Excerpt from first interview with Lalla in case 2, 6th January 2017

	Hassaniya	French	English
T	Ewol… manah ve tab moubatik eynte engalek saratan ?	La première fois… ça veut dire à l'hôpital, ton suivi, quand t'ont-ils dit que c'est un cancer ?	The first time ... it means that at the hospital, your follow-up, when did they tell you that it's cancer?
P	Ela 2014 leyn jeyt le ekhisa i emrad el nisa ve iyad tou houw ili galli ela the el marad.	C'est en 2014 quand je suis venue voir le gynécologue à son cabinet c'est qui m'a dit que c'est cette maladie.	It was in 2014 when I came to see the gynaecologist at his [private] clinic. It's he who told me that it's this disease.
T		C'est lorsqu'elle a vu le gynécologue ici en 2014 c'est lui qui a dit que c'est un cancer.	When she saw the gynaecologist here in 2014, he said it's cancer.
R		Et comment ça s'est passé ? Elle était choquée ou… ?	And how was it ? Was she shocked or ...?
T	Chenhi kan radet fi elek enti ma…?	Quelle était ta réaction avec… ?	What was your reaction with...?
P	Ensa thaguile, en khalat hat.	C'était insupportable, j'ai eu très peur.	It was unbearable, I was very afraid.
T		Elle a eu trop peur. Oui c'était difficile.	She was very afraid. Yes, it was difficult.
R		Est-ce qu'elle a pensé… est ce qu'elle a déjà pensé ce cas ça peut être le cancer ?	Did she think ... did she ever think that it could be cancer?
T	Kenti andek vikra en saratan chen hou ?	Avais-tu une idée de ce que c'est le cancer ?	Did you have an idea of what cancer was?
P	Ehe aleme bihe elenou marad khatir wela… towv	Oui je savais que c'était une maladie grave et… c'est tout.	Yes, I knew it was a serious illness and ... that's it.
T		Donc oui elle avait déjà l'idée que le cancer c'est une maladie dangereuse.	Yes, she already had the idea that cancer is a dangerous disease.
R		Et comment ça se passe avec le… est ce que le médecin l'avait informé elle ou son mari donc la famille ?	And how did it go with the ... did the doctor inform her or her husband, thereby the family?

	Hassaniya	French	English
T	We tabib hathe el akhisa i el nisa gal halek enti walla gal hal had men el dar walla ?	Et le gynécologue te l'a dit ou l'a dit à quelqu'un de la famille ou bien ?	And did the gynaecologist tell you or someone else in the family?
P	Gal hal ane… ma gal hali moubachartan. En ne dir degat towv ele nou adi leyn vout nevech el bezoule leyn adel lehe ameliye. Gale enou basit yagher jahed min hel el dar. Galou enou ela hathe el marad. We towv.	Il l'a dit à moi… il ne me l'a pas dit directement mais juste de faire des injections que ce n'est rien jusqu'à ce que le sein… je ferai une opération. Il m'a dit c'est rien mais il a dit à la famille. Il lui a dit que c'est la maladie. C'est tout.	He said it to me... he didn't tell me directly but just to have some injections, that it's nothing until the breast... I will do an operation. He told me it's nothing, but he told the family. He told them it's the disease. That's it.
T		Donc il ne lui a pas dit ça directement mais il a dit que oui c'est une maladie on va mettre les injections… tu vas prendre quelques injections et après je vais enlever le sein mais il y a un autre membre de la famille auquel il lui a dit que c'est cette maladie donc c'est le cancer.	So, he did not tell her directly, but he said it's a disease, we're going to give injections... you're going to have a few injections and then I'm going to remove the breast. But there's another family member to whom he told them that it's this disease, it's the cancer.
R		Donc c'est qui, qui l'a dit le cancer ? C'est un membre de la famille qui l'a dit ?	So who, who told her it was cancer? Was it a family member who said it?
T	Ewo men gal halek ?	Et qui te l'a dit ?	And who told you?
P	Galou hali houm ela thak el rajel eli jah houw hal hali ane.	C'est eux ici qui me l'ont dit. C'est à celui qui est venu le voir qu'il a dit et me l'a dit.	It's those here who told me. It was him who came to see [the doctor] who was informed, and he told me.
T		Donc la personne qui l'a informé lui a transmis ça.	So the person who was informed by the doctor transmitted the information
R		Le même moment ?	The same time?
T	Nevess nehar walla ?	Le même jour ou bien ?	The same day or..?

	Hassaniya	French	English
P	Nevess nehar.	Le même jour.	The same day
T		Le même jour.	The same day
R		Et qu'est-ce qu'elle pense de la situation là ? Est-ce que c'est bien géré... l'annonce ?	And what does she think of the situation there? Was it well managed ... the announcement?
T	We che gaye le ve tarigha ili en galou lek bihe hathe el marad ? Kanet radet fi elek elihe be gowle tou ?	Et qu'est-ce que tu penses de la manière dont on te l'a annoncée cette maladie ? Ta réaction sur ça était… sur l'annonce ?	And what do you think about the way in which you've been told this disease? Your reaction to it was ... on the announcement?
P	Ane ela hasseyt enou ela houw.	Moi j'ai senti que c'était ça.	Me, I felt it was that
T		Oui elle avait… elle pensait que c'était ça peut-être. Donc elle s'attendait qu'on lui dise. Lorsqu'on lui a dit ça elle s'attendait presque à l'annonce qu'on dise que c'est ça.	Yes, she had ... she thought it might be that. So, she was expecting to be told. When she was told, she was almost expecting the announcement to be what it was.
R		OK. Donc qu'est-ce qu'elle comprend dans le nom de cancer ? Qu'est-ce qu'elle comprend ?	OK. So, what does she understand from the name of cancer? What does she understand?
T	Che te vehmi… che vahma dark ve hathe el marad ? An saratan ?	Qu'est-ce que tu comprends… qu'est-ce que tu comprends maintenant de la maladie ? Du cancer ?	What do you understand... what do you understand now about the illness? About cancer?

P, patient-participant; T, Translator; R, Researcher

Appendix 16: Sample coding framework

Coding framework used in four interviews with Binta in case 3

Code	Sub-category	Provisional theme
Desiring to prevent cancer in others	Emphasising need to understand cancer to treat and prevent it	Breast cancer
Emphasising the importance of prevention over curing		
Expecting that knowing the cause of cancer will be prevent it		
Suspecting that there are cancer risks specific to Mauritania		
Accepting that knowledge on causation is helpful to guide treatment		
Portraying cancer as a sequence of events	General knowledge of cancers	
Being aware of different cancers		
Portraying cancer as something temporary		
Mentioning three and 5 years in reference to cancer appearing		
Mentioning 5 or 6 years for cancer to appear		
Understanding that a lack of vitamins have a role in cancer		
Understanding that breast lumps which change with menses are not serious		
Understanding that cancer has stages		
Understanding that cancer is localised in a part of the body		
Understanding that cancer takes years to appear		
Understanding that new replacement cells cause cancer slowly		
Understanding there are different types of cancer		
Emphasising that cancer always starts with dead cells		
Perceiving that cancer does not come alone		
Reinforcing the idea that cancer is normal	It is normal	
Acknowledging patients face tensions as their identity and role are threatened	It's impact on people	
Portraying cancer as something preventing well-being		
Denying any awareness of the causes of cancer	Minimising her knowledge of cancer	
Belittling her knowledge of cancer		
Limiting her knowledge of cancer to breast cancer		
Considering she had no knowledge of cancer prior to her illness		
Emphasising her lack of understanding of the causes of cancer		
Minimising her knowledge of breast cancer	Minimising her knowledge of cancer	Breast cancer
Trivialising her knowledge of cancer before the diagnosis		

Code	Sub-category	Provisional theme
Trivialising her understanding of cancer		
Proposing that the causes of cancer in RIM are not known	No one knows about cancer	
Perceiving that her doctors don't know the cause or character of cancer		
Perceiving that no-one knows the causes of cancer		
Feeling frustrated that there is no information from Mauritania on cancer		
Implying that cancer research is not complicated	Positive about future research	
Suspecting that researchers will find out the cause of cancer	Positive about future research	
Restricting knowledge about cancer to scientific information	Restricted access to knowledge	
Suggesting that cancer patients can not know the cause of the cancer	Restricted access to knowledge	
Being concerned that cancer presents differently	Uncertainty and unpredictability of cancer presentations	
Emphasing being able to stand in important in her prayers	Balancing things she can't do with things she can	Coping, enduring or suffering
Emphasising her ability to walk		
Balancing her inability to stand with her ability to walk		
Perceiving that illness changes the patient into a slave and no longer a person	Cancer changing her role and identity	
Perceiving her diagnosis has made her more stubborn		
Considering that she used to be independent and working		
Suggesting that illness makes patients more stubborn		
Generalising that most patients become more reasonable with time	Comparing herself to other patients	
Describing the impact of chemo decreasing with time	Considering treatment completed	
Considering she coped well with the cancer treatments		
Thanking God the treatment is completed		
Emphasising the finality of her cancer treatment		
Distinguishing between compliant and non-compliant patients	Demonstrating compliance to the protocol	
Emphasising her compliance to tests		
Emphasising her compliance to the doctor's plan		
Portraying herself as compliant to all the dr's requests	Demonstrating compliance to the protocol	Coping, enduring or suffering
Accepting of a three months wait for injections to help the pain	Demonstrating compliance to the protocol	
Perceiving illness as slowly weaking the person, their dynamism and role in the family	Deteriorating over time with cancer	

