

Understanding the psychosocial needs of breast cancer survivors in the United Arab Emirates: a qualitative study

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Abstract

Background Breast cancer is the most common cancer among women in the United Arab Emirates; yet there is little known about the psychosocial concerns of the survivors. Research shows that meeting the psychosocial needs significantly contributes to cancer survivor's wellbeing and potentially elevates the quality of the patient's life. Therefore the study aims to understand the psychosocial needs of breast cancer survivors through a qualitative approach.

Methods A qualitative study was conducted using semi structured in-depth interviews among ten breast cancer survivors. The recorded texts were coded and salient themes were generated using an inductive approach. Thematic analysis of the interviews was done observing for meaning, repeating phrases and keywords.

Results Analysis yielded three major themes which included survivors' living experience with breast cancer, concerns of breast cancer survivors and the survivors' expectations of healthcare delivery or support needed. The breast cancer survivors had psychosocial concerns that are not well understood and addressed by the healthcare. The experiences, concerns and expectations differ from individuals and through the continuum of survivorship.

Conclusion Understanding the unmet psychosocial concerns of the cancer survivors is essential to design a structured survivorship program and offer timely and effective interventions. This would improve survivorship care in the country and offers opportunities to redesign cancer services towards patient-centred care.

Keywords Breast cancer · Psychosocial needs · United Arab Emirates · Qualitative study · Cancer survivorship

1 Introduction

Breast cancer in the UAE is the most common cancer affecting women regardless of nationality or gender [1]. It constitutes almost 20% of all cancer cases annually [2]. Women in the Gulf region are more likely to develop breast cancer at least a decade earlier than western countries [3]. This statistic is quite alarming as in younger women, breast cancer is generally more aggressive and less likely to have sustained response to treatment than in older women [4,

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5]. Breast cancer requires aggressive treatment and the person undergoes a lot of transition through surgery, radio and chemotherapy and subjected to prolonged side effects of these treatment. These side effects beyond the health issues affect sexual functions, body image, social life, employment, relationship with family and friends, which can affect the psychosocial wellbeing of the individuals. These psychosocial needs differ with age and younger women have shown higher levels of emotional distress. [6] Many studies have documented on the unmet psychological care of cancer survivors, their preferred sources of care and support required for survivors [4–7]. These psychosocial needs differ based on individual survivors and there is a difference in perception of psychosocial needs between the care provider and the survivor [7]. The major coping strategies adapted by the cancer survivors are social support from family and friends, peer support groups and religious groups [8]. A review on psychosocial needs of breast cancer patients have elaborated on the physical, social and emotional distress the patients undergo, the lack of adequate information and how family support and partners health can affect the wellbeing of the survivors [9]. Though these studies provide valuable insights majority of these studies are done in the western population. Therefore, understanding the psychosocial needs of the breast cancer survivors in a multicultural society like UAE is paramount to enhance survivorship programs.

Despite the high prevalence of cancer, there is a paucity of published data and limited understanding of the unmet needs of cancer patients in the Middle East [4]. Moreover, there is no structured survivorship program either at national or local level in the country. Psychosocial support services are generally provided upon request and referrals are made as needed. Studies have indicated several gaps and barriers in the provision of high-quality cancer care such as lack of routine assessment of survivors' psychosocial concerns. It also highlights the need for further research in psychosocial needs and cancer survivorship care [9]. The identification of needs clarifies the areas where actions and resource allocation are needed in the cancer care setting to help cancer patients overcome their difficulties also result in reducing healthcare utilization and cost by prioritizing the urgent needs, and potentially enabling problems to be prevented or reduced through appropriate evidence-based early interventions. Addressing breast cancer survivors' needs in the early stage of their survivorship provides guidance for new strategies in healthcare settings that could potentially reduce the burden of the disease and treatment in the long run thereby improving their quality of life. The UAE has a unique population structure with expats constituting 89% of the population and 11% of Emirati population, the expats belong to multiple nationalities and various ethnic and cultural backgrounds. This diversity in the population makes it imperative to understand the different psychosocial needs experienced by the cancer survivors. Therefore, this study aims to understand the psychosocial needs of breast cancer survivors and help successfully bridge the research gaps in the context of culture and diversity in the United Arab Emirates. Thereby offering valuable direction for future research and evidence to inform the optimal cancer care and provision of psychosocial cancer care for all cancer survivors in the UAE.

2 Methods

2.1 Study design and study setting

A qualitative study method was employed to understand the concerns and needs of the cancer survivors and its impact on their quality of life. The study was conducted at Tawam hospitals, UAE following IRB approval from Tawam hospital. Informed consent was obtained from all the study participants with pre-arranged debriefing sessions prior to commencing the interviews. Data confidentiality was maintained throughout the interviews which were securely stored with the protected measures in place to avoid disclosure of patients' identity.

