

“If It Is Written by Allah, There Is Nothing That Can Stop It”:
Saudi women’s breast cancer narratives

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Abstract

The purpose of this study was to identify cultural models of breast cancer held by Saudi women and to explore how these may influence early detection and treatment-seeking behaviors. Data were collected via semi-structured interviews with breast cancer survivors (n=20) from two Western cities in Saudi Arabia. Respondents were recruited through social networking, using purposive, snowball sampling. Illness narratives elicited during interviews were transcribed, coded and then analyzed using a modified grounded theory approach. Results suggest that fatalism, perceived threats to traditional role fulfillment, and a preference for traditional therapies commonly mark the breast cancer experiences of Saudi women, influencing their early detection and treatment-seeking behaviors. A more nuanced understanding of emic viewpoints could help to improve public health messaging and intervention strategies in Saudi Arabia.

Keywords: *Breast cancer; Saudi Arabia; women; illness narratives; traditional medicine*

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I. Introduction

Breast cancer is the most common type of cancer among women in Saudi Arabia, accounting for 21% of all cancer cases (Ibrahim et al., 2008). Compared to Western Europe and the United States, breast cancer in Saudi Arabia has an earlier age of onset, and afflicts mostly premenopausal women. Additionally, 40% of the breast cancer cases detected are advanced and aggressive (Ezzat et al., 1999). Due to the adoption of behaviors that increase cancer risk such as smoking, inactivity, and poor nutrition, as well as the epidemics of obesity and high urban pollution, rates of breast cancer are expected to continue to increase in the coming decades (Ibrahim et al., 2008). A burgeoning body of epidemiological research tracks the prevalence and incidence of breast cancer in Saudi Arabia (Alghamdi et al., 2013; Alothaimen et al., 2004; Elkum et al., 2007). However, comparatively little is known about the cultural models held by Saudi women diagnosed with breast cancer. The purpose of this study was to identify cultural models of breast cancer held by a sample of Saudi women as expressed through their illness narratives. The identification and interpretation of common themes across narratives enabled us to explore the ways beliefs and social pressures influence early detection and treatment-seeking behaviors in this population.

II. Background

In a descriptive epidemiological analysis of the 2001-2008 Saudi Cancer Registry, Alghamdi and colleagues (2013) found that the number of breast cancer cases increased steadily from 2001 to 2006, and that rates were highest among younger Saudi women aged 30 to 44 years. According to the 2002 Saudi National Cancer Registry, breast cancer incidence among those younger than 40 comprises 26.4% of all female breast cancers in Saudi Arabia, relative to 6.5% in the United States (Elkum et al., 2007). In a study comparing clinical characteristics and treatment outcomes between those younger and those older than 40, Elkum and colleagues (2007) determined young age to be an independent risk factor for relapse in operable Saudi breast cancer patients—the inverse of age-related trends observed globally.

In addition to exploring clinical etiologies, several studies have investigated breast cancer knowledge, attitudes, and behaviors among Saudi women. Mahfouz and colleagues (2013) conducted a cross-sectional study in Abha city and found that women showed low levels of knowledge about cancer and low rates of breast self-examination (29.7%), clinical breast examination (8.3%), and mammography (6.2%). These findings were paralleled in a survey study conducted in Hail designed to elicit knowledge of breast cancer and related perceptions and behaviors (Hussein et al., 2013). Researchers found that 61.5% of participants had low levels of basic, breast cancer knowledge, and 50.1% of female participants above the age of 16 did not practice breast self-examination. Similarly, studies by Dandash et al. (2007), Milaat (2000), and Al-Amoudi et al. (2010), showed a critical lack of knowledge across occupational groups, including teachers, students, and health care providers.

In addition to lower than anticipated general knowledge about cancer (even among clinicians), reports have identified several barriers to early detection and treatment-seeking behaviors among Saudi women, including negative attitudes towards conventional medicine and strong beliefs in traditional therapies, inadequacies in health education beginning in high school, mistrust between patients and physicians, and language barriers between providers and patients (Amin et al., 2009). Further, in a review of a tertiary care center in Saudi Arabia, Abdelhadi (2008) argued that unnecessary delays (6-15 weeks and 32-38 referrals/handoffs) prior to receiving medical treatment create mistrust of the health system among breast cancer patients. Similarly, Akhtar and colleagues (2005), in a retrospective analysis of breast cancer patients who received care from a tertiary health care institution in Saudi Arabia, found that the quality of breast cancer care in the country was well below international standards.