Code	Sub-category	Provisional theme
Implying she is waiting for the pains to come to her	Deteriorating over time with cancer	
Portraying she is currently doing well	Doing well or better	
Thanking God that her mouth is feeling better		
Appreciating that she is more indepedent in her self care than before		
Acknowledging a psychological crisis	Emotional stress	
Acknowledging that she is not at peace		
Contrasting her emotional pain at not knowing with her symptoms and side effects		
Suggesting that emotional states can change day to day		
Hinting that she grieves for the loss of her previous identity		
Defining normal as visiting her friends and walking with them	Identifying what is important to her	
Highlighting going to toilet and praying as important to her		
Going to the village with the breast swelling		
Perceiving that 'westerners' care for people		
Proposing that she has given me sufficient information		
Joking that boring people don't visit her	Keeping a sense of humour	
Laughing at her stubbornness		
Laughing at me not getting her joke		
Laughing at question 5		
Laughing when describing information leaking from the family		
Suggesting I lack a sense of humour		
Using laughter to emphasise she does not know M7		
Laughing at how everyone who comes to the house helps		
Use of laughter when talking of cancer in the past tense		
Using laughter to describe curing the cancer		
Accepting the term living with an illness in the termporary sense	Living with cancer	
Minimising the significance of the breast lump in her diagnosis	Minimising or trivialising the cancer and its impact	
Limiting her problems to the breast	Minimising or trivialising the cancer and its impact	Coping, enduring or suffering
Limiting the cancer to the breast		
Minimising the extent of her cancer at time of mastectomy		
Perceiving her breast cancer was banal		
Simplifying the lump biopsy		
Denying fear		
Denying having any reason to be afraid		

Code	Sub-category	Provisional theme
Simplifying the process of port and chemo in Tunisia		
Considering her cancer treatment went well		
Hinting the mastectomy had no effect on her		
Perceiving that breast cancer treatment is the same globally		
Portraying an acceptance of her uselessness as normal for her		
Denying any financial difficulty from the cancer		
Limiting her problems or symptoms to pain		
Denying any changes since last interview (3.4)		
Trivialising her symptoms		
Emphasising her independence		
Refusing to acknowledge that she finds it difficult to cope		
Portraying an indifference to whether she gets better or worse		
Suggesting that there is no other choice than to cope and accept an illness	Perceptions and projections of herself	
Idealising her ability to cope with pain		
Portraying herself as strong and independent in her coping with pain		
Justifying going to the village		
Perceiving herself as useless to her family	Perceptions of herself	
Identifying herself as useless prior to the cancer		
Reinforcing her uselessness in the family		
Considering herself as stubborn and disobedient		
Considering she was never very active		
Perceiving herself as a good person		
Considering that she was prone to non-serious illnesses		
Emphasising that she has had much exposure to healthcare and operations		
Being surprised at the impact of some heat on her in the village	Physical symptoms, disability and dependence on others	
Catastrophising how she felt with the heat in the village	Physical symptoms, disability and dependence on others	
Acknowledging the impact of losing her independence	Physical symptoms, disability and dependence on others	Coping, enduring or suffering
Considering she used to be self-sufficient		
Acknowledging her need for some help		
Acknowledging her difficulties in standing and sitting		
Acknowledging her inability to sit for a long time		
Acknowledging a severe pain		
Acknowledging her pain is difficult		

Code	Sub-category	Provisional theme
Acknowledging that she is not comfortable		
Acknowledging that there it is difficult coping with the pain		
Defining the limits of her mobility		
Describing a worsening pain		
Describing the impact of pain on her breathing and mouth		
Emphasising the pain makes it difficult to stand or sit		
Emphasising the permanence of her pain		
Feeling restricted in her mobility and leaving the house		
Being unable to stand because of the pain		
Recognising and accepting that she is not fully independent		
Acknowledging the impact of disabiltiy on her		
Limiting her activities to toilet and sitting		
Finding the pain present but controllable in the past		
Remaining vague about her being uncomfortable		
Remarking she felt unwell with the heat in the village		
Suggesting her leaving the house is dependent on others		
Suggesting that her social activities are very limited		
Acknowledging that she would like to be autonomous in everything	Physical symptoms, disability and dependence on others	
Pitying those patients with chemo cycles close together	Pitying others	
Avoiding other patients due to fear	Protecting herself from negative stories	
Isolating herself from other patients to protect her well-being	Protecting herself from negative stories	
Explaining that patients seek a cure when symptomatic	Seeking medical care	
Using medication to help the pain	Seeking medical care	
Using paracetamol when in pain	Seeking medical care	Coping, enduring or suffering
Emphasising the need to consult a doctor if symptoms	Seeking medical care	
Distilling the reason for attending urgence to fix the presenting problem	Seeking medical care	
Refuting the idea of living with cancer	Thinking positively about being cured	
Suggesting having an illness is a time of waiting for the illness to leave		
Suggesting she is disease free		
Thanking God she was cured from the after effects of the mastectomy		
Portraying that the cancer has left her		
Understanding the chemo was effective		

Code	Sub-category	Provisional theme
Hinting that she still waiting for healing		Coping, enduring or suffering / decisions
Attempting to contact the dr when hair was falling out	Treatments were difficult	
Being reassured being told hair loss as normal		
Hinting that doctors struggle to pull patients through chemo		
Acknowledging the mastectomy was difficult		
Thanking God she had time between her chemo cycles		
Acknowledging the chemotherapy was worse than the mastectomy		
Acknowledging the impact of chemo on her		
Associating fever with chemo		
Perceiving chemo like dying and being resuscitated		
Experiencing pain from the chemo		
Limiting a patient's choice to waiting at home or seeing another doctor	Choice between active or passive	
Acknowledging she was annoyed by the diagnosis being hidden from her	Doctor concealing her diagnosis	Disclosure of diagnosis
Emphasising no-one spoke openly of her diagnosis with her		
Acknowledging the impact of not hearing a clear diagnosis		
Emphasising that she did not learn it was cancer until later		
Justifying the actions of those who hid her diagnosis		
Knowing that multiple doctors lied to her about the biopsy results		
Suspecting the dr told them more tests were necessary to appease her and avoid diagnosis		
Being told the biopsy results concluded that further tests were necessary		
Believing the doctor knew about her cancer after the first tests	Doctor concealing her diagnosis	Disclosure of diagnosis
Hinting that the biopsy confirmed what the doctor already knew		
Feeling frustration that no doctor told her the diagnosis		
Perceiving that the first tests revealed the cancer to the doctor		
Suspecting the dr hid the diagnosis from her before the mastectomy		
Acknowledging that doctors bypass the patient and inform the family		
Arguing that doctors should not fully disclose information to patients	Qualifications for who can learn their diagnosis	
Considering that full disclosure to the patient can cause harm psychologically		

Code	Sub-category	Provisional theme
Limiting disclosure to those who can accept with peace		
Considering that people have different capacities to accept diagnoses		
Suggesting that it is possible to judge who can (and can not) be told diagnosis beforehand		
Making a parallel between stages of cancer and people's responses to diagnoses		
Simplifying disclosure as a simple act done by anyone	Simplifying disclosure	
Defining no difference between disclosure by family or doctor	Simplifying disclosure	
Proposing that doctors are trained in disclosure	Simplifying disclosure	
Suggesting that doctors delegate responsibilty of disclosure to the family member	Simplifying disclosure	
Idealising how a family member can disclose the diagnosie at a better time	Simplifying disclosure	
Illustrating the way patients find out like spilling water	Spread of information	
Perceiving that the patient will find out eventually	Spread of information	
Disparaging the information provided about the diagnosis	Working out her own diagnosis	
Acknowledging she has never faced the crowd waiting to see the dr (nephrology)	Appreciation of escort	Experiences of care
Feeling very fortunate to have a chaperone	Appreciation of escort	
Having an escort at the nephrology	Appreciation of escort	
Hinting that everyone except her is in control	Being passive or periphery in everything	
Portraying herself as passive in having her bloods taken	Being passive or periphery in everything	
Feeling passive in where she is seated	Being passive or periphery in everything	
Perceiving her presence as not necessary for nephrology review	Being passive or periphery in everything	Experiences of care
Perceiving that she is not privy to how drs decide on disclosure	Being passive or periphery in everything	
Accepting the view of the brother as her own	Being passive or periphery in everything	
Struggling to communicate with the hospital staff in Tunisia	Challenges to see the dr	
Contrasting written and oral appt bookings		
Hinting that there is no system to the order of patients seen		
Perceiving staff are sometimes difficult to find at the CNO		
Frustrated at having to wait a long time to see the dr		
Feeling frustrated when her appt was not recorded		
Proposing that patients should be seen in order of their arrival		
Considering they did not know or understand the CNO when they travelled abroad	Complimenting the CNO	