2.2 Study participants

Ten participants (Table 1) were selected through non-probability purposive sampling to obtain rich in-depth information on their multidimensional needs and were initially identified and selected from the Cancer Registry database at Tawam Hospital. They were contacted over the phone for the convenient time to attend the interviews during their follow-up visit at Tawam Hospital Breast Care Centre.

Table 1 Details of the study participants

Participant	Age	Nationality	Religion	Histology	Stage
Participant 1	46	Philippines	Muslim	Infiltrating duct carcinoma, NOS	2B
Participant 2	31	Egypt	Muslim	Infiltrating duct carcinoma, NOS	3A
Participant 3	36	Russia	Christian	Infiltrating duct carcinoma, NOS	2A
Participant 4	50	South Africa	Muslim	Infiltrating lobular carcinoma, NOS	2A
Participant 5	62	Iraq	Muslim	Infiltrating duct carcinoma, NOS	1A
Participant 6	41	UAE	Muslim	Infiltrating lobular carcinoma, NOS	2B
Participant 7	39	UAE	Muslim	Infiltrating duct carcinoma, NOS	1A
Participant 8	44	UAE	Muslim	Infiltrating duct carcinoma, NOS	2A
Participant 9	50	UAE	Muslim	Infiltrating duct carcinoma, NOS	2A
Participant 10	54	UAE	Muslim	Infiltrating lobular carcinoma, NOS	2B

2.3 Study tool

The interview guide was developed to guide and probe further semi-structured interviews keeping in mind study aims, researcher's interest and contribution to the community which included information about breast cancer occurrence, the living experience with cancer and survivors' utmost concerns during the survivorship. To ensure that the topic areas would be reflective of the participants' experience as well as being appropriate and understandable, the questions were pre-tested with two breast cancer patients and two oncologists.

2.4 Semi-structured face-to-face interviews

30–45 min, face to face in depth interviews were conducted to acquire insight into issues via gaining understanding of breast cancer survivors' experiences and to make the participant feel that their story is important. The interviews were voice recorded and transcribed manually for analysis within a few days after the interview. Each interview was assigned a unique code, prior to each interview, written consent was obtained from each participant. The interviews were conducted until the data reached saturation, where there was no new information contributed during the interview based on the questions and domains mentioned in the interview guide.

2.5 Data analysis—thematic analysis

Given the scarcity of research conducted in the UAE on cancer survivors' psychosocial needs and lack of evidence based psychosocial interventions in this region, for a deeper understanding of survivors' lives and their concerns [10], thematic analysis with an inductive (bottom up) was considered the most appropriate method to conduct this study. Six-phased linear method of thematic analysis of the data was carried out by creating transcripts from audio recordings which were carefully heard and thoroughly understood to attain deeper familiarity with the depth and breadth of the content of data as well as to create thick descriptions from them. The entire dataset was read repeatedly to search meanings, patterns and other key words or phrases, to draw ideas and identification of possible patterns. The entire dataset was organised into meaningful groups and codes were manually assigned to the data segments that provided the information from the raw data in a meaningful way [10, 11]. A template was created to justify the inclusion of each code to assist in interpretation and clear evidence to add credibility to the research and to enable the reader to judge whether the final outcome is rooted in the data generated. Data was coded based on notes that were written and highlighted to indicate potential themes. Following coding, the entire data was collated together within each code that formed the basis of themes. Themes were created from the data itself without having any presumption in mind. Upon producing the list of the codes, they were sorted out into initial themes. Themes were identified as salient by participants' responses based on something important to them as well as perceived frequent if the number of participants raised the similar theme not on the basis of frequency of statements made. Each code was written with a description and mind-maps were created to form an overarching theme. Some initial codes formed main themes whereas some were assigned as sub-themes, and some were discarded. Themes were generated inductively from the raw data thus were strongly linked to the data themselves. Data coding was performed without trying to fit it into pre-existing ideas or preconceptions. Themes were created with a good number of predefined codes to

