**Title:** Women’s experiences of advanced breast cancer in a resource-limited Arab context: A Stakian multi-case study

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**KEYWORDS**

Neoplasms, Breast cancer, Arab, Cross-cultural, Case study, Qualitative, Psycho-oncology, oncology, cancer

# **ABSTRACT**

**Objective:**

Breast cancer is the most common cancer for women, globally. Women are more likely to present with more advanced cancer and palliative care needs in low-resource contexts. There is limited research on Arab, Muslim and African women’s experiences of advanced breast cancer. The aim of this study was to explore and understand the experiences of advanced breast cancer in the Islamic Republic of Mauritania.

**Methods:**

Using a constructivist Stakian multi-case study approach, eight cases were constructed with women with advanced breast cancer (n=8), family members (n=10) and health professionals (n=9). Data were collected longitudinally (up to nine months per case) and included semi-structured interviews and audio-journals. Data from 58 interviews and 31 journal entries were thematically analysed.

**Results:**

Three key themes were identified: 1. Destiny: Maure women appreciate that Allah is all powerful and maintains control over their destinies and their breast cancer. 2. Patience & Acceptance: a fear of causing offence to Allah influences how women express their experiences of breast cancer and its treatments. 3. Journeying in search of a cure: Maure women have limited access to information around their cancer and its treatments. Women use their own observations and interpretations to understand their breast cancer and guide their pursuit of treatment and a cure.

**Conclusion:**

Maure women feel reassured that life and cure remain possible because of Allah’s sustenance; but are aware that the gift of life is fragile. They experience restricted power over how they express negative experiences, access to information, and healthcare decisions.

# **BACKGROUND**

Breast cancer is the most common cancer diagnosed in women, globally1. Its incidence is highest in high-income regions, but its mortality is highest in low- and middle-income countries (LMIC)1-2. In LMICs, 20 to 30% of new breast cancer diagnoses are metastatic, compared with less than 8% in high-income regions3. Metastatic or advanced breast cancer is associated with a worse prognosis, increased symptom burden and lower quality of life4 5. In Arab countries, advanced breast cancer is associated with more restricted access to information and involvement in decision making than for earlier cancers4 6. Fearon et al.4 and Hashemi et al.6 propose that these differences are because the women’s families and health professionals fear that women with advanced cancer are more likely to lose hope and abandon treatment. There is limited research from the lower income Arab countries, with no previously published research on the experiences of breast cancer from the Islamic Republic of Mauritania.

Mauritania, a member of the League of Arab States7, is a lower middle-income country in North West Africa. Access to the limited available services is inequitable, with the majority of structures centralised in the capital, Nouakchott. 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.

Breast cancer is the most common cancer amongst women in Mauritania, estimated at between 25 to 30 percent of all cancers in women8. Many of the those presenting to the CNO with breast cancer have advanced cancer. The larger study, on which this paper is based, explored the experiences of women with advanced breast cancer, their families and health professionals in Mauritania. In this paper, we will focus on the experiences of the women, using data from the families and health professionals to shed light on the women’s own experiences.

# **METHODS**

A Stakian constructivist multi-case study was carried out between November 2016 and May 20189-11. Case study research is employed in many areas of research including business science, education, and healthcare12. It involves a holistic and indepth exploration of a real-life, particular bounded context or phenomenon. Case study research relates to what is to be studied more than to an underlying epistemological paradigm or methodology13.

Stake proposes that foreshadowed issues serve as boundaries for the case study, helping to avoid the creation of vast quantities of redudent data10 14. Foreshadowed issues are theoretical orientations determined through personal experience and the literature. Our foreshadowed issues (table 1) served to guide our case study, including the construction of the case and data analysis.

Table 1: Foreshadowed issues

|  |  |
| --- | --- |
| 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 |

## **The case**

Purposive sampling was employed to recruit Maure women with advanced breast cancer. A sample of size of four to ten women was planned, consistent with qualitative research which seeks a deep understanding of a phenomen 10. Each case was embedded with mini-cases consisting of family members and healthcare professionals.