Code	Sub-category	Provisional theme
Contrasting past healthcare in RIM with the present	Complimenting the CNO	
Portraying cancer care has improved in RIM recently	Complimenting the CNO	
Being confident that all her blood tests were accurate and reliable	Confidence in the reliability of tests	
Learning from drs abroad not to trust scan reports from RIM	Conflict between doctors / Limiting concerns about RIM to scan reports	
Delivering the biopsy result to the doctor	Demonstrating compliance to the protocol	
Demonstrating her compliance to the tests		
Demonstrating her compliance with the referral to the CNO		
Emphasising she had tests done prior to going to the village		
Expecting people to be compliant with the dr's requests		
Rejecting the idea of arguing with a doctor		
Suggesting compliance is part of relationship and obligation with the doctor		
Suggesting that the doctor's advice be accepted without question		
Receiving medications for her anaemia		
Understanding that tests are part of her routine		
Accepting to have the biopsy in RIM	Having biopsy at CNO	
Idealising the care provided by doctors	Idealising care provided	
Being referred to M7 by letter from another dr	Journey through diagnosis and cancer care	
Being sent from gyn to the CNO	Journey through diagnosis and cancer care	Experiences of care
Being sent to oncology after the mastectomy wound healed		
Considering that her anaemia was diagnosed because of her routine health problems		
Considering that the anaemia led to the diagnosis		
Having blood tests for her anaemia		
Outlining 5 months between finding lump and biopsy		
Waiting three months for the biopsy result		
Hinting that the wound took 1 month to heal (possibly)		
Understanding they would remove the breast prior to operation		
Proposing that the reliability of scan reading is poor in RIM	Lacking confidence in RIM	
Feeling a lack of confidence in the CNO	Lacking confidence in RIM	
Remarking that the only information on cancer came from a different doctor	Limited explanation on the diagnosis	
Having confidence in the CT scans in RIM but not the interpretation	Limiting the competency in RIM	

Code	Sub-category	Provisional theme
Accepting that poor interpretation of scans is a reason for travelling abroad	Motivations for travelling abroad	
Emphasising the need to pursue a diagnosis in healthcare	Need to persevere until they get a diagnosis	
Considering that the dr needs to see the dossier and patient	Perceptions of doctors and staff	
Defining negligence as lack of righteousness		
Limiting negligence to laziness and not working		
Considering drs should be intelligent		
Emphasising the importance of knowledge, politness and humaness in drs		
Considering that M7 is not negligent		
Crediting the doctor with recognising the cancer prior to the breast lump		
Having confidence in the dr in Tunisia		
Perceiving that the doctors were confident of her blood tests		
Being aware that the dr sees a lot of patients		
Emphasising that she believed the dr in Tunisia		
Portraying confidence in her doctors		
Emphasising that one should have confidence in what the dr says		
Portraying that all her doctors have been sincere		
Portraying that the decision to travel abroad did not reflect negatively on the CNO	Perceptions of doctors and staff	Experiences of care
Accepting need to wait due to the dr's workload		
Accepting she does not have the same level of knowledge as the gyn dr		
Emphasising her lack of insight into the doctor's motivations		
Emphasising that the gyn dr knows more about her condition and we ask him		
Understanding that the CNO does everything except surgery for cancer		
Perceiving the doctors' objective is to care for patients		
Emphasising that doctors seek to help all patients		
Balancing criticism of scan interpretation with respect for their Xray interpretation		
Criticising the welcome at the CNO (3.3)		
Arguing that waiting for a dr is dangerous to the patient's health		
Considering that patients should not have to wait to see the dr		
Taking her RIM scans abroad for interpretation		
Portraying that she made a nephrology appointment to discuss her ideas	Reasons for doctors appointment	

Code	Sub-category	Provisional theme
Considering that it is natural that most patients prefer to have care abroad	Reasons for going abroad	
Remarking how things were done without her having to ask or pressure for it	Relationship with doctors	
Perceiving no place to request hospitalisation from the dr		
Recognising M7 as a specialist		
Recognising that M7 has a lot of patients		
Informing the Tunisia dr about the test results		
Feeling reassured that she was treated as any one else in Tunisia		
Having her mastectomy acknowledged by the Dr in Tunisia		
Agreeing that communication is important for drs		
Appreciating the work ethos of the M7		
Considering that the doctor accomodated her appt because he recognised her		
Considering there is no place to demand anything from the doctors		
Emphasising she had no prior relationship with M7		
Explicitly asking doctors what her cancer is	Relationship with doctors	Experiences of care
Limiting her contact at the CNO to M7		
Linking waiting to see dr and the patient's importance		
Perceives M7 as fair in how he treats patients		
Remarking the change in doctors		
Remembering the name of gyn Dr		
Suggesting that doctor's earn the patient's compliance		
Perceiving that no other drs help M7 in consultations		
Choosing a dr in Tunisia		
Portraying that doctors reply when she asks questions		
Interpreting the dr in Tunisia was interested in her breast results		
Seeing a specialist because of pain	Seeking medical care	
Having blood samples taken at home	Staying at home as much as possible	
Having medical care at the hospital and at home	Staying at home as much as possible	
Describing the trauma of a failed port insertion in RIM	Traumatic experiences with no benefit	
Acknowledging that suffering from the failed port insertion		
Feeling that the port insertion was doomed from the start		
Suggesting her body was torn by the failed port insertion		

Code	Sub-category	Provisional theme
Perceiving that the port insertion was trauma for no benefit		🟩
Trivialising her follow up with other specialists	Trivialising follow up with specialist	
Trivialising the appt with nephrology	Trivialising follow up with specialist	
Advising others to have cancer treatment in RIM	Trivialising the decision to travel abroad for treatment	
Trivialising the decision to travel abroad for chemo		
Perceiving no need to justify travelling abroad for healthcare		
Portraying no difference in care between RIM and Tunisia		
Being unaware of need for chemo prior to mastectomy	Unprepared for treatments	
Being unprepared and shocked at her hair loss	Unprepared for treatments	
Perceiving that everyone else knew about hair loss	Unprepared for treatments	
Understanding the breast lump was not important from the gyn dr's response to questions about mastectomy	Unprepared for treatments	Experiences of care
Emphasising she did not know the diagnosis prior to the mastectomy		
Emphasising that chemo is more difficult when there is no information		
Emphasising that she nor the family received information about hair loss		
Hinting that the mastectomy was a surprise for her		
Jumping from general tests to removal of a breast lump		
Negating receiving any information about chemo in tunisia		
Suggesting that the mastectomy was a surprise for her		
Limiting to receiving information only after the mastectomy		
Establishing boundaries for showing emotional distress	Boundaries of what can be expressed	Expressing emotions, questions and opinions
Hinting towards boundaries of what she will (can) talk about		
Refusing to answer question 5		
Refusing to talk about her faith		
Requesting no questions on her faith		
Reverting to destiny when refusing to comment on her difficulties		
Hinting that thinking she will be healed and will die as non-islamic		
Justifying her limited capacity to hide her pain by blaming the visitor staying too long	Concealing symptoms and her limits of concealing them	
Emphasising the importance of visitors looking rather than listening to know when to leave		
Acting as if there was no pain		

Code	Sub-category	Provisional theme
Contradicting her being able to hide her pain and the visitor knowing someone was in pain		
Admitting there are limits to her hiding her pain with visitors		
Portraying herself as strong and well in front of visitors		
Feeling obliged to making visitors feel welcomed		
Judging those who express pain as having a weak faith	Expressing pain is a sign of a weak faith	
Proposing that experiencing pain is anti-islamic	Expressing pain is a sign of a weak faith	
Acknowledging a severe pain the past	Expressing symptoms when in the past	
Acknowledging she had pain	Expressing symptoms when in the past	Expressing emotions, questions and opinions
Suggesting nothing can harm Muslims emotionally	Idealising the benefits of being a Muslim	
Suggesting that Muslims have an obligation to consider cancer in a certain way	Idealising the benefits of being a Muslim	
Transitioning from fear to acceptance of her diagnosis	Justifying her emotional stress	
Limiting her psychological crisis to the effect of her father dying		
Denying any problem other than her father dying		
Considering her response to the diagnosis was normal		
Laughing at portraying herself as compliant and problem free	Using laughter to lighten acknowledgements of challenges to coping	
Using laughter when acknowledging a severe pain		
using laughter when describing her feeling of uselessness		
Using laughter when reinforcing her acceptance of God's destiny		
Denying any change in the family household	Family dynamics	Family
Acknowledging a natural change in family dynamics with time		
Exagerating how a little girl can lead the household because of illness		
Suggesting the cancer brought no changes to her role in the family		
Accepting her brother organises her hospital appointments		
Acknowledging no change in her lack of role at home	She has no role in the family	
Trivialising her position in the family prior to and post the cancer	She has no role in the family	
Distinguishing between her other health problems and the cancer	Cancer vs. her other health problems	Seeking, observing, interpreting, understanding
Defining the chemotherapy as completed	Chemotherapy is completed	
Interpreting the gyn Dr's ambivalence to mastectomy as minimalising her breast cancer	Deciphering the doctors attitude to her and her cancer	

