

PAPER

Isolation and prayer as means of solace for Arab women with breast cancer: An in-depth interview study

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Abstract

Objective This study explored Arab women's experiences following the diagnosis and treatment of breast cancer.

Methods Face-to-face in-depth interviews were conducted with 20 Arab women attending a public hospital in Abu Dhabi, United Arab Emirates, following a recent diagnosis of breast cancer. All interviews were transcribed verbatim and analysed using the thematic method.

Results Arab women's experiences following their breast cancer diagnoses and treatments included the themes of (1) protecting one's self from stigma, (2) facing uncertainties and prayers, and (3) getting on with life. Overall, the ways to find solace were through isolation and prayer, which are heavily influenced by religion and spiritual practices. They recommended that to help women with breast cancer, a campaign to raise awareness for early screening is needed as well the need to form a peer-led support group for women with breast cancer consisting of breast cancer survivors so that they can learn from each other's experiences.

Conclusions Arab women with breast cancer experienced a myriad of social, cultural, psychological, and relationship difficulties that impacted their overall health and well-being. The findings also found that these women were not passive agents. They sought to solve problem, move forward, and recreate the meanings in their lives in their own unique ways. Action is needed for possible ways to implement religion-health partnerships between breast cancer nurses, peer-led support groups, palliative care services, and religious institutions.

KEYWORDS

Arab women, cancer, culture, experiences, oncology, qualitative, religion

1 | INTRODUCTION

The types of cancer, with the highest mortality among women in the United Arab Emirates (UAE) are breast, liver, cervix, colorectal, and stomach cancer.¹ In the UAE and in many Arab countries, breast cancer accounts for 28% of all cancers, of which 78% are women below the age of 55 years.^{2,3} The exact incidence is difficult to report as a large portion of the population in the UAE is migratory and there is no centralised cancer registry system.⁴ Data often only become available after patients are admitted. In Abu Dhabi, more than 130 patients are new cases annually, in which 65% of the women, regardless of their nationality, are at late stages of cancer compared to approximately 15% in the United States.^{4,5}

Despite having access to national screening programs, only 75% of the women with breast cancer in the UAE avail themselves after

experiencing signs and symptoms.⁶ Several studies have confirmed that Arab women with breast cancer present themselves late to health facilities for treatment due to cultural, religious beliefs, family opinions and attitudes, fear, and stigma.⁷⁻⁹ In Egypt, symptom awareness, modesty, and patient-doctor interactions were found to inhibit early diagnoses.¹⁰ In Qatar, Oman, and Saudi Arabia, the word "cancer" remains a taboo never to be uttered due to its negative connotation.¹¹⁻¹³ In the UAE, there are no extensive community health education programs nor any radio or television channels that broadcast health-awareness programs due to the diversity of nationalities and languages.^{4,14} The widespread adoption of primary health care with associated disease prevention, health promotion, and health education is also a challenge due to the cultural fear of spreading potential bad news and cultural reluctance to publicly discuss health issues such as breast cancer.^{12,15}

The literature reports that women in many Western countries do not use the available breast-screening services and present with advanced symptoms.¹⁶ Structural barriers to attending screening include a lack of health insurance, distance to medical facilities, inability to take time off from work, and difficulty in navigating complex health care systems and interacting with medical staff.¹⁶ Psychological and sociocultural barriers include poor health motivation, denial of personal risks, fatalism, mistrust of cancer treatments, and the fear of becoming a burden on family members; these barriers can often preclude proactive breast screening or rapid response to symptoms.^{6,17} In the Arab culture, women's decisions and actions are seldom autonomous as most of the decisions are determined by men, who may be unaware of or even disapprove of breast-cancer screening.^{6,14} While some attention has recently been directed towards reasons for late presentation for breast cancer in Arab nations, to date, Arab women's experiences following the diagnosis and treatment of breast cancer has not been well investigated in the UAE.