Given the high costs of advanced cancer care, efforts are currently being made in Saudi Arabia to encourage early detection. These initiatives, however, have been minimally successful (Abulkhair et al., 2010; Akhtar et al., 2010). For example, one large-scale pilot intervention program implemented in Al-Qassim yielded disappointing results, despite its holistic approach (Akhtar et al., 2010). Efforts to raise the program's cultural competency, including utilizing female health professionals and engaging influential male figures in the region to endorse the program, resulted in a less than 18% participation rate among eligible women in the region.

To date, the majority of work on breast cancer in Saudi Arabia has been clinical or epidemiological in nature, and, as a result, has not focused on providing an in-depth analysis of knowledge, attitudes, and behaviors as lived and expressed by Saudi survivors themselves. Thus, there is a critical gap in the literature regarding emic or folk models of this disease and its treatment options. One notable exception, a study conducted by Nichols and colleagues (2013), presents an inductive thematic analysis of semi-structured interviews with Saudi breast cancer patients. However, because the data for the study conducted by Nichols and colleagues were collected in an effort to develop a culturally valid health needs assessment tool for breast cancer patients, data were analyzed for congruency with published needs assessment tools only; emergent cultural themes and models were not fully explored. As such, to our knowledge, our study is the first to examine cultural models of breast cancer held by Saudi women.

III. Methods

Participants

All participants were Saudi breast cancer survivors¹ over the age of 18. Participants had all either been diagnosed with breast cancer themselves, or were supporting a friend or family member through a diagnosis (see Table 1 for a summary of sample characteristics). The sample consisted of 20 women, the majority of whom (60%) had a breast cancer diagnosis. The sample was comprised predominantly of married mothers over the age of 30 who were not employed outside of the home. Educational status varied within the sample and was relatively evenly split between those with less than 12 years of education and those with at least one college degree.

¹ We use breast cancer "survivors" here to refer to those individuals diagnosed with breast cancer as well as family and friends who function as supports for the women affected. This term acknowledges that the impact of this disease extends well beyond the individual living with a diagnosis and attempts to invert the perception of sufferers as victims.

<u>Characteristic</u>	<u>N</u>	<u>(%)</u>
<u>Age</u>		
Under 30	4	(20%)
30-50	7	(35%)
Over 50	9	(45%)
<u>Marital Status</u>		
Single	6	(30%)
Married	10	(50%)
Widow	3	(15%)
Divorced	1	(5%)
<u>Education</u>		
12 years or less	8	(40%)
Some college	3	(15%)
College degree or more	9	(45%)
<u>Employment</u>		
Employed	6	(30%)
Unemployed	11	(55%)
Retired	3	(15%)
<u>Number of Children</u>		
None	7	(35%)
1-3	5	(25%)
4 or more	8	(40%)
<u>Experience</u>		
Personally diagnosed	12	(60%)
Related to someone diagnosed	7	(35%)
Friends with some diagnosed	1	(5%)

Table 1: Sample Characteristics (N=20)

Following approval by the Institutional Review Boards for Human Subjects Research at participating institutions, participants were recruited via purposive snowball sampling (Bernard, 2006). The first author contacted key community members and health care professionals in two Western cities in Saudi Arabia and notified them of the study. Community leaders and willing health professionals were then provided with a recruitment script for informing and referring eligible women to the researchers. Women who were interested in participating contacted the first author via email or over the telephone, and after their questions were answered, in-person meetings were scheduled. Interviews took place in a private location of the respondents' choosing (e.g., home; private exam rooms at hospital). Prior to beginning the interview, participants were questioned to make sure they fit the eligibility criteria (adult, Saudi women, above the age of 18, and either had been diagnosed with breast cancer themselves, or were supporting a friend or family member through a diagnosis), verbal consent was obtained, and pseudonyms were assigned to the participant to protect confidentiality. Sessions were either recorded (n = 11) or, when audio-recording was declined by the respondent, documented with hand-written notes (n= 9).

Data were collected via semi-structured interviews designed to elicit participants' breast cancer narratives. The interviews generally lasted between 10 and 30 minutes, depending on the amount of information interviewees wished to share, and were conducted in Arabic. Recorded interviews were translated into English and transcribed. All interviews were then coded using inductive or open coding—an approach to data analysis common to grounded theory whereby *en vivo* codes or emic themes are allowed to “emerge” via a close study of interview transcripts as texts (Charmaz, 2006; Creswell, 2007; Glaser & Strauss, 1967). Preliminary analysis of the first five interviews revealed that participants focused heavily on the dissonance between traditional beliefs and the pressure to conform

to biomedicine. Thus, subsequent interviews included additional follow-up questions focused on eliciting participants' biomedical experiences, as well as their traditional beliefs. The goal of the added questions was to explore in more detail the initial categories identified during preliminary interviews. Once all interviews had been completed, transcribed and coded, the shared experiences and cultural models of the participants were identified, developed and translated into a schema or model designed to help map participants' responses; these formed the foundation for our interpretations (Charmaz 2006; Creswell, 2007).