help guide analysis and most relevant themes were identified in relation with the research questions. Detailed notes were taken about the development and theme creation that helped establish confirmability in the audit trail. Themes were reviewed and refined by developing candidate themes into final themes by re-reading the entire data to assure the coherence of themes and sub-themes with the dataset and accurate representation of the data. A thematic map (Fig. 1) was developed after defining and redefining by identifying the essence of what they are about and were analyzed to determine which aspect of the data is captured by each theme. The analysis appeared to reach thematic saturation at a point when no additional themes were found from the reviewing of successive data regarding each investigated category. A detailed analysis for each individual theme was conducted to identify the story that each theme tells in relation to the research question. Themes were not finalized until all the texts were included which were relevant to the research questions. All themes were given concise names to the identified themes to provide a quick sense about what the theme is all about. The analysis was peer reviewed and participants' statements were subject to rechecking by a reviewer as well as with the relevant participant either by phone or voice notes. To ensure the final themes were supported by the original data, the original interview transcripts were re-read several times. Findings were developed and all methodological notes were taken to the audit trail to add trustworthiness and credibility. A reflexive journal was maintained throughout the research to ensure findings and conclusions were interpreted in a trustworthy manner and whether the literature is in line with the conclusion or not. The final results were aimed to be shared with the participants for their feedback to allow linking between respondents' views and representations.

3 Results

There were three main themes that emerged from the thematic analysis which were survivors' living experience with breast cancer, concerns of breast cancer survivors and the third was survivors' expectations of healthcare delivery or support needed.

3.1 Theme 1: living experience with breast cancer

- Sub-theme 1: diagnosis of cancer

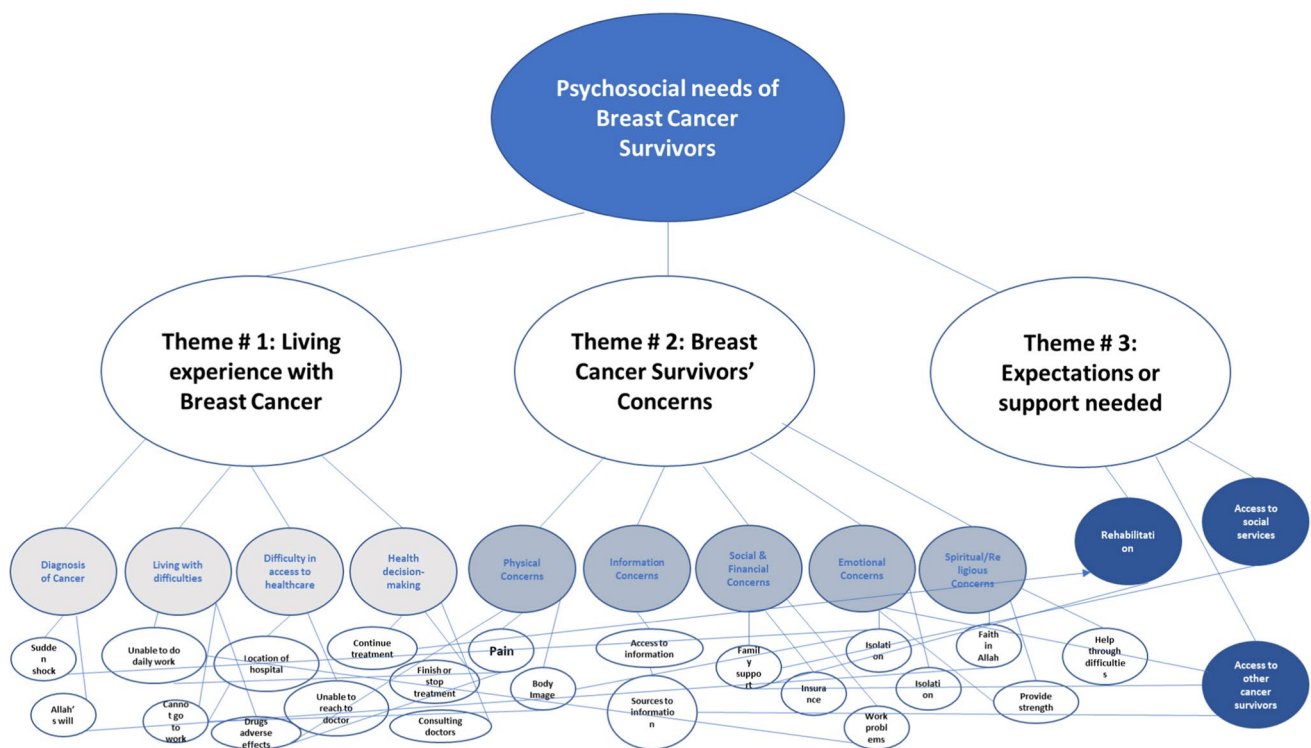


Fig. 1 Thematic map—psychosocial needs of breast cancer survivors

- Sub-theme 2: living with cancer/difficulties
- Sub-theme 3: difficulty in access to health care
- Sub-theme 4: health decision-making

3.2 Theme 2: breast cancer survivors' concerns

- Sub-theme 1: physical concerns
- Sub-theme 2: information concerns
- Sub-theme 3: social & financial concerns
- Sub-theme 4: emotional concerns
- Sub-theme 5: spiritual/religious concerns

3.3 Theme 3: survivors expectations of the healthcare delivery

- Sub-theme 1: patient satisfaction
- Sub-theme 2: patient expectations

3.4 Theme 1: living experience with breast cancer

3.4.1 Sub-theme 1: diagnosis of cancer

Most cancer survivors expressed that cancer diagnosis struck them with shock and was an unanticipated event.