Women with breast cancer are mostly shrouded with fear, myths, and connotations reaching far beyond the objective clinical understanding of the disease.^{12,14,18} Moreover, women with breast cancer experience depression,¹⁹ anger,¹³ feelings of shame, and worthlessness, which affect their overall quality of life, especially during the first year of diagnosis.¹⁷ In Arab countries, cancer is viewed as a stigma that affects their lives. Women with cancer resort to concealment of their disfigured or deformed body to avoid being treated negatively by the society.^{12,17} Mastectomy can result in women feeling inadequate and vulnerable and have problems with body image, sexuality, relationships, and goals for the future.^{20,21} The site and stage of cancer, whether one is in treatment, and the time since they were first examined are additional factors that affect how they perceive their illness.²²

To increase the awareness of the importance of breast cancer screening and treatment, health care professionals need to identify the manner in which women deal with cancer. In addition, there is an increasing interest in how health beliefs, practices, and behaviours are shaped by sociocultural and ethnic identities including race, religion, and language and how these are manifested in times of illness.^{22,23} Culturally, specific knowledge is important in order for nurses and health care professionals to determine appropriate ways to support women with breast cancer. Current clinical cancer treatment and support services remain largely biomedical with very little attention to Arab women's personal, familial, cultural, and religious experiences when examined with and undergoing treatment for breast cancer. Therefore, this study explored the experiences of Arab women in the UAE following the diagnosis and treatment of breast cancer.

2 | METHOD

An exploratory descriptive design was used. The approach to data collection and analysis was underpinned by the theory of illness trajectory.²⁴ In this theory, having breast cancer creates a disruption in 3 aspects of their life including physiological functioning, social interactions, and the conceptions of one's self. Responses and coping to disruptions are interwoven into various contexts in the women's life,

their interactions with other people, and within the UAE sociocultural society.

Purposive sample of women undergoing treatment for breast cancer at a major metropolitan government hospital in Abu Dhabi, UAE, was identified from the hospital registry and invited to participate in the study. The inclusion criteria were Arab women aged 18 years and older, examined with breast cancer and undergoing treatment, Arab nationals living in the UAE, and able to give informed consent. The exclusion criteria were terminally ill hospitalised women and those with serious comorbidities such as cognitive impairment or severe psychological dysfunction that could affect their ability to participate in the interview.

2.1 | Procedures

Ethical approval was obtained from the Human Research Ethics Committee of the University and Al Ain Medical District, UAE. Additional permissions were obtained from the Undersecretary of Curative Medicine, Federal Ministry of Health, and the Director of the Health Authority in Abu Dhabi. A total of 28 women were approached to participate in the study, but 8 refused due to being too busy or needing permission from a male relative who was not forthcoming. The 20 participants who consented to be interviewed were informed about the purpose and nature of the study and assured that their confidentiality will be maintained and pseudonyms will be used in any publications arising from the study. They were also informed that they could withdraw from the study at any time without this affecting their treatment.

All interviews were conducted at a time and place convenient for the participant such as in their homes and coffee shops nearby. The length of each interview ranged between 45 to 60 minutes. The first author, a trained mental health nurse, conducted all the interviews in Arabic using an interview guideline. Data saturation was reached upon the completion of 20 interviews. Examples of questions asked included

Please share with me your initial reactions when you were diagnosed with breast cancer. What does this cancer mean to you? Did you share this with your husband, family, or friends? What were their reactions? How did you manage the diagnosis and the treatment that followed?

2.2 | Analysis

All audiotaped interviews were transcribed verbatim in Arabic and then translated into English by the first author who is an Arabic-English bilingual researcher. Two bilingual research assistants checked the accuracy of the transcripts and the forward and backward translations on a sample of 5 transcripts. Thematic analysis was used to cluster key patterns of meaning from each transcript.²⁵ Credibility, confirmability, and trustworthiness of the data were conducted.²⁶ Credibility of the women's responses was achieved through audio recordings of the interviews. To support confirmability, the same interviewer conducted all interviews. Trustworthiness was adhered to by the research team reviews, mutual agreement of the major themes and subthemes, and

the use of quotes from the voices of the participants. All members of the research team have knowledge of the Arabic culture and lifeways and have worked in the Middle East.