IV. Results

In listening to women's breast cancer narratives, it soon became evident that although there was considerable variation in the details of how each woman was diagnosed and treated, the impact on her family, as well as other related issues, several key themes were repeated in most or all of the interviews. These themes related specifically to how breast cancer is perceived. We identified three predominant themes that help to explain not only how Saudi women understand breast cancer as a disease, but also why detection and treatment are often so delayed: 1) breast cancer as an inevitably fatal disease; 2) breast cancer as a threat to traditional gender role fulfillment; and 3) a preference for traditional therapies over biomedical treatments.

Breast Cancer as an Inevitably Fatal Disease

The most pervasive theme conveyed by the women interviewed was that breast cancer is an inevitably fatal disease over which they have no control. This sense of fatalism was discussed repeatedly using expressions that conveyed a lack of power over the outcome and the belief that cancer and its consequences are predestined. This belief is primarily grounded in religious ideologies that reflect deeply-engrained and culturally constructed attitudes toward aggressive diseases—namely that all afflictions are brought about by God and that nothing can be done to prevent cancer or death if that is God's will. This lack of control is compounded by the beliefs that the evil eye causes breast cancer and that women have minimal to no decision-making power during the course of biomedical treatment.

Each of the women interviewed expressed the belief that all afflictions are brought about by God, and that God's will *cannot* be contested. Basma (a young college student) for example shared the story of her mother's breast cancer. When asked if she was taking any preventive measures against the condition given her mother's experience, she responded: "If it is written by *Allah*², there is nothing I can do to stop it. My faith in *Allah* is strong, and I don't really think there is anything I can do to prevent myself from getting breast cancer if that is what *Allah* has in store for me."

All of the participants shared similar sentiments expressing that nothing could prevent breast cancer or death if God willed it. As Jenan, a young mother and high school English teacher, explained: "Of course it is all predestined and written." Participants viewed beliefs that contradicted this view as evidence of a lack of faith. Ibtisam, a lively 60 year-old retired teacher, spoke about her reaction to being diagnosed this way: "I left everything in the hands of *Allah*, and nothing is brought upon a believer unless it is written by *Allah*."

This belief is magnified by the concurrent belief that '*ain*³, or the evil eye, causes breast cancer. In fact, the evil eye was the most commonly cited cause of the condition. Ramya, a 36-year-old woman being treated for breast cancer, shared her story as she received her chemotherapy. When asked what she thought caused the condition she stated: "In France, they used to tell me that 30% of cases of cancer are due to poor diet and 10% are due to heredity.

² The Arabic word for "God".

³ A concept rooted in religious ideology in which harm is inflicted on one by envy or jealousy; synonymous with the evil eye.

The rest, they told me: ‘We don’t know what causes the rest of the cases’. We have the answer here– the rest of those cases are due to ‘*ain*.’ She noted that she got breast cancer after attending a wedding, a common connection made by participants. Badia, a soft-spoken 54 year-old breast cancer survivor and home-maker, said:

Well, because I was at a wedding. And my daughters were with me, but my oldest daughter didn’t come. Then one lady came and told me, “are those your daughters?!” Then another woman said, “if you saw her oldest daughter,” then the first lady said “you can’t even tell she has kids!” Then the other woman said “yes, she is not like us. We die to get thin – she is comfortable with her husband and her kids”. *Wallah*⁴, it wasn’t even a week later, can you imagine?! Not even a week. So I think this is the cause. And then, imagine, the same lady who said that about me, she told me you got ‘*ain* at the wedding on that day! Imagine that! *Wallah*, that same lady.

Citing ‘*ain* as the cause of breast cancer was also common among younger participants. In telling the story of her mother, Basma described:

May *Allah* have mercy on her soul. She had many good things in her life. She always looked beautiful when she went out. My mother, may *Allah* have mercy on her, was so proud of her family, and she always spoke about us to others. I think people were jealous of this and gave her ‘*ain*. They would not say *MashaAllah*⁵. She was always so generous, *Allah* have mercy on her. [...]She died just one month after my brother’s wedding. In the wedding, she looked so beautiful and healthy. People kept asking if she really was sick without saying *MashaAllah*. I do think that they gave her ‘*ain* at the wedding, and that is why she died so quickly afterwards.