Participant 1: "It was by sudden".

Participant 6: "I was shocked and devastated to hear that I have cancer".

Some individuals shared that their initial response was denial, which is a protective response against the threat. Some cancer survivors consider the disease as a will from Allah and accepted as their destiny. The spiritual connection with God does help believers in dealing with the diagnosis of cancer with hope and positivity while providing a strong coping mechanism through faith.

Participant 4: "I was surprised but it was my destiny, it's from Allah and I took it easy".

3.4.2 Sub-theme 2: living with cancer/difficulties

Cancer patients saw themselves and life in a different way or found that others think of them differently after cancer. Most survivors found that this transition period after being diagnosed with cancer is about finding out what is meaningful for them now.

Participant 7: "If you compare me one and half year back and now it is different; when I had the treatment, I understood it's my life now".

Participant 3: I felt my life changed to slow and I became more thoughtful and considerate towards my family than myself".

The findings also showed that breast cancer treatment can have an impact on one's body, psyche as well as self-confidence. Depending on the type of treatment, one's body can change drastically in a short period of time which was reflected in the interviews.

Participant 5: "Until now, you know I cannot wear a bra. It's very hard for me to wear the bra because when I wear the bra, my pain increases. For example, until now when my nieces and nephews come and hug me, my breast is like somebody hit me and I feel pain".

Expressing sexuality remains important and cancer affects how a woman perceives her sexual identity, for instance, an altered body image. Participants reflected that it can affect the way one thinks and feels about her body image and self-confidence to the extent that one could worry that people will treat them differently because of the change to the body image.

Participant 6: "My view of myself changed and it was going to change immensely after and coming to terms with my new body, I can tell you at this point that I do not have a partner in my life, but this is gonna impact me having one again".

3.4.3 Sub-theme 3: difficulty in access to health care

This sub-theme mainly focuses on difficulties faced by cancer survivors in accessing cancer care as well as concerns about care coordination with healthcare providers. This includes attributes of the healthcare delivery system such as geographic distribution of cancer care facilities as well as attributes of healthcare providers, for instance, lack of knowledge about cancer care or treatment. Identification of such barriers is critical in order to address and implement strategies that could help on both individual as well organisational level.

Some patients travel from a far distance to attend scheduled appointments for the consultation with their doctors or to receive treatment; this adds additional stress and burden as fatigue and pain are the most common concerns among cancer survivors.

Participant 1: "I am very far from the hospital (Al Ain); Sometimes I cannot reach the doctor".

Participant 8: "You know, I am driving from Abu Dhabi to Al Ain and it's considerably very far for a patient".

Patients also felt that healthcare providers do not communicate effectively. The quality of doctor-patient relationship is critical and can affect clinical outcomes, patients' quality of life and satisfaction with care thus communication gap can result in lack of trust and could be highly worrisome to some patients.

Participant 5: "All doctors are like take it... take it... how can I take it? Even I asked them, did you have a patient like me?" This happened, and they said let's try. What's let's try?"

3.4.4 Sub-theme 4: health decision-making

Each patient brings her own personal values and beliefs to the decision-making process. There could be a number of psychological or socio-cultural factors that influence patient decision making about seeking or delaying timely care.

Participant 2: "Then I said, it happened but it will go; But it took time and there was my sister's wedding and then I said not now till my sister's wedding is over. You know then after that I went to see the doctor here in Sharjah".

Participant 3: When I was taking care of him, I knew I had a lump but when he passed away after that I decided to go and see the doctor; "Before that I was ignoring my condition".

Informed decision making is central to patient-centred care where the physician provides the information to the patient and then the patient makes the decision. Patient preferences and values must be considered and respected by the healthcare providers with regard to the outcomes of options. Most cancer patients need extensive and detailed information to recognise and appreciate the effect treatment has on their lives. Thus, it is important that healthcare providers understand patients' priorities and perceptions of their treatment which may change over time and include them in discussions during decision-making.

3.5 Theme 2: breast cancer survivors' concerns

Theme 2 encapsulates psychosocial issues as described by the breast cancer survivors.

3.5.1 Sub-theme 1: physical concerns

Women with breast cancer face many physical challenges associated with disease and mainly treatment such as changes in weight and in body compositions, menopausal symptoms, persistent fatigue as well as psychological symptoms associated with the alteration in body image resulting from either surgery, adjuvant therapy or side effects of chemotherapy or hormonal therapy.