Code	Sub-category	Provisional theme
Interpreting the Tun dr's silence as agreement with the test results and plan		
Perceiving her doctor was happy with her progress		
Emphasising that the post-mastectomy wound took a long time to heal	Delayed healing post mastectomy	
Giving importance to the research	Desiring, seeking and finding information on her diagnosis	
Employing her medications as key words for her internet search	Desiring, seeking and finding information on her diagnosis	Seeking, observing, interpreting, understanding
Desiring to know more about cancer	Desiring, seeking and finding information on her diagnosis	Seeking, observing, interpreting, understanding
Hinting that she desired and saught someone to speak openly with her		
Framing her knowledge of cancer as that which she has received		
Seeking and creating her own understanding of cancer		
Seeking information first from dr and then internet		
Seeking information from the doctors		
Seeking information on cancer only after her diagnosis		
Seeking information on the causes of cancer		
Seeking initial advice from her escort		
Understanding cancer as dead cells		
Understanding her disability is unrelated to her kidney problems		
Using her medications as a focus point for seeking information		
Using the internet to answer specific concerns or questions		
Using the internet to find information		
Actively searching information on cancer		
Linking amount of information provided to level of emotional distress		
Avoiding the term succesful for the treatment	Interpreting reasons and goals of treatment	
Holding the 'removal' and 'clean-up' in parallel		
Interpreting the chemotherapy was to clean the remaining cancer		
Perceiving chemo as purifying the body		
Perceiving that the purpose of the mastectomy was to find out more information		
Equating symptomatic relief and cure		
Perceiving the biopsy as an operation		
Perceiving the doctor's response to her pain was to order lots of tests and stop some medications		
Directly linking problems with non-compliance		

Code	Sub-category	Provisional theme
Acknowledging the randomness of effectiveness of prescriptions	Interpreting relationship between compliance to the protocol and problems	
Portraying that difficulties relate directly to uncompliance to the dr's plan		
Judging symptoms of others according to her experiences		
Synthesising her experience of pain and her knowledge of her cancer		
Trivialising the presence of a breast lump in others according to her own experience	Interpreting relationship between compliance to the protocol and problems	Seeking, observing, interpreting, understanding
Considering that life and cancer are incompatible	Life and cancer are mutually exclusive	
Suggesting a gradual appearance of cancer	Monitoring her progress or deterioration from start through cancer care	
Understanding that she was due chemotherapy and radiotherapy at the CNO		
Acknowledging her breast was heavier and painful at the beginning		
Referencing the time of finding the breast lump to the operation		
Remarking her breast swelling		
Using sleeping to measure her improvement		
Perceiving that all her body is deteriorating		
Believing that her experiences matching what she was told about cancer starting		
Detailing the dates for the breast lump trajectory		
Linking her health problems, anaemia and diagnosis of BC		
Being warned that further tests would be necessary if breast lump not changing		
Playing on the words 'reanimation' and 'reactivé'		
Contrasting effective prescriptions with errors		
Denying any lump at the beginning		
Emphasising how the breast swelling was initially small		
Distinguishing between these days and days of the cancer		
Feeling encouraged that her health is improving		
Portraying illness as coming and going		
Emphasising that the cancer was caught early on		
Perceiving she had no external signs of breast cancer		
Interpreting her pain as coming from her bones	Questioning her symptoms	
Limiting her pain to her bones		
Feeling thankful that her symptoms are not serious		
Acknowledging she is not sure of why she has pain		
Calculating the normality of a symptom to judge an action plan		

Code	Sub-category	Provisional theme
Considering fever, chest pain and pain in side as normal	Questioning her symptoms	
Having an understanding of her anaemia	Questioning her symptoms	Seeking, observing, interpreting, understanding
Questioning what caused her disability	Questioning her symptoms	
Questioning what is causing her pain		
Remarking that her worsening pain coincided with a dr's appt		
Remarking that the pain can come at any time		
Seeking to understand whether new symptoms are normal or not		
Suggesting that hair loss is a sign of other things going on in her body		
Thinking that her pain is due to stopping the medication		
Understanding her pain is coming from the bones		
Understanding that her swelling could change with the menstrual cycle		
Understanding her mood is affected by those around her		
Perceiving that scan reports from RIM are worthless	Questioning investigations, treatments and medications	
Considering medication helped her pain		
Perceiving her veins were not conducive to chemo		
Hinting at the possibility that there was no cancer present at time of biopsy		
Describing her problems with kidney insufficiency		
Questioning whether her kidney medications caused her disability	Questioning the cause of the illness	
Acknowledging that she did not understand why further tests were necessary	Questioning the protocol	
Seeking to know whether to stop or continue certain medications - nephrology	Questioning the protocol	
Seeking to understand the doctor's decisions	Questioning the protocol	
Judging her anaemia as severe	Questioning the protocol	
Describing the pain as coming to her	Relationship with the cancer	
Hinting that she considers cancer as an 'it'	Relationship with the cancer	
Describing cancer as coming to her	Relationship with the cancer	
Expressing her understanding that she cancer still affects her	Relationship with the cancer	
Explaining that she was only told the diagnosis after she already worked it out	Working out her own diagnosis	
Crediting only herself as working out and learning her diagnosis		
Emphasising her confidence in her diagnosis post mastectomy		
Interpreting the mastectomy as confirmation of her breast cancer		
Suspecting she had cancer prior to the confirmation		

Code	Sub-category	Provisional theme
Perceiving that the tests showed something abnormal	Working out her own diagnosis	Seeking, observing, interpreting, understanding
Reinforcing that the gyn Dr explained he found nothing wrong prior to the mastectomy	Working out her own diagnosis	
Considering faith as a personal thing and I am not part of it as I am not a Muslim	Demonstrating her commitment to Islam	Spiritual
Equating the culture Mauritanian and Islamic		
Expecting me to become a Muslim if I understood correctly		
Forcing me to say bismillah before drinking		
Framing her questioning my faith as a command of God		
Persuading me to become a Muslim		
Proposing my throat is blocked by not saying bismillah		
Wanting me to become a Muslim		
Wishing for me to become a Muslim		
Framing her freedom as a patient as an Islamic command		
Emphasising her belief in God		
Crediting me as a little bit Muslim		
Distinguishing between Christians and Christians of the Book		
Portraying her trust is only in God and his destiny		
Portraying Islam as protective against all psychological distress		
Portraying she takes refuge in God at all times		
Prioritising belief in God and conviction over anything else		
Prioritising her faith over westerners' humanity		
Reinforcing the idea that she does not fight God		
Suggesting that evangelism is a natural part of being a Muslim		
Thanking God for the mastectomy		
Viewing prayer beads as part of faith		
Considering that destiny is God's chosen plan for an individual	Destiny vs. fatalism	
Denying that destiny can be changed		
Hinting that God controls our actions		
Balancing her acceptance of destiny with having no choice other than acceptance		
Recognising that everyone dies		
Considering destiny as all encompassing		
Considering destiny is neither good nor bad	Destiny vs. fatalism	
Defining destiny		
Emphasising inability to do anything without God		Spiritual

Code	Sub-category	Provisional theme
Emphasising the exclusivity of belief in God for health		
Equating belief in destiny and belief in God		
Equating destiny with God's desire for that person		
Explaining how destiny controls her actions and those who act upon her		
Holding God guiding and controlling together		
I and my destiny are one		
Illustrating God's will and destiny with a brick wall		
Merging faith in God and faith in destiny		
Portraying an individualised destiny		
Portraying destiny as what God wills and not related to humans		
Portraying hope as something coming from God		
Prioritising the exclusivity of destiny in life		
Proposing that destiny can be bad or good		
Proposing that destiny goes to the very core of the individual		
Viewing destiny as written		
Directly crediting God with her cancer, paralysis and uselessness	God choosing to give her cancer and her symptoms	
Specifying that God actively chose the body location for the cancer		
Stating that God gave her the cancer		
Viewing God as the source of everything	God controls everything	
Emphasising the importance of visiting in Islam	God helps through commanding visiting the sick	
Perceiving God helps her through the visitors	God helps through commanding visiting the sick	
Portraying that no one is need in RIM because of Islam	Idealising support for everyone in RIM	
Accepting that having both faith and humanity is the ideal	Importance of faith and humanity	
Demonstrating she actively sought the advice of different doctors	Meeting her obligations in seeking a cure	
Asking God to give her a long life and riches	Normal hopes and desires	
Asking God for peace during the chemo	Normal hopes and desires	
Defining the desires of a normal person	Normal hopes and desires	
Defining healing as returning to her normal state	Normal hopes and desires	Spiritual
Defining hope	Normal hopes and desires	Spiritual
Defining humanity as equality and unity between all people	Normal hopes and desires	
Emphasising that everyone wants a long life and money	Normal hopes and desires	
Hoping that God will heal her	Normal hopes and desires	
Suggesting hope is big and perhaps otherworldly	Normal hopes and desires	