**Recruitment**

The medical oncologist at the CNO provided information to women who met the inclusion criteria at their Tuesday morning out-patient clinic. If interested, the first author and interpreter were introduced to the women. Verbal and written information were provided for the women and family in French and Hassaniya. Women were able to provide written informed consent in two ways because of the unreliable local postal system. They could complete the consent forms at home and return them to a secure locked box at the CNO, or they could be complete them during the initial information giving meeting. A cooling-off period of at least two weeks was provided between consent and the first data collection. Recruited women were asked to nominate family members and health professionals to participate in the study. These additional recruited participants were embedded as mini-cases in the eight cases10.

There were two phases of recruitment with six cases recruited between November 2016 to February 2017 with a further two between September to October 2017.

## **Data collection**

Each case was followed for up to nine months. Serial semi-structured interviews were carried out with the women, family members and health professionals. Regular audio-journals were recorded by family members. Interviews were conducted by the first author with assistance of an interpreter in mutually convenient locations. The interview guide was tested with an orderly at the CNO to confirm its clarity and cultural acceptability. All interviews were audio-recorded and securely stored in a digital format until the validation of the transcription.

## **Data analysis**

All interview and journal audio-recordings were transcribed verbatim and translated from Hassaniya to French by professional transcribers. Identifiable data were anonymised. Transcripts in French were exported into N-Vivo for Mac®. Analysis and synthesis of the data followed Stake’s suggestions to alternate focus between the uniqueness and particularity of the individual cases with that of the broader phenomena of advanced breast cancer as experienced across the cases10.

This multi-case study involved two techniques of thematic analysis. Firstly, the individual transcripts were analysed inductively, described as data-driven by Braun and Clarke15. All interview and audio-journal transcripts were read and re-read to enable familiarisation with the data. Transcripts were then coded line by line. Coding frameworks were created for each participant (see supplementary file 1-1 for example). Secondly, the foreshadowed issues served as lenses through which the case and cross-case level data were analysed. This 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 explored15.

**ETHICAL CONSIDERATIONS**

Ethical approval was provided by the Faculty of Health and Medicine Research Ethics Committee at the University of Lancaster (reference FHMREC15060).

# **RESULTS**

Eight women participated in the study (see table 2). Ten family members were recruited to mini-cases, which were embedded in seven cases. Nine health professionals (seven male doctors, one female nurse and one male nurse) were recruited to a healthcare mini-case, which was embedded in each case.

A total of 58 interviews were carried out, 23 with women with breast cancer, 23 with family members and 12 with health professionals. These lasted a mean of 53, 52 and 47 minutes respectively. Thirty-one audio journal entries were recorded by six family members.

Table 2: 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 |
| Chemotherapy | 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) Estimation

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

This paper presents three identified major themes and ten subthemes which describe the experiences of Maure women with advanced breast cancer.

### **Theme 1: Destiny**

#### Breast cancer is normal

Women accepted that breast cancer was part of their destiny, the unavoidable and unchangeable will of Allah. They considered that He consciously and purposefully gave them the cancer; deciding its location, size and spread. They appreciated that because breast cancer was under Allah’s control then everything was 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’16.

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.

*Case 5, Aissata: interview 1*

#### Death is inevitable and unpredictable

Death was seen as a central element of destiny; normal, natural and inevitable for every person. Death is ordered and organised because of Allah’s conscious control over destiny but unpredictable because Allah is distant, and His ways are unknowable for humans. There was no relationship between the women’s inevitable death and their breast cancer.

It's part of his faith to believe that only Allah can kill. There is no need to tell her that she will die in two months or two years, because that doesn’t change anything, she will always tell you that only Allah kills.

*Case 4, cousin: interview 3*

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*

### **Theme 2: Patience & Acceptance**

#### Appreciating the gift of life

Women viewed their life as a gift from Allah, but a fragile, unpredictable gift that required His continuous sustenance. They feared that any lapse of respect for life could result in Allah reclaiming His gift. Life was to be cherished, irrespective of any experiences or circumstances, and so the women remained thankful, polite and respectful to Allah. 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*

#### Concealing and expressing difficulties

Participants acknowledged that there were numerous negative experiences associated with breast cancer but they were careful in how such experiences were expressed. Silent endurance of negative experiences was considered to be the ideal response because it most clearly exhibited Patience & Acceptance and avoided the risk of appearing impolite to Allah. When the experienced suffering made such stoicism impossible, the women remained guarded in how they expressed themselves.