Participant 1: "My major concern was physical appearance like, no hair, skin change".

Participant 5: "Pain, physical concerns for sure. Pain was the most difficult."

3.5.2 Sub-theme 2: informational

Cancer patients have better health outcomes when they are more informed about their disease and more involved in their treatment choices. Information provided to cancer patients relieves anxiety and helps them make informed treatment decisions.

There was a mixed response when participants were asked about their information concerns; most women were fully satisfied with the information provided to them and mentioned that there was no difficulty in obtaining information, yet few showed their concerns about information delivery from healthcare providers.

Unfortunately, it is not uncommon that while cancer patients are generally well treated medically for their disease, their healthcare providers fail to address cancer related psychosocial or emotional aspects in a helpful manner or worse they are not screened routinely for this aspect of cancer.

Participant 5: "I am asking them to give me information. Did it happen before, is it something naturally happening? Do you have other cases or not? So, in that situation, they just want to do what they learned".

Participant 6: "They go very efficient in everything but the psychological and emotional side, nobody said you are gonna be depressed afterwards".

"If you are gonna see the mirror for the first time, you are gonna break down in tears. Nobody prepared you for that".

Some women do individual research and build their own knowledge through various channels, yet they are not fully prepared to face unforeseen circumstances.

Participant 7: "I don't remember but I don't think I was told if I face such and such issues, I can go to this person or that person, but I think this is something you need".

3.5.3 Sub-theme 3: social & financial concerns

The cost of health care, lack of insurance, low income or employment issues all could contribute to major financial stress. The sub-theme 3 describes the impact of social and financial difficulties or concerns on women with breast cancer. Financial worries were mentioned mostly by expatriates since all Emirati women were covered by national insurance called "Thiqa". The UAE government provides Emiratis full health coverage; thus, no financial worries or concerns were mentioned among Emirati cancer survivors.

Participant 2: "No, I had no financial or social issues; is covered by insurance alhamdulillah".

Participant 5: "No, I didn't have any financial problem because this is all from the government".

Although health insurance is covered for all UAE residents (mostly by employers), expatriate cancer patients continue to experience problems accessing the care they need. Insurance coverage expansion and enhancement of current mandates have been the most visible concerns expressed by the expatriates in this study.

Participant 8: "My insurance is very bad, now I took treatment under mandate because my insurance doesn't cover anything".

"For my surgery I had money problems and I couldn't manage the money for surgery".

Participant 6: "They said that I have to pay ten thousand and I said I can't do that... I can't afford it".

Some patient's health coverage was not covered by the insurance thus they were supported by a mandate issued by the UAE government to support cancer patients (mainly expatriates) by providing financial support to those who could not afford and have limited financial resources.

Participants also mentioned her difficulties in delaying her treatment session because of delays in the approval process from the insurance which sometimes resulted in her missing sessions until approval was granted.

Participant 6: "Sometimes I would come, and the approval will not go through entirely so a couple of sessions I had to miss. When I had started my chemotherapy, the first session had to be postponed because they didn't approve it. Lot of the time, initially the first few weeks of my chemo, I didn't do it. After that it had to be postponed to next Wednesday because it wasn't approved. I have had a lot of issues in the beginning".

The physical and psychological problems can be exacerbated by or result in serious social problems. Most women anticipate positive relationships with their loved ones to gain strength and to maintain their psychological well-being.

Participant 1: "I talked to my husband; That was from my husband, I was strong".

"I have found so much support from my family, from my relatives that's what gave us strength hamdullila".

Apart from family, having a good social circle and having good friends do not just ease emotional distress but some really understand the pain and difficulties in performing daily tasks and provide as much support as possible.

Participant 6: "I had lots of friends assisting me".

"Everybody was most helpful".

"I am not lying, I swear to God, every day I had lunch, I had dinner. It would be left at my door. Every day she sent somebody from the cleaning company, every day my apartment got cleaned because I cannot, I must not do anything. Alhamdulillah".

Support from employers is crucial. Employment concerns were only mentioned by two women but positively.

Participant 7: "My director in the school, he knows what happened to me. Actually, he gave me one month off when I started my chemo so I can continue my job".

Most of the women mentioned immense support from their family and friends yet every person's life experience is different. There were some participants who did not receive any support from their family or friends. They expressed their disappointments and difficulties due to lack of support from their very close people.

Participant 7: "You know through this sickness, almost all my people changed, people whom I was with and thought they are close, and I thought they are my relatives".