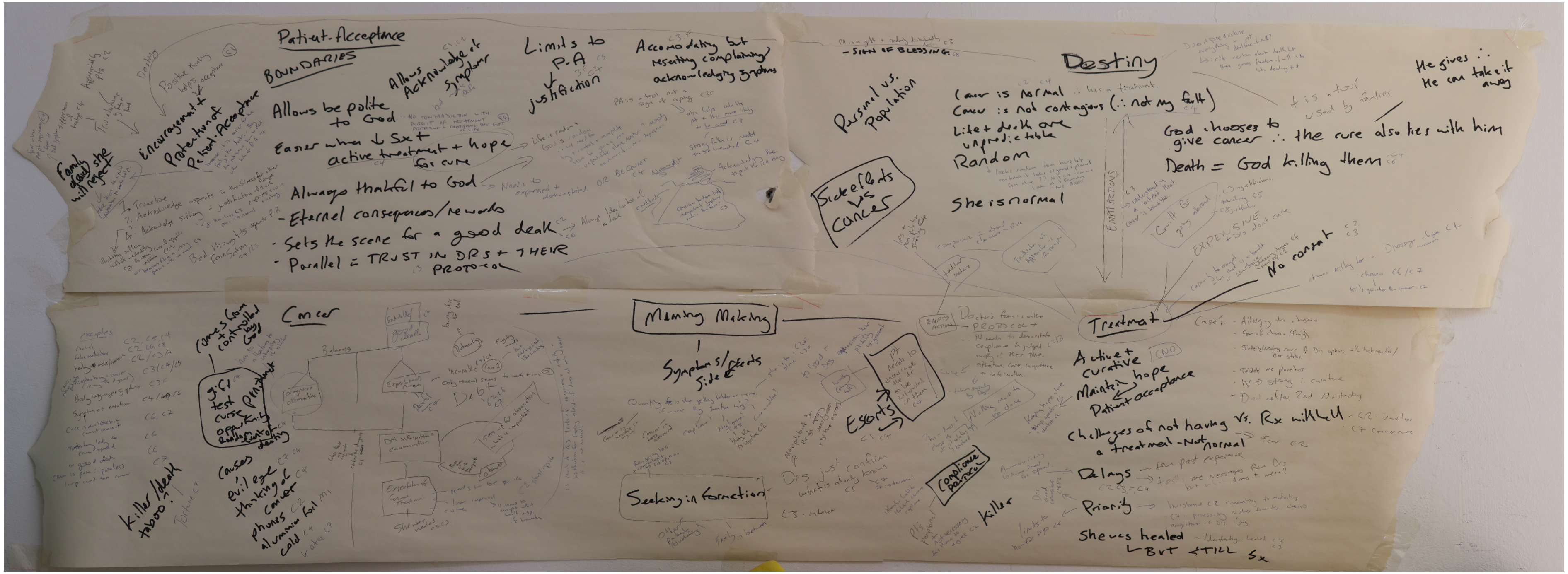
Code	Sub-category	Provisional theme
Considering nothing is possible without God's involvement	Nothing is possible without God	
Viewing trust in God and pain medications as non-contradictory	Parallelism of faith and medication	
Feeling she has finished her acceptance of cancer by relying on God	Relying on God leads to acceptance of the cancer	
Perceiving that God leads us to his healing	Requirements for healing	
Portraying God's will as trumping doctor's ability or character	Requirements for healing	
Proposing that all healing is God actions	Requirements for healing	
Denying any obligations towards 'empty actions'	Sibeu	
Defining sibeu	Sibeu	
Neglecting 'empty actions'	Sibeu	
Being cognisant she could get better or worse	The unpredictability of life, illness and death	
Considering causes and treatments as random events controlled by God		
Denying any encouragement from positive stories of people being healed		
'A person is well and suddenly'		
Accepting that sudden illness may be more complicated than perceived		
Being aware that destiny and cancer is unpredictable		
Describing the randomness of destiny and illness		
Emphasising not having any control over destiny		
Perceiving life and illness as random	The unpredictability of life, illness and death in destiny	
Considering that we can not judge the quality or value of life	The unquestionable intrinsic value of life	
Proposing that families give freedom to the patient to choose	Accepting help from the family	Support
Accepting physical support from her brother		
Accepting the need for someone to help collect her medications		
Considering that all the family help her at home		
Distinguishing between tasks inside her (toilet) and outside (laundry(		
Appreciating that she is only helped by those within the family	Accepting help from the family	Support
Appreciating that a medical student in family takes her blood		
Appreciating the medical student doing the blood tests		
Acknowledging she needs help with cooking, cleaning etc.		
Acknowledging she was fully reliant on others for a time		
Acknowledging she was in need of help in the past		

Code	Sub-category	Provisional theme
Being accompanied by her brother to Tunisia		
Telling her brother when she started to lose her hair		
Explaining the role of the family as gatekeepers during visits		
Limiting help to females		
Portraying that everyone in the household helps her		
Using the telephone to request help in the home		
Portraying collection of medications as only thing she needs help with at home		
Defining emotional support as being told it was trivial and only needing purifying	Appreciating reassurance and trivialisations	
Specifying that words which go to the heart are welcomed		
Appreciating stories of people healed from cancer and returning to normal		
Being reassured by friends' trivialisations of cancer		
Receiving advice from family and friends to eat, drink and walk		
Receiving trivialising versions of a breast cancer diagnosis		
Defining emotional support as that she is the same as others	Being viewed by others as normal	
Perceiving that we know of her pain from previous interviews	Expectations of others to be aware of her condition	
Appreciating that her family is available if she needs help	Help available when needed	
Portraying that there is no financial need in RIM because of the society	Idealising support for everyone in RIM	
Emphasising that Tunisia was difficult because she knew no one	Lonely abroad	
Appreciating the prayers of others	Prayers of others	
Considering prayers as an important part of visitors	Prayers of others	
Understanding that people prayed for her to be healed	Prayers of others	
Perceiving having less visits with time	Visitors	
Perceiving she had lots of visitors at the beginning		Support
Appreciating having lots of visitors		
Appreciating her friends welcome and greetings		
Appreciating her friends' positive chat		
Appreciating new people visiting her		
Appreciating visitors who can have a laugh		
Being aware her friends wanted to know her condition		
Considering that all visitors respect the rules for visiting		
Considering that there are rules on how to visit the sick		

Code	Sub-category	Provisional theme
Considering that visitors receive credit for visiting the sick		
Denying any annoyance or inconveniences from her friends		
Denying any negative side to having visitors		
Emphasising how nakedness needs to be avoided during visits		
Expecting visitors to not stay too long		
Explaining how visitors can fulfill their obligations without seeing the patient		
Explaining the network of family and friends who visit		
Guarding the dignity of the patient during visits		
Having no control over when visitors leave		
Listing passing time, giving money, or telling stories to help those whom are visited		
Perceiving a benefit from visitors because it is commanded in Islam		
Perceiving her visitors have positive motivations for visiting		
Perceiving that everyone has something to give during social visits		
Perceiving that her visitors come to greet her		
Portraying that it is natural for visitors not to stay long		
Portraying she had lots of emotional support		
Suggesting she had met new people through them visiting her		
Emphasising that RIM culture is no different to others		Support
Considering that it is natural that most patients prefer to have care abroad	Acknowledges that everyone prefers to go abroad	Travelling abroad
Describing the trauma of a failed port insertion in RIM	Acknowledging a traumatic experiences in RIM	
Acknowledging that suffering from the failed port insertion	Acknowledging a traumatic experiences in RIM	
Advising others to have cancer treatment in RIM	Demonstrating her respect for care in RIM	
Portraying that no one is need in RIM because of Islam		
Simplifying the process of port and chemo in Tunisia	Idealising the care provided in Tunisia	
Accepting to have the biopsy in RIM	Limiting RIM problems to the scan reports	
Perceiving that scan reports from RIM are worthless		
Proposing that the reliability of scan reading is poor in RIM		
Having confidence in the CT scans in RIM but not the interpretation		
Taking her RIM scans abroad for interpretation		

Code	Sub-category	Provisional theme
Accepting that poor interpretation of scans is a reason for travelling abroad		
Learning from drs abroad not to trust scan reports from RIM		
Portraying cancer care has improved in RIM recently	She would do it differently now	
Considering they did not know or understand the CNO when they travelled abroad	The CNO was not known at that time	
Contrasting past healthcare in RIM with the present	The CNO was not known at that time	
Portraying no difference in care between RIM and Tunisia	Trivialising the decision as all care is the came	
Justifying travelling to Tunisia post mastectomy		
Perceiving that breast cancer treatment is the same globally		
Denying any specific concerns or worries for why they went abroad for care	Trivialising the decision to travel abroad for treatment	
Portraying that the decision to travel abroad did not reflect negatively on the CNO		
Trivialising the decision to travel abroad for chemo		
Perceiving no need to justify travelling abroad for healthcare		

Appendix 17: Mind map during data analysis



Appendix 18: Ethics approval

Lancaster
University

Applicant: Dave Fearon
Supervisors: Sean Hughes and Sarah Brearley
Department: Health research
FHMREC Reference: FHMREC15060

05 April 2016

Dear Dave,

Re: Life journeys with advanced breast cancer in Mauritania: A mixed methods case study.