MashaAllah is a term that translates to “as Allah intended.” It must be voiced whenever one expresses admiration in order to prevent inflicting the evil eye. As noted by Basma, the combination of jealousy and failure to say *MashaAllah* when admiring her mother’s beauty and health resulted in the infliction of ‘*ain* and ultimately her death from breast cancer. Similarly, Najwa, a young college student who was training to become a teacher, shared the story of her friends’ breast cancer experience. They were two sisters who had been diagnosed shortly after their wedding. In Najwa’s words:

They were both very young, healthy women, and no one in their family had ever had breast cancer. And they got the cancer right after their wedding. It must have been ‘*ain*. All the girls wanted grooms like the ones they got, and they were clearly jealous. That must have been the reason.

In addition to appearing beautiful and healthy at a wedding, other reasons for being afflicted by the evil eye include being academically inclined, being highly educated, having a strong relationship with one’s husband, and having an outgoing personality. Given that the evil eye is seen as both a cause of cancer and as imposed by an envious person, it is perceived as something that one has no hope of controlling.

Survivors’ perceptions of a lack of control over the progress and outcome of the disease are further exacerbated by a lack of information provided to women about breast cancer causation, as well as women’s very

⁴ An Arabic expression that translates to “I swear to God”.

⁵ A term that translates to “as Allah intended.” It is believed that stating *MashaAllah* is mandatory when ones expresses admiration in order to prevent inflicting the evil eye.

limited control and decision-making power during the course of treatment. Fayza, a Masters degree-educated, retired university administrator, spoke about her uncertainty regarding what the physicians were doing prior to the diagnosis. She explained: “I went in, and he checked me. I got local anesthesia and a biopsy was taken. I wasn’t sure why though, the doctor didn’t tell me why.” Similarly, Badia expressed: “I didn’t know that after the surgery there were other things like chemotherapy. He told me about chemotherapy, but I knew nothing about it.”

Given the lack of information provided about the condition and the procedures or treatments recommended, the women described feeling very little power around decision-making over the course of treatment. In Saudi Arabia, consent is not always sought from the patient herself, but more often from her family members or male guardian. Heba, a physics instructor at a local high school, shared the story of her aunt’s experience with breast cancer:

Like I said, the situation was quick. I think—those days, my father, because at the time she was not married, she was divorced—my father because he is her brother, he is the one who gave them consent to proceed with the surgery. He is the one who took her to the hospital. So the doctor advised him to have her get the surgery as soon as possible. Of course he agreed, because he is responsible for her. She was not in a position that allowed her to refuse or – they did not take her opinion in this, based on what I remember. Because of this, afterwards, she said: ‘You rushed me’. She blamed the person who agreed to the surgery.

Similarly, Jameela, a widow educated through grade six, spoke animatedly as she referenced her reaction to finding out she had had a mastectomy:

I didn’t want to do the surgery because I didn’t want a piece of me to be taken away. But a young Saudi doctor convinced me to do it [...] and I went ahead with it. Can you imagine? I didn’t know about where the surgery would be until they told me afterward. I didn’t find out until after the surgery that my breast was gone!

Further exemplifying fatalistic attitudes, most of the women mentioned the inevitability of death in their narrative, particularly when speaking about their initial reaction to the diagnosis. Lama, a 63 year-old widow, said: “I was just waiting to die [...] When I think of cancer, I think of death.” Similarly, Jameela expressed that when she found out, she was “just waiting to die.” Ramya spoke about her and her family’s thoughts after the diagnosis: “Our thoughts were all about death.”

The belief that breast cancer is inevitably a fatal disease is rooted in religious and cultural construction of gender, motherhood and God’s will. Repeated references to religious ideologies and phrases illustrate the integral role religion plays in the lives of Saudi women; religion also provides the groundwork for contextualizing any experience, particularly those that involve difficulty and loss. Overall, the participants conveyed deeply rooted beliefs that ultimately shape their suffering and healing experiences with breast cancer. An external locus of control (Rotter, 1954) in the form husbands, fathers or other male guardians coupled with religious beliefs regarding aggressive diseases produce fatalistic attitudes toward breast cancer among Saudi women that in turn impact early detection and treatment trajectories.

These are compounded by the lack of decision-making power over the course of treatment and what Inhorn (1994) has called medical mystification, or the process of obscuring the diagnostic and treatment process by failing to explain clinical interventions and/or by using complex and alienating medical terminology. Medical mystification can result in women remaining uninformed; they often do not fully understand the course of treatment given the ambiguous or minimalist explanations. This reduces their sense of control and places power in the hands of the physician or the woman’s male guardian. Thus, the intersection of unequal power dynamics (between men and women and women and physicians) and deeply held religious beliefs together foster a fatalism that is a major

deterrent to monitoring, early detection and treatment.