3.5.4 Sub-theme 4: emotional concerns

Breast cancer experience requires a person to consider an array of psychosocial and emotional demands, mainly emotional. The experience of breast cancer diagnosis and treatment may result in considerable emotional distress that brings fear and challenges about a woman's identity, self-esteem, body image as well as relationships.

Although breast cancer diagnosis affects a person from many different psychosocial aspects, emotional concerns are the highest and the most challenging among this population.

Participant 7: "Dealing with emotions, maybe, was the biggest challenge for me because you need lots of strength and it is very important for you to have supportive people".

Participant 6: "Emotional concerns were the most important issues I had to deal with".

Most women share the news of their diagnosis with their closest family members, others may hide the news from their family members for various reasons.

Participant 10: "I didn't tell anyone about it because you know, they would be worried about me. I didn't want that, so I kept it to myself. And you know when people hear about it, they will be shocked; oh, how would you do it, it is dangerous. I didn't want that negativity".

Breasts are important for female beauty, identity and sexuality. It creates women's' body image and can affect relationships between couples. It is not always about appearance but sometimes loss of sensation or sexuality. Dealing with body image concerns after breast cancer diagnosis and treatment is a process rather than an event.

Participant 5: "The look of the surgery is very bad. It is affecting me psychologically".

Other women mentioned that looking at herself in the mirror was an emotional experience.

3.5.5 Sub-theme 5: spiritual/religious concerns

Most women showed their reliance on God as well as the future in God's hand as they have faith that God loves them and there is always a reason in God's plan. They acknowledged that the support from God gave them the strength to deal with the life-threatening disease. Participants mentioned their relationship with Allah (God) has flourished and they found themselves even closer to God than ever before. Participants mentioned that they have increased their prayer practice by investing their time more toward recalling and reminding Allah and reading the Quran.

Participant 1: "Muslim always has faith, so I said alhamdulillah". "It worked for me so I should say alhamdulillah as I have faith".

"When we have faith, it helps us pass through all the difficulties hamdullila" "Islam is a gift; it is really a gift. It helps us to pass everything. I found a way to deal with it through my faith".

Participant 3: "Most importantly with my faith in Allah, there were difficulties, but I managed all hamdullila".

3.6 Theme 3: patient experience with healthcare providers

Coping with breast cancer requires different kinds of support at different times. Getting support and being satisfied with the care they receive is important for breast cancer survivors' wellbeing and adjustment to the new normal. Almost all women showed a good level of satisfaction with the care they received from their health providers.

3.6.1 Sub-theme 1: patient satisfaction

The study result showed that most patients treated were satisfied with the support received from the health care providers and hence had minimum concerns with healthcare delivery.

Participant 2: "Yes, I am satisfied with the care I received". "They (health providers) treated me a good way. All the people were good even when I had radiation, they were helpful people hamdullillah".

Participant 3: "I don't think there is anything missing from the healthcare department. I received all the updates I needed from my doctors and nurses and the doctor was calling me to check on me how I am doing so I got sufficient support from the healthcare department".

3.6.2 Sub-theme 2: patient expectations

The qualitative result showed that there were some unique concerns or expectations shared to improve the current services such as adding Nutritionist in treatment planning, improved pharmacy services, enhanced or expanded mandate to cover comorbidities, improvement in information delivery, emotional and physical support provision by doctors. Some patients expressed their concerns that services needed to be improved and be more efficient; for example, one participant wanted to have sessions with a nutritionist while another was concerned about the slow delivery of pharmaceutical services.

Participant 1: "I really needed a nutritionist. You just need someone to advise you on how one can deal with appetite. What should we eat and what we shouldn't eat? That is what I needed most".

Furthermore, some participants felt that healthcare professionals needed to provide more information and another person pointed out that they should provide emotional support as well.

Participant 8: "Maybe if doctors can provide emotional support. I prefer if I receive more support from health providers about the physical issues I have. Maybe doctors can also provide emotional support".

Although health insurance is covered for all UAE residents (mostly by employers), expatriate cancer patients continue to experience problems accessing the care they need. Insurance coverage expansion and enhancement of current mandates have been the most visible concerns expressed by the expatriates in this study.

Participant 9: "If hospitals can provide enhanced coverage for those who cannot afford the treatment, this would be very helpful".

4 Discussion

To the best of our knowledge, this is the first qualitative study that explores and addresses the psychosocial needs of breast cancer survivors in the UAE and highlights the existent gaps in the literature. Based on the interviews and the thematic analysis, the study identified three main themes which were survivors' living experience with breast cancer, concerns of breast cancer survivors and the third was survivors' expectations of healthcare delivery or support needed. The analysis demonstrated that the breast cancer survivors in the UAE have unmet psychosocial needs and required psychological and emotional support throughout their cancer journey. These psychosocial needs were prevalent in both groups including UAE nationals and Emiratis. In general, the concerns and needs expressed by the breast cancer survivors in this study were consistent with survivorship issues that have been addressed in the literature. [6–9]. However, this study provides some unique and rich findings which are particular to the middle east population. These results strengthened the finding from the previous study conducted on cancer survivors' needs in the UAE which demonstrated that breast cancer patients require a wide range of psychosocial care in the UAE [4, 12].