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Diane Hopkins (01542 592838 fhmresearchsupport@lancaster.ac.uk) if you have any queries or require further information.

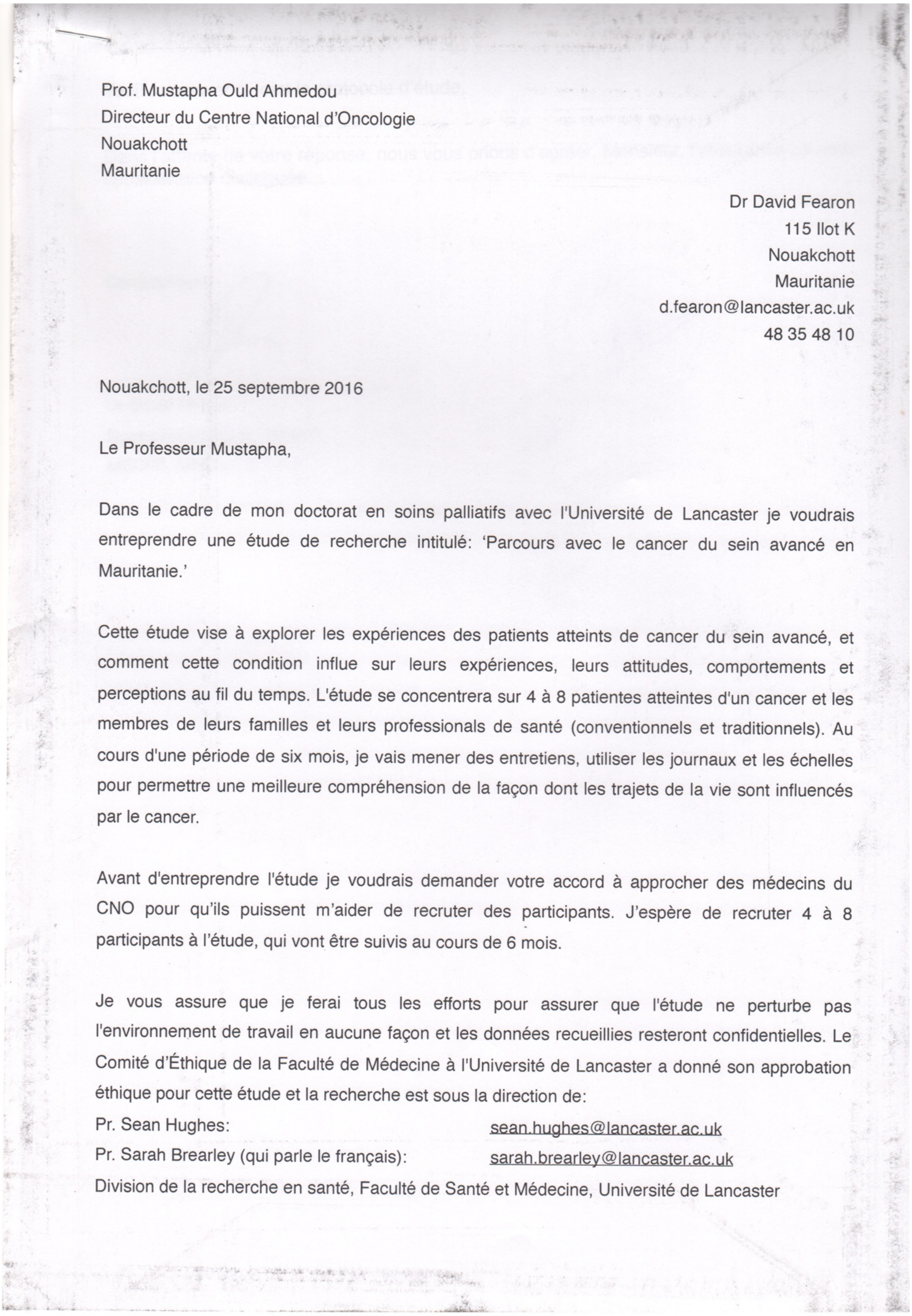
Yours sincerely,

Diane Hopkins

Dr Diane Hopkins
Research Development Officer

CC Ethics@Lancaster; Professor Roger Pickup (Chair, FHMREC)

Appendix 19: Local governance approval



Prof. Mustapha Ould Ahmedou
Directeur du Centre National d'Oncologie
Nouakchott
Mauritanie

Dr David Fearon
115 Ilot K
Nouakchott
Mauritanie
d.fearon@lancaster.ac.uk
48 35 48 10

Nouakchott, le 25 septembre 2016

Le Professeur Mustapha,

Dans le cadre de mon doctorat en soins palliatifs avec l'Université de Lancaster je voudrais entreprendre une étude de recherche intitulé: 'Parcours avec le cancer du sein avancé en Mauritanie.'

Cette étude vise à explorer les expériences des patients atteints de cancer du sein avancé, et comment cette condition influe sur leurs expériences, leurs attitudes, comportements et perceptions au fil du temps. L'étude se concentrera sur 4 à 8 patientes atteintes d'un cancer et les membres de leurs familles et leurs professionals de santé (conventionnels et traditionnels). Au cours d'une période de six mois, je vais mener des entretiens, utiliser les journaux et les échelles pour permettre une meilleure compréhension de la façon dont les trajets de la vie sont influencés par le cancer.

Avant d'entreprendre l'étude je voudrais demander votre accord à approcher des médecins du CNO pour qu'ils puissent m'aider de recruter des participants. J'espère de recruter 4 à 8 participants à l'étude, qui vont être suivis au cours de 6 mois.

Je vous assure que je ferai tous les efforts pour assurer que l'étude ne perturbe pas l'environnement de travail en aucune façon et les données recueillies resteront confidentielles. Le Comité d'Éthique de la Faculté de Médecine à l'Université de Lancaster a donné son approbation éthique pour cette étude et la recherche est sous la direction de:
Pr. Sean Hughes: sean.hughes@lancaster.ac.uk
Pr. Sarah Brearley (qui parle le français): sarah.brearley@lancaster.ac.uk
Division de la recherche en santé, Faculté de Santé et Médecine, Université de Lancaster

Veuillez trouver ci-joint le protocole d'étude.

Dans l'attente de votre réponse, nous vous prions d'agréer, Monsieur, l'assurance de notre considération distinguée.

Cordialement

Dr David Fearon
Doctorant en Soins Palliatifs
MBChB, MRCGP, DTMH

Oui

Ministère de la Santé
CENTRE NATIONAL D'ONCOLOGIE
Le Directeur

Appendix 20: Distress protocol

This protocol is taken from the African Palliative Care Association (2011)

The researcher and translator administering the tool are expected to be compassionate, patient and respectful at all times during the interview and administration of the APCA African POS. If during the interview or the administration of the APCA African POS the participant becomes distressed (e.g. they show strong emotions or start to cry) then the researcher/translator will stop the interview and will use the following distress protocol, as appropriate:

If the participant shows distress (e.g. if they show strong emotions or start to cry) then the researcher/translator will say the following:

I understand that what we are discussing is emotionally difficult for you.

[wait and if the participant is still in distress proceed to one of the following sentences; otherwise carry on with asking the questions]

a. [Patient-Participant]. **We can stop asking you questions if you wish. To do so will not affect your care and treatment.**

b. [Case-Participant - family member] **We can stop asking you questions if you wish. To do so will not affect the patient's care and treatment.**

[wait and if the participant says he / she wishes to stop proceed to following sentence; otherwise carry on with asking the questions]

You have already been given a contact number for a counsellor in your information sheet, however I can give it to you again if needed. You may contact this person to talk through any of the issues or else you may talk through them with me if that would help. You are free to withdraw the information you have given me today, would you like to do this?