3 | RESULTS

The participants' age ranged from 30 to 65 years old (mean = 50 y). Fourteen participants completed a university degree. Twelve participants were married, 7 were employed, and there were 17 Muslims and 3 Christian participants (Table 1). Eleven had stage IIB, and 9 had stage III breast cancer. The intervals between symptom discovery (felt lump in the breast) and diagnosis ranged from 8 to 24 months, and none had never had breast screening. Nineteen women had combined surgery, chemotherapy and radiotherapy. The Arab women's voices provided meaningful insights into their experiences in 3 themes with detailed elaboration on their unique cultural and religious beliefs. Pseudonyms were used to present the participants' quotes supporting the themes.

3.1 | Protecting one's self

Upon knowing their diagnosis, the women started to protect themselves by projecting blame not for ignoring the presence of the lump but that on someone else. They reported that there was nothing to worry about and decided not to talk about it openly. The women explained how Arab communities viewed cancer as a deadly disease, and no one was allowed to discuss it.

"The name [cancer] is frightening and my family avoids mentioning the name of this disease. We are not allowed to say it because if you say it, it will also affect you." (Hajjie)

TABLE 1 Demographic characteristics of the participants

	Participants	Age	Marital Status	Religion	Education	Employment
1	Laudy	40	Married	Christian	University	Housewife
2	Hajjie	65	Widow	Muslim	Secondary	Housewife
3	Fatima	57	Married	Muslim	Secondary	Housewife
4	Suha	46	Marrie	Christian	University	Employed
5	Mona	42	Married	Muslim	University	Employed
6	Amina	30	Single	Muslim	University	Employed
7	Salma	55	Divorced	Muslim	University	Housewife
8	Nada	55	Divorced	Muslim	Secondary	Employed
9	Najwa	55	Married	Muslim	University	Housewife
10	Nancy	58	Single	Christian	University	Employed
11	Naema	47	Married	Muslim	University	Employed
12	Rula	48	Divorced	Muslim	University	Housewife
13	Noura	38	Married	Muslim	Secondary	House wife
14	Sana	42	Divorced	Muslim	University	Employed
15	Fatin	60	Divorced	Muslim	Secondary	House wife
16	Siti	32	Married	Muslim	University	Housewife
17	Hanom	60	Married	Muslim	University	Housewife
18	Fazila	54	Married	Muslim	University	Employed
19	Sabiah	58	Married	Muslim	Secondary	Housewife
20	Sahar	56	Divorced	Muslim	Secondary	Housewife

The stigma associated with cancer is associated with many consequences in their lives. The stigma affected employed women who were asked to resign from their jobs. Thus, after their treatment, the women sought another job where medical certificates were not be required. For them, cancer will forever stigmatise them.

When you break an expensive cup then you try to fix it, it will never be the same as before. You will always feel that this cup is now ugly and you will hide it. I am now like this cup, even if I recover from this cancer. Still people around me will always feel and deal with me with caution and this is what I hate most. (Hanom)

The women reported that they lost their social relationships and that their friends and family stopped visiting them. The women found solace by isolating themselves from people who do not understand the disease or thought that cancer was contagious, but most of all prevented themselves from being ridiculed and pitied. This isolation resulted in the women becoming more anxious, frightened, and angry. When they started the treatment, their anger changed to sadness and helplessness because they could not talk to their husbands or family members about it. However, they found solace in health care professionals, as they were able to discuss their fears, who allowed time for the women to express their worries. The women reported these encounters to be positive experiences.