The findings from this study show that the life experiences of being diagnosed with cancer, living with cancer and surviving through the treatment has impacted the lives of the survivors in various ways that included changes in their perspective, behaviour and lifestyle. Studies have shown that cancer survivors experience various difficulties in their daily lives including physical, emotional, social or economic difficulties [13, 14]. These concerns include but are not limited to adjusting to new normality, adjustment with stress and other psychological issues, managing expectations, dealing with emotions and several other concerns. The diagnosis and treatment of cancer can provoke serious psychosocial disruption in a manner that anxiety and depression can elevate significantly in comparison to normal individuals [15].

Study found that psychosocial and emotional impact of cancer is so profound that patients had adjustment and stress issues mainly related to treatment. Physical needs were expressed during the interviews which included pain and fatigue as the most concerning aspects of physical concerns which was consistent with previous studies [16, 17]. Apart from pain and fatigue, several other physical concerns were expressed by the survivors for instance, body image, appearance, hair fall, sleep disturbance, weight, appetite and other health issues mainly due to the side effects of cancer treatment which affected them both psychologically as well as emotionally. Study showed that survivors experienced serious psychosocial symptoms emphasizing emotional and physical side effects such as body changes, pain, fatigue, hair loss, weight changes that impact their ability to carry out the daily living, roles and responsibilities as reported in the literature [16, 17]. Results showed that loss of breasts or breast tissue to minimise the risk of having breast cancer or to treat cancer, resulted in body image concerns in most of the women which affected the survivor's psychological health. By losing such feminine physical characteristics, some women developed social stigma which induced stress and a physical burden of the disease in them. Literature shows that surgery not only created an intensified sense of loss for some women, but it potentially unleashed psychological reactions since it damaged the symbolic connection of the breast to femininity and sexuality [18].

With regards to access to care, most women understood the significance of their symptoms straightaway yet delayed consulting a doctor about their breast symptoms. Previous studies in the region also confirmed the similar findings that despite advancement in breast cancer treatment, a considerable lack of awareness has been reported about breast health mainly due to sociodemographic characteristics and cultural factors [19–21]. It was observed that women in this region regardless of their nationalities actively took part in the treatment decision-making. With regards to autonomy in the decision-making process, the study results show that women who were certain and did take part in their treatment choices at their comfort level demonstrated confidence and greater treatment satisfaction. Katz et. al. reported similar results in his study in the US population suggesting that more informed and engaged patients are more satisfied and have better outcomes [22].

The need of information and being well-informed was strongly expressed during the interviews. Literature suggests that Arab women with breast cancer with limited access to reliable information may struggle to transition to a new normal even several years after the treatment [23]. In this study, survivors expressed their desire to have more information to manage treatment side effects and to deal with cancer that had an impact on their daily functioning. It is a critical aspect of cancer care and previous studies reported that physicians mainly focus on biological or physical symptoms or medical strategies and usually do not address or provide information about the psychosocial impact of breast cancer [24, 25]. Survivors opted to be linked with online forums, searching the internet for the specific information [26] or talked to other survivors to educate themselves. Findings further explained that information concerns exist throughout cancer survivorship and must be addressed at all levels of cancer trajectory as circumstances and needs change overtime or vary at different points in the disease process. Participants also noted that their physicians did not try to understand the patients' difficulties in terms of physical issues thus were left unattended or unaddressed. One possible reason for this lack could be the practicing model of physician centred care rather than patient-centred care which is rare in this region. Only few expatriates expressed their challenges with the insurance approval process as they had to either wait and postponed their planned treatment, yet no patients declared major financial or insurance issues as they utilized government mandate to afford the treatment. Results also indicated that most of the patients managed their employment with the support of colleagues and employers yet, some mentioned problems such as having needs for time off from work due to treatment [27].