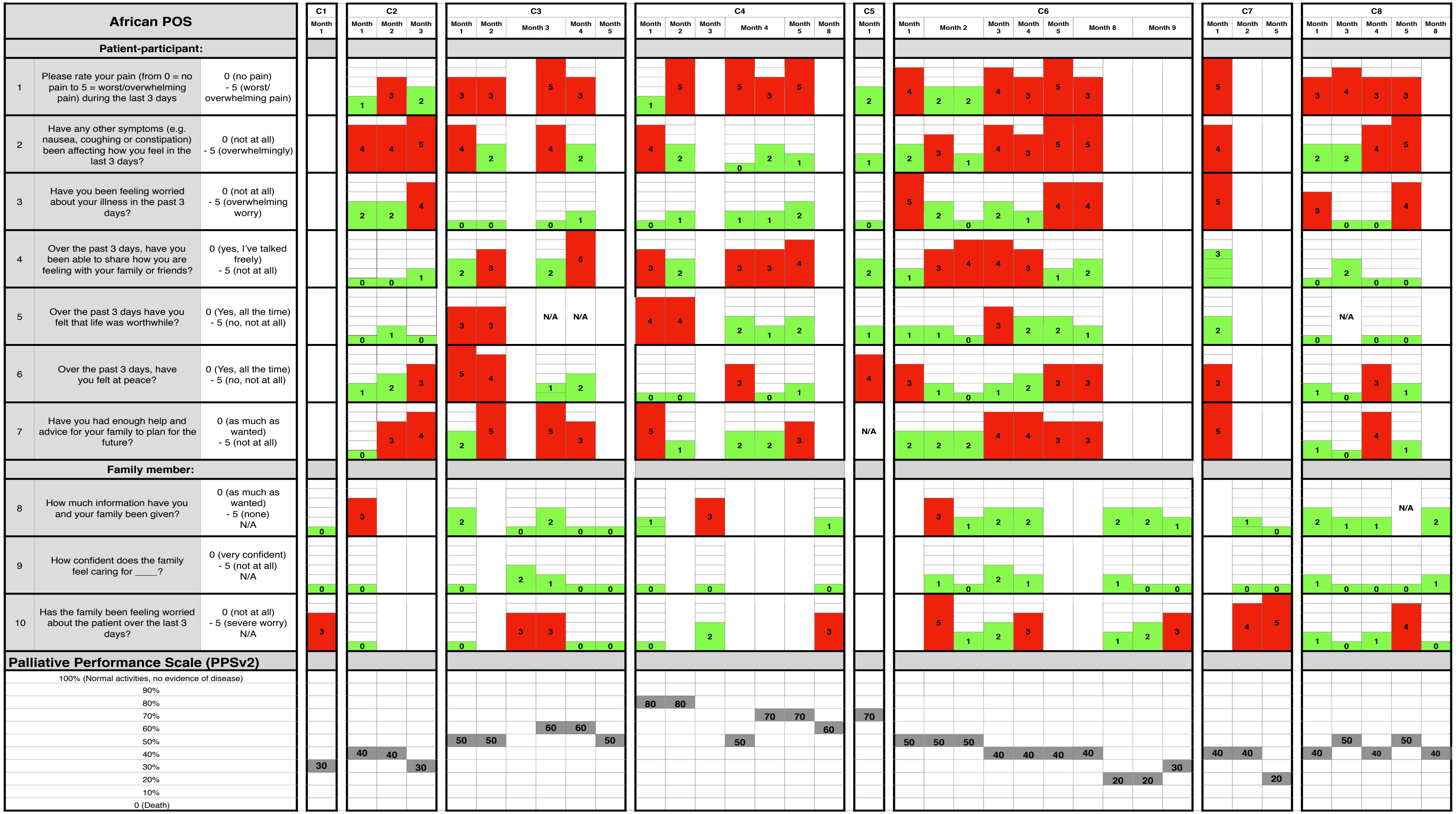
[wait and record answer]

If this research has harmed you in any way, I do apologise and you can contact myself, David Fearon, at a later date or Mohamed Salem, at the National Cancer Centre on 48 35 48 10 for further advice and information.

Thank you very much for your time and effort.

IMPORTANT: If the researcher/translator have a high level of concern about a participant (e.g. if they suspect a participant is very depressed and possibly suicidal) they must discuss this as a matter of urgency with the director of the National Cancer Centre to proceed with appropriate action to further assist and aid the participant in question, if this is felt appropriate.

Appendix 21: Quantitative data findings



African POS			C1	C2			C3					
			Month 1	Month 1	Month 2	Month 3	Month 1	Month 2	Month 3		Month 4	Month 5
Patient-participant:												
1	Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (no pain) - 5 (worst/ overwhelming pain)		1	3	2	3	3		5	3	
2	Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all) - 5 (overwhelmingly)		4	4	5	4	2		4	2	
3	Have you been feeling worried about your illness in the past 3 days?	0 (not at all) - 5 (overwhelming worry)		2	2	4	0	0		0	1	
4	Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (yes, I've talked freely) - 5 (not at all)		0	0	1	2	3		2	5	
5	Over the past 3 days have you felt that life was worthwhile?	0 (Yes, all the time) - 5 (no, not at all)		0	1	0	3	3		N/A	N/A	
6	Over the past 3 days, have you felt at peace?	0 (Yes, all the time) - 5 (no, not at all)		1	2	3	5	4		1	2	
7	Have you had enough help and advice for your family to plan for the future?	0 (as much as wanted) - 5 (not at all)		0	3	4	2	5		5	3	
Family member:												
8	How much information have you and your family been given?	0 (as much as wanted) - 5 (none) N/A	0	3			2		0	2	0	0
9	How confident does the family feel caring for ____?	0 (very confident) - 5 (not at all) N/A	0	0			0		2	1	0	0
10	Has the family been feeling worried about the patient over the last 3 days?	0 (not at all) - 5 (severe worry) N/A	3	0			0		3	3	0	0
Palliative Performance Scale (PPSv2)			30	40	40	30	50	50		60	60	50

African POS	C4							C5
	Month 1	Month 2	Month 3	Month 4		Month 5	Month 8	Month 1
Patient-participant:								
1	1	5		5	3	5		2
2	4	2		0	2	1		1
3	0	1		1	1	2		0
4	3	2		3	3	4		2
5	4	4		2	1	2		1
6	0	0		3	0	1		4
7	5	1		2	2	3		N/A
Family member:								
8	1		3				1	
9	0		0				0	
10	0		2				3	
Palliative Performance Scale (PPSv2)	80	80		50	70	70	60	70

African POS	C6									
	Month 1	Month 2		Month 3	Month 4	Month 5	Month 8		Month 9	
Patient-participant:										
1	4	2	2	4	3	5	3			
2	2	3	1	4	3	5	5			
3	5	2	0	2	1	4	4			
4	1	3	4	4	3	1	2			
5	1	1	0	3	2	2	1			
6	3	1	0	1	2	3	3			
7	2	2	2	4	4	3	3			
Family member:										
8		3	1	2	2			2	2	1
9		1	0	2	1			1	0	0
10		5	1	2	3			1	2	3
Palliative Performance Scale (PPSv2)	50	50	50	40	40	40	40	20	20	30

African POS	C7			C8				
	Month 1	Month 2	Month 5	Month 1	Month 3	Month 4	Month 5	Month 8
Patient-participant:								
1	5			3	4	3	3	
2	4			2	2	4	5	
3	5			3	0	0	4	
4	3			0	2	0	0	
5	2			0	N/A	0	0	
6	3			1	0	3	1	
7	5			1	0	4	1	
Family member:								
8		1	0	2	1	1	N/A	2
9		0	0	1	0	0	0	1
10		4	5	1	0	1	4	0
Palliative Performance Scale (PPSv2)	40	40	20	40	50	40	50	40

Palliative Performance Scale (PPSv2)
100% (Normal activities, no evidence of disease)
90%
80%
70%
60%
50%
40%
30%
20%
10%
0 (Death)

🟥	Worse functioning or well-being
🟩	Better functioning or well-being

Appendix 22: Summary of the themes from the mini-case

Participant		H1	H2	H3	H4	H5	H6	H7	H8	H9
Being afraid of cancer		✓(1)				✓	✓			
Blaming patients	For choosing to remain ignorant	✓(2)			✓		✓		✓	
	For their delayed diagnosis		✓(3)				✓	✓	✓(4)	✓
	For their spread of cancer	✓	✓	✓					✓(5)	✓
Cancer treatments are difficult and sometimes worsen the situation				✓(6)		✓	✓		✓	✓(7)
Demonstrating pity or empathy for patients		✓	✓	✓	✓(8)	✓	✓	✓	✓	✓(9)
Disclosure of information is a tool wielded with precision according to the doctor's objectives			✓		✓(10)		✓	✓	✓	✓
My work concerns only physical problems							✓	✓		
My work is difficult	Practical work conditions and staff relationships	✓		✓		✓		✓		✓(11)
	Families are too demanding	✓		✓	✓	✓	✓	✓	✓	✓

Participant		H1	H2	H3	H4	H5	H6	H7	H8	H9
	Being blamed by families and patients for delays and problems	✓			✓			✓	✓	
	My patients all die	✓				✓				✓
	Not doing what we should be doing				✓	✓				
Patients should demonstrate patience-acceptance while being committed to the protocol		✓(12)	✓	✓	✓	✓	✓	✓		
Patients work out their own diagnosis			✓		✓		✓	✓		
Preference to not disclose diagnosis or to do so in a few rare cases		✓	✓	✓	✓	✓	✓	✓	✓(13)	✓
Prioritising compliance to the protocol		✓		✓	✓		✓	✓(14)	✓	✓
Respect for traditional medicine						✓				
Women are ignorant		✓	✓		✓		✓	✓	✓	
Use of facilitators		✓			✓(15)		✓	✓	✓	

1. [an orderly brings him his meal to his room in a hot metal container] Here is the meal! They brought me the meal on aluminium! I refuse to eat it because it comes hot, it warms the aluminium, we can't treat people who suffer from cancer and we get a cancer because aluminium or because of the plastic. It is, it is… we work in very difficult conditions.