Thanks for giving me the chance to talk to you because, as you know, we cannot talk about this disease in front of anyone. It is not a shameful thing, but people believe that this disease is a deadly one and nowadays people only talk about nice things. (Nada)

3.2 | Facing uncertainties

The women faced the uncertainties of the diagnosis and the outcomes of the treatment. They reported that their lives would forever change due to the effects of treatment on their body image, especially for those who had mastectomy. For the women who were engaged or married, they reported the uncertainty of maintaining intimate relationships with their husbands. For some women, the intimacy difficulties experienced were so strong that it resulted in relationship breakdowns and marriages ending.

I was engaged and we were preparing for our wedding. After the operation, I felt that his parents changed and they stopped visiting me. My fiancé stayed with me until I completed the treatment and then he told me that he wanted to leave because his family told him that he was still young and it was not fair to stay with someone who has cancer. (Amina)

My husband could not bear to look at the scar on my chest. He stayed with me six months after the surgery and then he got married to another woman. He used to come every now and then. Afterwards, he stopped seeing me or the kids. (Fatin)

Several women reported extreme feelings of sadness of probably not being able to fulfil their roles as mothers and wives and could no longer look after their husbands and children. They reported that they could no longer do things in the house, clean, decorate, cook, or entertain friends. To find solace, most of the women reported that their religious beliefs helped them to cope with the deep-rooted cultural stigma and uncertainties. The women turned to spiritual beliefs to find solace in which life and recovery were in God's hands regardless of whether they were Muslim or Christian.

When I feel weak and I start crying, I pray to God and ask him for his mercy. I believe that nobody will die until his/her time comes. Take it as a rule: no disease, no diabetes, no hypertension, and no heart problem, and not anything. Only when your time comes will you die. (Sahar)

3.3 | Getting on with life

They found solace by actively finding and talking to other women with breast cancer undergoing treatment and breast cancer survivors.

I found out that there are lots of women who have breast cancer even younger than me. Some were in their thirties, or even younger. They told me about the treatment to control the tumour and then they had surgery. I felt relaxed when I talked to these women because I felt that I was not alone. (Suha)

They found solace in praying and reading holy books to feel relaxed, overcome their psychological distress, and receive the strength to accept their cancer and get on with their lives.

Thanks to God, I believe that everyone has her own destiny and I have to accept what God has written for me. I also believe that God accepted my prayers and made me at peace with myself. I read the Quran frequently and pray five times. I went to Hajj [Pilgrim to Mecca]. I feel much stronger and at peace. (Fazila)

The women also recommended the creation of breast cancer support groups consisting of women with breast cancer and breast cancer survivors. They expressed the desire to share their lived experiences and for opportunities to support one another. They reported that there are many women who do not have support at home so they need someone who has gone through the experience.

"The best person who can help us are the women who went through the same situation." (Nancy)

"We need someone who can treat our souls at the same time the doctor is treating our bodies." (Siti)

Few women in the study were able to get on with their lives because they had supportive husbands and family. Although they kept the diagnosis a secret at first, they acknowledged that they needed support to be able to get through the treatment and its side effects. These women became more aware of any changes in their bodies and immediately sought help from health care professionals.

I have changed a lot after knowing the diagnosis and treatment. I love life more now. My husband and I started going on vacations and enjoy life more. You never think that life is short. I need to do things as soon as possible. I appreciate life more now. I have changed the way I look at my health. I attend my follow-up schedules to see my doctor and whenever he asks me to do something, I just do it to get on living as long as I can. (Naema)

4 | DISCUSSION

The themes represented the complex illness trajectory in which Arab women experienced the diagnosis of breast cancer by getting on with life primarily through obtaining solace and using prayer. The women voiced considerable social stigma and cultural reluctance to disclose their diagnoses and resort to isolating themselves. This practice may be link to the deep-rooted cultural stigma of cancer that operates in the Middle East as a taboo not to be discuss with family members. This is similar to findings reported in many Asian countries associating cancer as contagious.^{27,28}