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*

Sometimes I don’t want to scream, not to disturb people but the pain was too strong. The clothes which I used to try to stifle my cries were useless.

*Case 4, Oumou: interview 2*

It was uncommon for women to openly acknowledge and emphasise their suffering. When they did, such expressions reinforced the women’s efforts to obtain help and to motivate others to have pity and empathy towards them. The women accepted that such expressions risked others viewing them as weak, cowardly and having little faith.

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*

#### Eternal perspectives

It was perceived by all the participants that a women’s patient and accepting response to breast cancer would result in the removal of their sins and improved chances of entering paradise. These eternal rewards were so highly esteemed that breast cancer was viewed as a gift and not just a test. In contrast, family members found it challenging when a women’s responses 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.

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

*Case 4, cousin: interview 2*

### **Theme 3: Journeying in search of a cure**

#### Empty actions

Women searched for a cure in spiritual, traditional and biomedical treatments. This pursuit was affirmed as appropriate because it demonstrated to Allah and others that the gift of life was cherished. It was emphasised that the curative potential of any treatment was nil, except when made useful and effective by Allah. Women, family members and health professionals employed the term ‘sebab’ or ‘سبب’ to refer to any such treatment. Sebab, literally translated as ‘cause’, has been translated in this study as ‘empty-action’ to reflect the perception that an action’s effectiveness was exclusively dependent on Allah.

It’s only Allah who can heal us; the hospital is useless, it's just an ‘*empty-action’ [سبب]*

*Case 8, Khadija: interview 2*

If a patient is cured, it isn’t me who has healed her. I was the ‘*empty-action’* *[سبب]* […] My belief is that it’s not the radiotherapy, but the good Allah.

*Healthcare mini-case, H4: interview 2*

#### Building knowledge

Women had limited prior awareness of breast cancer and what they did know made them afraid. They sought information in order to better understand their breast cancer and how it may be cured. Women compared the effectiveness, costs, and dangers of the ‘empty-actions’ available to them.

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*

Women perceived that much of the information provided to them was trivialising and misleading. It was common for the women to learn of their diagnosis following their mastectomy, often performed without the women’s consent.

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.

*Case 3, Binta: interview 1*

*Negotiating access*

The predominantly male doctors were viewed by the women and family members as powerful gatekeepers to breast cancer information and treatment. Delays in accessing doctors were common and frustrating. To help facilitate access, the women paid to see doctors in their private clinics, or recruited more powerful relatives and friends, such as doctors and nurses, to act as conduits for information.

In the end [the hospital doctor] didn’t [refer her to the oncology centre]. 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*

In addition to experiences of neglect, several women described emotional and physical abuse during their healthcare encounters, for example during dressing changes and pleural aspirations. They felt obliged to endure such experiences because refusal or complaint risked losing their access to the only care available.

#### Navigating diversions

The women’s cancer journeys were long and challenging. Experiences which were unexpected and difficult to understand were especially stressful. For example, women were unprepared for the side effects of chemotherapy, and blamed it for causing multiple problems such as paralysis, breathlessness and pain. Women feared that negative experiences were signs that their cancer was spreading.

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*

A progressive deterioration of well-being led women to reframe their understanding of breast cancer and what it meant for them. 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.

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*

# **DISCUSSION**

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## **Allah and destiny**

Our findings suggest that the belief in Allah provides limited comfort by itself. For belief to bring comfort, it must be accompanied with a continuous respect for the sovereignty of Allah and submission to His will, their destiny. Destiny can be at times viewed as synonymous for Allah in our findings, allowing the women to avoid directly attributing bad things to Him. Combative terminology seen elsewhere, such as fighting and battling cancer, is absent in our findings because of the risk of conveying hostility towards Allah and the rejection of destiny.

Belief in destiny has been criticised as a comfort mechanism to placate those who lack access to reliable healthcare, and associated with increased feelings of helplessness and disengagement from healthcare17. Our findings do not support this viewpoint. Destiny gives Maure women hope that the world is ordered and not random. Breast cancer is a normal illness because it was created and given to them by Allah, who can also remove it18. This suggests the need to distinguish between belief in destiny which gives hope and fatalism which disempowers and disengages.