Threat to Traditional Role Fulfillment

Becoming a wife and mother are important rites of passage for Saudi women as they play a critical role in the shaping of their identities as members of society (Foucault, 1979; Sawicki, 1991). Participants believe that a breast cancer diagnosis means a woman will almost certainly fail to fulfill these traditional roles. The absence of hair and breasts as symbols of femininity, the absence of breasts and/or normal ovulatory function as symbols of motherhood, and the increased likelihood that a woman will not live to carry out her responsibilities to her husband and grown children all combine to make breast cancer a “death sentence” for both the woman’s social body and her phenomenologically experienced individual body (Scheper-Hughes & Lock, 1987). Failure to fulfill culturally prescribed roles of mother and wife also compromises a woman’s ability to satisfy her own internalized sense of responsibility and duty. Together these can further undermine a woman’s position in society. Najwa explained that when her friend was diagnosed shortly after her wedding, the newlyweds got divorced: “Maybe her husband could not handle the pressure and responsibility. They were newlyweds, and he was not expecting this. Suddenly his beautiful wife had no breasts and was bald. Maybe he couldn’t love her anymore.”

Similarly, Basma focused on the centrality of marriage in a young woman’s life and the role a woman’s mother plays in guaranteeing that a new wife grows into a “good wife and mother.” When asked if she was engaged or planned to get married soon, she said “no” and explained: “Every girl should have her mother with her on her wedding so that she can ask her questions and get advice and feel comfortable.” Having lost her mother to cancer, Basma was concerned about her own ability to fulfill traditional gender roles, while also feeling the loss that resulted from her own mother’s inability to fulfill the responsibilities of motherhood.

In addition to the recognition that breast cancer prevents women from fulfilling their traditional roles, several of the participants also expressed the belief that breast cancer may result *from* a woman’s inability to do so. As Ibtisam noted: “I also did not get married or have children – so that could have caused it.” Similarly, Fayza said: “Then I went to an internal medicine doctor, and he told me that the lump was just mammary glands because I wasn’t married.” The assumption was that if she had married, she would have given birth to and nursed a child, thus preventing the breast cancer. Wejdan, a mother of six explained it this way: “I had six children and did not breastfeed any of them. I read once in a poster that that could cause breast cancer.” The inversion of explanations for causation and evidence for preventative or protective factors were very commonly conflated, not only in the stories of survivors, but also in the ways care providers and public health educational materials portrayed the disease. Jameela also cited failure to fulfill motherhood as a potential cause of her condition: “I [...] had 22 miscarriages so there could be something with my breast milk that could have caused it. This is what the doctor told me.”

Despite the conviction that breast cancer threatens a woman’s ability to be a wife and mother, participants consistently described strong familial support from husbands and children alike. One participant, Dr. Sara, a physician who was living with breast cancer, stated:

Many think it is a death sentence, or that they cannot marry. What we find, however, is that this is not the case. In fact, the majority of husbands are very supportive of their wives. One of the patients who was with me during my treatment, was on the verge of divorce. When she was diagnosed with breast cancer, her husband was exceptionally supportive and their relationship was revived.

Regarding her own experience, Dr. Sara described: “My uncle and my kids were great supporters. They gave me the strength to go on and gave me something to live for.” This was echoed by nearly every participant as they expressed gratitude for their family’s support. Noha, a 53 year-old retired teacher said: “*Allah* has blessed me with good children and an even better husband. *Alhamdulillah*.”⁶ Similarly, Fayza spoke about how cancer allowed her to discover how much her family loved her: “I found that my family loves me. They stood by me and would go with me to the hospital and spend the night with me.” Lama also spoke of her children’s support saying: “My children came with me to the hospital and even when all my hair fell out, my daughters would put makeup on me and buy my pretty scarfs and take me to weddings so that I can keep my mind off the disease. They gave me hope.” Najla described the reciprocity involved with the responsibility she and her siblings carried when their mother was diagnosed: “She gave up so much for us, we had to be with her during this difficult time. We took her to the hospital, stayed with her during chemo, and we would all take turns spending the night with her at home.”

Survivors’ narratives reveal the strong family ties that are an integral part of Saudi culture. Despite these, however, participants expressed that they felt the condition still undermined their ability to fulfill their traditional roles. Women who see themselves as nurturers and caregivers find it difficult to have those tables turned, and while they were grateful, this also produced a strong sense of failure and identity loss that added to the suffering associated with this disease and its treatment.