Upon learning the diagnosis, shock, disbelief, fear, uncertainty, intense loneliness, and isolation were reported by the women. These findings also were found in other studies of Arab and Muslim women with breast cancer.^{29,30} Many of the women reported difficulties when trying to accept the diagnosis and treatment, including maintaining marriages and intimate relationships, hiding their disease from their employers, and struggling with the outcomes of treatment and surgery. In particular, the uncertainty of losing their husbands and fulfilling their responsibilities as wives and mothers was also reported in others studies of women with breast cancer in Pakistan²³ and other South Asian women.^{27,28} For the women who had mastectomy, the changes in their body image mostly affected their relationships and felt ashamed and humiliated about their new appearance. This finding is in line with previous research where breast cancer sufferers reported psychological sufferings stemming from negative body image, a lack of sexual intimacy, and relationship problems considering the sexual significance of breasts to femininity and attractiveness in contemporary societies.^{21,29}

Finding solace in turning to religion and prayer diverted the Arab women's attention away from stressful thoughts and intense emotional experiences and, most importantly, helped to get on with their lives as written to them by God's will.^{31–33} These women found solace through reading the Quran and engaging in ritualised prayers. A deep sense of spirituality provided them with a new meaning and purpose in life to get on with living. Studies have found that having a relationship with God provided a consistent and reliable source of support and coping.^{34,35} Studies have shown that when Arab breast cancer survivors practice their religious beliefs, it restored their equilibrium by regaining a positive self-identity, sense of control, self-confidence, quality of life, and hope for their future.^{36–39} In our study, all the Arab women with breast cancer of different faiths shared the importance of spirituality as a source of solace.

Upon the completion of treatment, the Arab women reported believing in physical and psychological recovery but with lingering fragility. They expressed the need for continued support, including a psychologist who can sit and talk to them, especially for those who are still unable to accept the diagnosis to help them continue this stressful journey. Studies have reported that support from health care professionals was strongly associated with reducing the uncertainties of women with breast cancer, and inducing positive adjustments to breast cancer and positive attitudes to the healing process.^{37,38} The Arab women also expressed the need for support groups consisting of women breast cancer survivors especially for those who do not have support at home. Studies of social support and adjustment to breast cancer have examined support apart from family members including peers at work.^{37,38} The women also suggested that to overcome the stigma associated with any type of cancer, a population-wide awareness campaign for early screening is needed in the UAE.

5 | LIMITATIONS

This study was restricted solely to Arab women with a small sample. These findings also excluded women who were currently in hospitals for palliative treatment. Women who required permission from a male relative were also excluded from participation, and this could have biased the results towards Arab women who have some social freedom.

6 | IMPLICATIONS

The Arab women with breast cancer experienced social, cultural, psychological, and relationship difficulties that impacted their overall health and well-being. However, the findings also found that these women were not passive agents and instead sought to solve problem, move forward, and recreate the meaning in their lives in their own unique ways. Therefore, it is imperative that nursing, medical, and allied health professionals providing health care services to Arab women with breast cancer have appropriate cultural knowledge to support these women.

Our data supports the development of peer-led support groups given that these women sought healthy new self-identities by talking to other women with breast cancer. Women-led survivorship groups would enable communities of ongoing support and build on the strength of existing women-centred networks in the Middle East. Of further utility would be recognising and integrating the role of prayer in future hospitals and community health interventions in keeping with supporting UAE and Middle Eastern women current belief systems. Such approaches would foster culturally aligned self-empowerment and provide a potential buffer from isolation and depression. Nurses in the UAE are in this unique position to support the development of such groups in the community to provide psychosocial and service-related education to peer leaders.

The findings have international significance with Arab diaspora across the world both in countries of origin and in host migrant societies. There is a need to have an in-depth understanding of the personal and culturally centred beliefs of Arab women within the

realms of their lives as wives, mothers, and other social roles. Such understanding in which Arab women struggle with breast cancer enables targeting health promotion campaigns and associated education that differ widely from the current more western centric approaches. Future research could also investigate possible ways to implement religion-health partnerships between breast cancer nurses, peer-led support groups, palliative care services, and religious institutions.

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