M1, second interview

2. You know Mauritania is a culture…how do you say it? A little slow compared to other countries. […] So that's the problem. They don't even care about it. They don't have ... I sometimes find patients, men and women, who say that it is better to stay blind, to not know the disease rather than knowing. To remain undiagnosed so she suffers from an illness to death, instead of knowing this disease.

M1, first interview

3. All the family is gathered together. It's a waste of time. They wait two weeks before deciding on a procedure [mastectomy]

M2, interview

4. Unfortunately the patients, they come late to seek medical care.

M8, interview

5. It's a cancer, it's a serious illness. Sometimes the patient has the surgery, but she does not continue with the ..., the doctors direct her to chemotherapy, but she never comes. They're lost from sight. She goes home, but comes back after metastatic recurrence, it's a catastrophe.

M8, interview

6. Curative treatment is always painful.

M3, interview

7. Ah, there are people who normally should not have to do chemo. If the person is weak... if they do the chemo... I've heard that the person with a metastasis should not normally have chemo. Instead of doing chemo, it would be better to do palliative

care. Because I’ve seen a lot of cases, the patient is fatigued, and we give them chemo, and after two or three days, she's dying.

M9, interview

8. Fairly often we receive patients who have spent two to three months, sometimes six, sometimes a year, with another doctor in another health structure. So, the patient is afraid, that she is going to suffer the same thing, the delay of the treatment so maybe they are right too. […] They will think that maybe we don’t want to treat them, or maybe we want to see them privately.

M4, second interview

9. [Talking about women with fungating breast cancer] It is a disease very… it is a very serious disease. For me, the cases I see, it bothers the patient and especially because of the smell, and for other patients it's a large tumour you see, and it bothers them.

M9, interview

10. Assistance is what I do, if I see a patient who is not disciplined or who is not cooperating with the chemotherapy and radiotherapy. I really tell him. I ask him the question what do you understand do you have as illness? I explain the disease to him as such and if he does not continue his regular treatment, he will decrease the chance of recovery.

M4, second interview

11. They say there’s a risk of infertility [with chemotherapy]. Sometimes I give the chemotherapy and the product enters my eyes, that's one of the risks. I go to see the doctor and I tell him that the product came into my eyes, he told me to put water.

M9, interview

12. A husband, his wife died, his daughters and his sons were there, there was no one who cried, they said nothing. They said Alhamdulilah (thank God!) Simply. Simply Alhamdulilah (thank God!) Because the father told them not to cry, not to cry,

they said Alhamdulilah (thank God!) They did not even shed a single tear. It really surprised me, he amazed me […] for us as Muslims it is a good thing.

M1, second interview

13. There is a problem of ... there is a problem that ... most of the doctors they are afraid to announce the illness, the diagnosis of this patient by what he thinks ... he is afraid that who ... if he announces he will lose the patient. It’s not worth announcing it... not to announce and think and leave the patient alone to be at peace...

M8, interview

14. But I never tell a patient that it’s something, that is to say, to avoid especially during the first consultation because in order for the patient to respect the treatment, to accept the treatment, it’s to avoid them being depressed or demoralised from the start because the patients who come with cancer have hope, she still hopes for a treatment that will stop the disease

M7, second interview

15. Yes, the problem is that in practice, in practice I rarely say no [to demands to see patients urgently]. Why? Because if I say I won’t, I may sometimes be called by my father! […] The family, the society is really small, especially for my family, it is a well-known family, is a family known in Mauritania. So, they will contact someone from my tribe, the big family, and I will be contacted within 1 hour of time.

M4, second interview

Appendix 23: Translation process of ‘empty-actions’

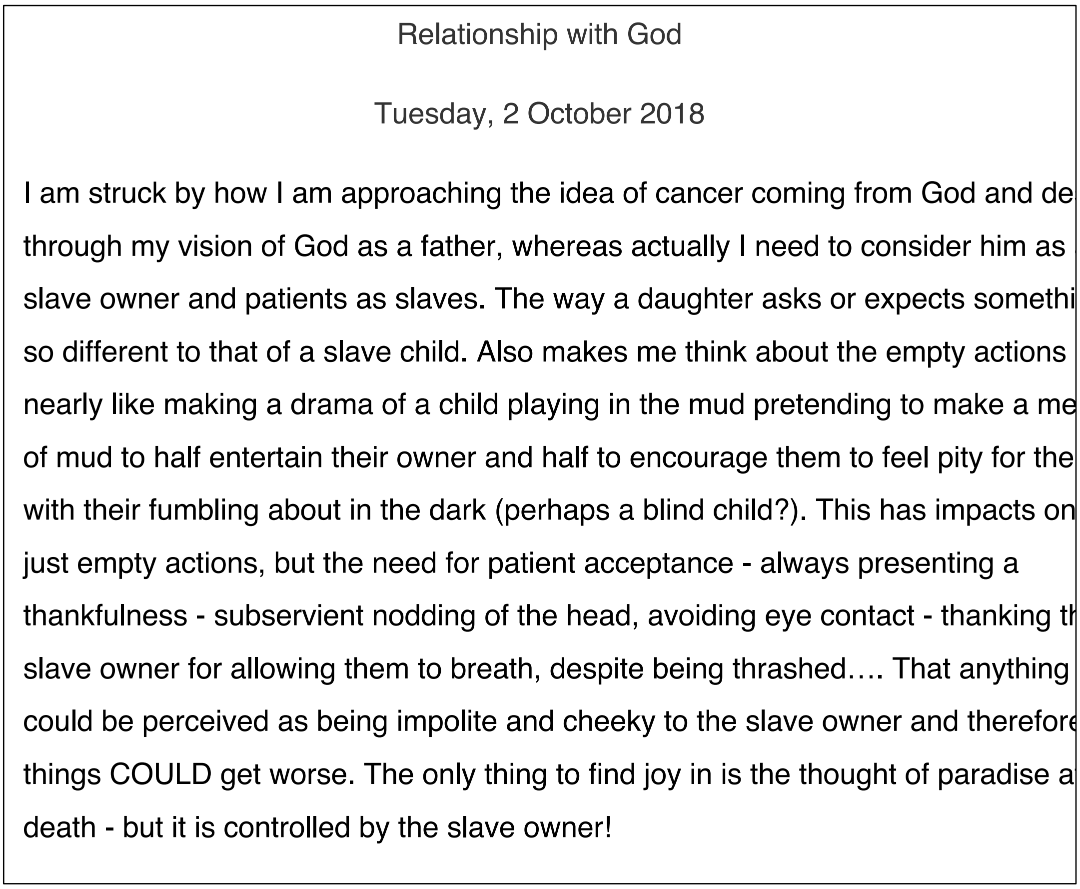
Participants employed the term, ‘سبب’ or ‘sebab’, when referring to the English term ‘treatment’ in the interview and audio journal transcripts. This was consistent in the data whether the respective treatment was biomedical or traditional in origin. Sebab is literally translated as ‘cause’ (Doniach, 1992). The transcribers figuratively translated it as ‘alibi’ or ‘pretext’ in the translation of qualitative data. These terms were chosen because they better communicated the women’s perception that any treatment is a pretext which only gives the illusion of having an effect. Any effect of an action is exclusively dependent on the will of Allah. In the analysis stage of this multi-case study, sebab, its meanings and potential translations were discussed by the core translation team as introduced in section 3.11. Consensus was reached to adopt the phrase ‘empty-action’ to illustrate how all treatments are viewed as equally empty in nature and only become useful and active when made so by Allah. Palliative care doctors and researchers in the UK, Sudan, Lebanon and Morocco were asked for their opinion on this.

Politeness and doctors

Friday, 28 September 2018

Many participants demonstrate trust and confidence in doctors and their competence - is that also similar to trust and polite appreciation of God - because what the doctors provide is fragile and could be taken away and they would have no recourse. This is what they have often experienced elsewhere - being powerless - even undergoing horrific experiences they have no option but to return. Such is the power that the health provider holds, because they hold the cure (or is an empty action to the cure). Is a cure actually like a key gateway thing in Harry Potter - that there is nothing special in itself - like a cup or a boot, however it has been imbided with power to become a gateway to another place.

Box A23.1: Excerpt from reflective diary



Relationship with God

Tuesday, 2 October 2018

I am struck by how I am approaching the idea of cancer coming from God and de
through my vision of God as a father, whereas actually I need to consider him as
slave owner and patients as slaves. The way a daughter asks or expects somethi
so different to that of a slave child. Also makes me think about the empty actions
nearly like making a drama of a child playing in the mud pretending to make a me
of mud to half entertain their owner and half to encourage them to feel pity for the
with their fumbling about in the dark (perhaps a blind child?). This has impacts on
just empty actions, but the need for patient acceptance - always presenting a
thankfulness - subservient nodding of the head, avoiding eye contact - thanking th
slave owner for allowing them to breath, despite being thrashed…. That anything
could be perceived as being impolite and cheeky to the slave owner and therefor
things COULD get worse. The only thing to find joy in is the thought of paradise a
death - but it is controlled by the slave owner!

Box A23.2: Excerpt from reflective diary