In addition, women also often see breast cancer as resulting from their inability to completely fulfill their roles as mother and wife. Not getting married, not having children, not having enough children, and not breastfeeding or not breastfeeding long enough, all put them at risk for breast cancer. These beliefs are particularly difficult to navigate because they mirror some of the clinical risk factors discussed in prevention literature and education campaigns. Participants in this study, however, were clear. Risks of cancer are tied to God’s will and to the failure to embody the cultural ideals of the “good mother” and/or the “good wife.” Though reduced breastfeeding, for example, has been identified as risk factors for breast cancer (Likis, 2002), the women interviewed did not accept this explanation as it emanates from the biomedical perspective or the clinical literature. Instead, they related these risk factors to traditional role fulfillment—a critical component of their social realities and cultural identities as women. This is a potent reminder that participants in a treatment encounter can identify a similar causation, and yet mean vastly different things.

Preference for Traditional Therapies over Biomedical Treatments

Participants also discussed treatment options and their perceptions of their efficacy, and ultimately expressed a distrust of Western biomedicine along with a preference for traditional therapies. The women interviewed believe strongly that the most powerful mode of healing is recitations of religious prayers and passages from the Qur’an⁷, combined with the consumption of *Zamzam*⁸ water, honey, and blackseed. *Zamzam* water is obtained from a well in *Makkah*⁹ and is considered to be holy water with healing properties. Blackseed is a plant derivative that is believed to cure all ailments. Najwa described how her friend began reciting Qur’an and prayers soon after being diagnosed, while Ibtisam discussed the use of *Zamzam* water to cleanse herself. Ibtisam also visited religious leaders that perform *ruqyas*¹⁰, or prayers and verses from the Qur’an recited over patients. Heba said: “With regards to the Islamic *ruqya*, one, of course, cannot question or doubt its efficacy. What is important is the sincere trust in *Allah*.

⁶ The Arabic expression for “Thank God”.

⁷ The holy book of Islam

⁸ Holy water obtained from a well in Makkah believed to have healing properties.

⁹ A city on the West coast of Saudi Arabia considered to be the holiest city in Islam.

¹⁰ A religious practice that involves the recitation of prayers and verses from the Qur’an believed to protect from and heal inflictions of the evil eye.

We heard stories that there are people who were completely recovered and healed just by seeking refuge in *Allah* almighty and used for example *Zamzam* water or the *ruqya*. It goes back to how strong the individual's faith is."

Similarly, Ramya explained: "Chemotherapy is a treatment, yes. But it is not like Qur'an....When we read *surat al-baqaraa*¹¹ everyday, we feel the difference even if we are not sick." Ramya refers to *surat al-baqaraa*— a chapter of the Qur'an often recited to protect people from, or cure them of, the evil eye or simply to help in times of difficulty. As Ramya's sentiment illustrates, there is a strong preference for traditional medicine among Saudi women, and yet, biomedicine is often sought immediately upon diagnosis, suggesting a desire (or perhaps familial pressure) to engage in biomedical treatment. The two forms of healing were not mutually exclusive as every woman interviewed described using both. However, religious and traditional healing practices were clearly preferred, especially as the disease progressed. Even when traditional methods did not cure the disease, they were still highly valued because they provided the patient with peace and comfort. In Basma's words:

We trusted the doctors initially, but when we saw that the treatments weren't working, we knew that the best way to go was with religious healing. At least with the recitation of *Qur'an*, she died peacefully. Sometimes treatments from doctors are effective, but we all realize that healing is only in the hands of *Allah*. Doctors and medicine are only tools, the ultimate healer is *Allah*.

Distrust of US-style biomedicine was often exacerbated by the numerous stories and references to medical mistakes, the need to rely on personal connections, and traumatic hospital experiences that circulated in communities. For the most part, the participants described how they were able to go to better-equipped hospitals and get quicker appointments because of their familial connections. Jameela, for instance, said: "I went to [a] hospital in Jeddah. My nephew, he is a doctor, he had a connection and got me an appointment." Despite this, the respondents acknowledged systemic shortcomings, realizing that if they had not possessed the necessary kinship connections, they would not have had access to timely care. Najwa explained: "Often it takes a very long time to schedule an appointment with a doctor, and when you do go, they sometimes don't even show up. It can be very frustrating, especially when dealing with such a dangerous disease as breast cancer." She noted that when her friends were diagnosed with breast cancer, that they were able to get an appointment quickly and to proceed with treatment due to their social connections. In her words: "If they didn't have those connections, they probably would have had to wait for a many months to see anyone."