Our findings describe the use of ‘empty-actions’ as a bridge between treatment seeking and destiny. This concept is also supported by the broader resource-limited healthcare setting of Mauritania, where it is difficult to identify relationships between treatments and effects. Life, illness, treatment and death are accepted as unpredictable, of which only death is certain18 19.

## **The capital of suffering**

Breast cancer is often described as being sent or allowed by God as a test of faith, with potential rewards for the individual depending on their response to it20. Stoical responses to pain and suffering are idealised in a range of ethnicities and contexts21 22. To better understand the expressions of suffering in our data, we propose that suffering can be viewed as capital. Suffering is a finite resource which can be either invested for rewards in the afterlife or expended in this world. Silent endurance of negative experiences is associated with increased eternal rewards, whereas any expression of suffering decreases them (see figure 1). In order to access help and relief of symptoms Maure women are required to express some of their negative experiences. Given the high eternal value of this capital resource, it is frustrating for those who spend it on expressing symptoms but fail to obtain relief.

Families are uncertain of how to respond when women express certain negative experiences, such as, anger and fear. Such responses are criticised as catastrophising, wasteful and risk appearing impolite to Allah. Women are therefore encouraged to be stoical when facing negative experiences. At times, such pressure can turn into spiritual, physical and emotional abuse, consistent with the literature documenting the global problem of violence against women in healthcare settings23.

## **Prioritisation of the spiritual**

Health professionals feel burdened in their role as guardians of breast cancer information because it is so incendiary and dangerous. They fear that they would be blamed by the family and by Allah, if their disclosure resulted in spiritual distress for the women18. Women therefore receive trivialising and misleading information, or none at all. Information is wielded as a malleable tool; modified and titrated as necessary to maintain a woman’s hope and spiritual calm while ensuring ongoing compliance to their prescribed ‘empty-actions’. This reinforces the women’s powerlessness, despite their expressed desire for information and understanding.

# **STUDY STRENGTHS**

This Stakian 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 inclusion of data from family members and health professionals enriched the understanding of the broader study contexts. They also provided insights specific to the cases, such as the decision-making process around troublesome symptoms.

**STUDY LIMITATIONS**

There were limitations related to the cross-language and cross-cultural nature of this study. Descriptions of experiences underwent translation prior to analysis. It remains inevitable that some of the nuance and vibrancy of the women’s voices were lost. I accept that my identity, as a foreign Christian male researcher in the presence of a male interpretor, has influenced this research and there are gendered power imbalances throughout the study24. At its essence, it is an exploration and interpretation of what Maure women with advanced breast cancer described to us. I was pitied for not being a Muslim and yet considered closer to their view of truth than an atheist or polytheist. Participants were willing to patiently answer my questions, despite suggesting that no Muslim researcher would pose such questions. Given the dearth of research in Mauritania, we hope that this study provides a foundation for further palliative and cancer care research in the region. We welcome a rich diversity of researchers, participants, methodologies and issues to build on our findings.

# **CLINICAL IMPLICATIONS**

This study has demonstrated how Maure women seek information and understanding of their breast cancer. They respect the knowledge and skills of health professionals but are frustrated at their lack of access to it. A strong belief in destiny is not incongruent with an equally strong desire and willingness to pursue treatment.

We have made available some of the experiences of advanced breast cancer in Mauritania to the broader oncology and palliative care community who are unlikely to visit the region. We propose that this knowledge is useful to improve care for other populations, especially women who prioritise the spiritual over the physical. These women may experience physical, social, emotional and spiritual suffering but may prefer not to express it. Any expression of negative experiences in such contexts comes at a cost to the women and should be taken seriously. Culturally appropriate approaches to providing care while enabling women to maintain their preferred external demeanour 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.

**Declaration of interest statement**

We as the authors declare that we have no potential conflicts of interest with respect to the research, authorship, and/or publication of this manuscript.

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**Data availability statement**

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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# Legends

Table 1: Foreshadowed issues

Table 2: Case demographics

Figure 1: Suffering as a calculation