In addition to the use of connections, several of the participants expressed doubt about the efficacy of biomedicine and the qualifications of physicians, mentioning possible misdiagnoses and medical mistakes. As Ibtisam shared: "Some of my friends think that I did not actually have breast cancer. So I am not sure if the diagnosis was correct." Lama recalled her experience with radiotherapy: "Can you imagine, when I was getting radiotherapy, they did not cover my eyes or provide any protection? Now I cannot see." Ramya shared a similar experience: "Here, they forgot the chemotherapy— you know how they put the chemotherapy with the IV solution together. So when my IV solution had run out, no one paid attention, and I continued to get chemotherapy without the IV solution so it burned my arm all the way down." Participants were upset by their negative experiences with biomedicine, yet many of them felt there was nothing that could be done about it. Arwa believed that the hospital was responsible for her condition: "I think they were the reason why I got breast cancer. I should have complained, but what would that have done? I should have been referred to a specialist, but I wasn't." These recounted

¹¹ A chapter of the Qur'an often recited to protect people from, or cure them of, the evil eye or simply to help in times of difficulty.

experiences with biomedical treatment in the narratives of participants illustrate a distrust of the system alongside a simultaneous desire to conform to social norms for clinical intervention.

Despite the expressed distrust of Western-style biomedicine, it was sought by every patient or patient's family member that spoke with us. This apparent syncretism, or bringing together of multiple (often conflicting) healing modalities, reflects both a pragmatism—that is, the desire to “try anything that might help”—as well as the hegemonic nature of biomedical standards of care in breast cancer treatment. The “universality” of such therapeutic regimes, however, does not blend smoothly, in this case, with the complex, culturally-specific belief systems and social realities described by Saudi survivors. Ultimately, this results in a dissonance between what women feel is the best course of treatment and that which they feel obliged to consent to.

V. Discussion

An examination of women's breast cancer narratives revealed three key themes: 1) breast cancer as an inevitably fatal disease; 2) breast cancer as a threat to traditional gender role fulfillment; and 3) a preference for traditional therapies over biomedical treatments. Figure 1 illustrates the relationships between these emergent themes. As the bidirectional arrows indicate, each of the cultural models embodied in the key themes influence, and are influenced by, one another. Survivors see a breast cancer diagnosis as a threat to traditional gender role fulfillment that carries significant social stigma. Fear of this stigma creates an incentive to avoid early detection, lessening the time one must live with stigma before death from the disease. The prevalence of late stage detection then feeds the perception that breast cancer is an inevitably fatal disease which, in turn, cycles back fueling and reinforcing the idea that breast cancer threatens a woman's ability to fulfill traditional gender roles as she is likely to lose her breasts, her hair, her fertility and even her life—all of which are symbolically and materially essential to the fulfillment of the socially expected roles of mother and wife. Fatalistic attitudes are further supported by constructions of the disease as God's will; when breast cancer is described as such, it enables women to maintain or regain a traditional identity as a “good” woman – an identity that is performed by engaging in traditional, religious therapies and critiquing biomedical treatments.

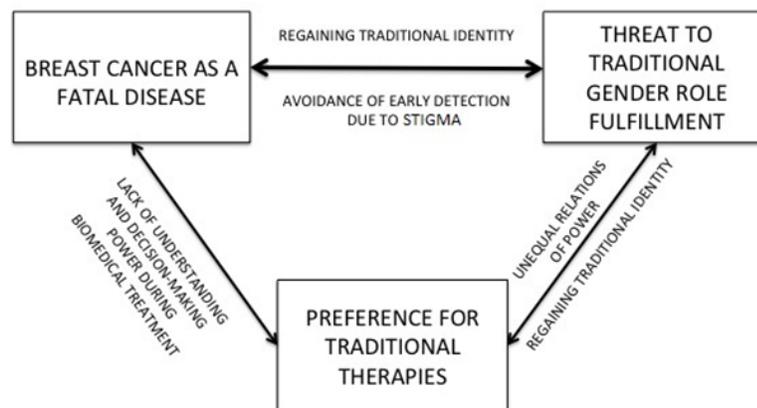


Figure 1: Schema of Key Themes. Breast Cancer Models and the Sociocultural Maintenance of Late Detection, High Mortality Cycles.

Despite the professed lack of faith in chemotherapy, surgery and radiation, women commonly undergo biomedical treatment often with a lack of understanding and decision-making power. A sense of powerlessness in decision making during treatment further fuels a sense of fatalism and lack of control that highlights the unequal relations of power that characterize relationships between woman and husband or guardian and patient and

physician. While biomedical treatments for breast cancer may be widespread in high resource nations, this study illustrates the complexity of the cultural models, meaning making and embodied experiences that form the subtext of “universal” therapies and so called standards of care. Biomedical treatment as it is currently provided in Saudi Arabia often does not align with women’s social and gendered realities, ultimately resulting in a dissonance that functionally discourages or prevents early detection, and thus, the possibility of effective treatment.

The cultural models elicited from the narratives of our study participants are paralleled, in part, in other studies on breast cancer survivors (Ashing-Giwa et al., 2004; Facione, 1993; Im, 2000; Kiss & Meryn, 2001). In a qualitative study exploring the beliefs about breast cancer among South Asian women in Western Canada, Johnson and colleagues (1999) found that many women attributed cancer to external forces including “curses” or “divine power.” Similarly, a qualitative study that examined the experiences of Latina women with advanced, metastatic cancers revealed that participants believed survivorship to be in the hands of God and the doctors (Haieem et al., 2012). Additionally, Yeo and colleagues (2005) identified explanatory models of cancer among Chinese-Australians, revealing that despite acculturation, informants maintained traditional Chinese beliefs and attributed cancer to factors such as karma, retribution, fate, Heaven’s or God’s will, geomancy, misfortune or bad luck, offending deities, and spells.

Similarly, concerns related to breast cancer as a threat to traditional role fulfillment have been found in other studies (Mathieson & Stam, 1995; Sulik, 2009). Karbani and colleagues (2011) found that South Asian breast cancer patients believe that cancer within a family significantly jeopardizes children’s marriage prospects and can lead to marital breakdown for those already married—a concern echoed by Saudi women in this study. Sheppard and colleagues (2012) conducted in-depth interviews with US black women with early stage breast cancer and found that spiritual beliefs and the patient-provider relationship were central to women’s lived experiences of the disease. Participants in the Sheppard study, like those in our project, also demonstrated a lack of knowledge regarding their diagnoses and treatment regimen options. Patients who demonstrated a better understanding of their disease and treatments were more likely to adhere to recommendations for therapies. Similarly, findings from Sulik’s (2009) study of 60 US breast cancer survivors suggest that patients who do not have a complete understanding of biomedical information or who hold beliefs that conflict with the dominant medical discourse, are less likely to use biomedicine as the primary frame for their illness identity. Collectively, this body of work is a potent reminder that much of what we see during the clinical breast cancer encounter is the proverbial tip of the iceberg; deeper and more complex disease models often lie below the surface influencing detection, treatment and outcomes.

VI. Conclusion

In conclusion, we have identified three key themes from Saudi women’s breast cancer narratives that help to explain persistent patterns of late detection and high mortality: 1) breast cancer as an inevitably fatal disease; 2) breast cancer as a threat to traditional gender role fulfillment; and 3) a preference for traditional therapies over biomedical treatments. Participants described a breast cancer diagnosis as a threat to traditional gender role fulfillment that carries significant social stigma. This stigma creates an incentive to avoid early detection so that the time spent living with stigma prior to death from the disease is minimized. The prevalence of late stage detection then feeds the perception that breast cancer is an inevitably fatal disease, and such fatalistic attitudes are further supported by constructions of the disease as God’s will, and thus, outside a woman’s control. In addition, despite the professed lack of faith in chemotherapy, surgery and radiation, we found that women commonly underwent biomedical treatment often with a lack of understanding and decision-making power. This powerlessness in decision making further fuels a sense of fatalism and lack of control, a link that is not unique to the breast cancer experience and true regardless of medical condition. As such, breast cancer treatment as it is currently provided in Saudi often does not align with women’s social and gendered realities, resulting in a dissonance that functionally discourages or prevents early detection, and thus, the possibility of effective treatment.

Although our findings lay a foundation for beginning to understand Saudi women's views and experiences, we recognize that patients and family members are not the only participants in the diagnosis and treatment process. Though we stand by the need to understand breast cancer experiences from the women's perspectives, subsequent research may "study up" to providers and health system administrators to offer a more holistic understanding of the processes involved, thereby providing more sufficient grounds to affect policy. The perspectives of Saudi oncologists, as well as a broader, regional sampling of breast cancer survivor narratives are both conspicuous in their absence. Only with the inclusion of additional voices can we begin to establish a more complete picture of the cultural models and clinical dynamics that are contributing to the high rates of late detection and breast cancer-related mortality observed in Saudi women. This study was designed to be hypothesis generating and to add "thick description" of the lived experience of breast cancer in Saudi Arabia to the larger body of epidemiological and clinical literature (Geertz, 1994). Other conditions could benefit from a similar assessment following the approach used in this study, wherein emic viewpoints are examined to better understand and address the lived experiences of disease. While we acknowledge that findings will need to be replicated and expanded upon in future studies, the parallels with research in other populations lend strength to our conclusions. Despite the acknowledged limitations, we believe a more nuanced understanding of emic viewpoints is urgently needed, as these viewpoints will likely prove essential in helping to improve public health messaging and early detection strategies in Saudi Arabia.

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