Social isolation or changes in social interaction occurred with some of the survivors as they felt isolated and lost their interest in maintaining relationships with colleagues and friends. This either could be due to grief of cancer, lack of self-confidence, concerns that change of appearance may reveal breast cancer diagnosis to others or to avoid the conversation on this topic. It is also worth considering that in Arab communities, as family members tend to hide illness and disease from the community since cultural values require them to keep family issues within the home [28]. In contrast to the previous literature which presents gender domination in Arab and Muslim culture with conservative views about their women to the extent that they object their partners and their families to be seen by clinicians [29–31]. This study findings showed that most participants had received a good level of support from their husbands and other family members which helped them cope up with their disease. For most women, family was an important source of strength to manage the disease, showing the importance of the role of family in both diagnosis and treatment stages. Findings showed that emotional needs which ranged from concerns associated with the cancer diagnosis itself, dealing with emotions and mixed emotions, fear of recurrence, genetic counselling, worrying about future and family particularly children, fear of losing job and loneliness were contributing factors which affected those women emotionally. Breast cancer also provoked

various concerns and fear including fear of recurrence and passing it to family, difficulties for family mainly children, sexuality and loss of self-esteem etc. Breast cancer survivors showed that the need to have emotional support and to speak to someone who can empathize, is critical to manage the disease during the survivorship which are consistent with previous studies [32]. Some patients showed their concerns about the absence of not having psychologist and emotional support services available during their care process to receive appropriate psychological or emotional care. However, this is usually the case in advanced countries where patients can request for a clinical psychologist [32]. These services are however, not usually part of the routine cancer care. Breast cancer survivors require holistic care from healthcare providers thus, it is important that at every stage along the cancer continuum, the care delivered must address physical aspects of the illness in addition to the mental health and coping strengths for both the patient and their family [33].

Spiritual or religious concerns related to patients' disease can affect their mental health and failure to meet these needs may impact their quality of life [34]. The study findings confirmed that religion was a fundamental aspect of women living with breast cancer in this region [35–37]. For cancer patients, spiritual or religious concerns are likely to reflect on existential issues due to uncertainty of their future [38]. These concerns are highly correlated with depression, anxiety and a measure of overall distress [39]. In this study, no spiritual or religious concerns were found, rather survivors' faith and belief in Allah (God) helped them accept the disease and suffering of cancer. Survivors described that their faith helped them through the difficulties and ease their struggles and religion became the source of strength during cancer survivorship. Participants mentioned that they have become closer to Allah than ever before and have increased their prayer practice. Literature suggests that cancer survivors who practiced religious activity more frequently had better health behaviours for instance, greater likelihood to follow their physicians' advice, an association that was mediated by self-assurance. In contrast, higher reports of religious struggle for instance, feeling abandoned or punished by God were associated with poor health behaviour, an association that was mediated by guilt [40]. Thus, it is important to screen cancer patients for their religious or spiritual distress and possibly for their beliefs that may influence cancer related health behaviour negatively such as beliefs that may compromise the adherence to guidelines and treatment. Nevertheless, further research is needed on whether religious or spiritual practices or cultural practices remain constant or changes across cancer trajectory. It is also important to be aware of cultural and religious differences when looking at patterns of adjustment to cancer. A knowledge of the role that religion and spirituality play in the patients' life may enable healthcare professionals to understand how religious or spiritual beliefs affect patients' response to cancer diagnosis and decisions about treatment. Therefore, while assessing cancer patients' spiritual or religious needs, healthcare providers must know that non-western cultures use different coping strategies than individuals from western cultures [41].

5 Limitations

Although this study provides insight into breast cancer survivors' concerns representing the larger cancer population in the UAE, it is not without limitations. It was not considered in this study whether or not the participants received all the care at another facility and attended Tawam Hospital for just follow-up and revealed only the current needs. Therefore, there could be a possibility that participants' concerns either could have been missed if the current care was given at the optimal grounds and they were all satisfied. Switching healthcare providers or treatment facilities might have implied some degree of bias in the evaluation of survivors' needs and this factor was not considered in the current study.

It is also important to consider that the concerns of breast cancer survivors were assessed at one point which gave critical insight into women's breast cancer needs and concerns at a potentially reflective point. The approach allowed identification of concerns at that particular phase which undoubtedly overlooked acute psychosocial concerns or needs that they might have confronted earlier thus introduce a recall bias. Moreover, the data obtained at one point of the study from the selective group of cancer survivors might not be able to capture the changes in breast cancer survivors' concerns over time and changes over the trajectory of cancer survivorship.

Although most women were able to speak English, it still needs to be taken into consideration that for those who did not, some material and nuance would have been inevitably lost in translation from Arabic to English. There could be a potential for bias in the selection of participants through purposive sampling. The participants were selected based on their availability and willingness to be part of the study, so it is possible that interviews with other participants would have yielded different results. Financial concerns were hard to assess and were not fully representative of entire population as most expatriates had health coverage whereas Emiratis were fully covered by national health insurance.

Other limitations including methodological as well as organizational limitations inherited in the study that might affect the generalization of the results must be acknowledged before drawing implications from the study findings. The results were intended to add depth and breadth to understanding cancer survivors' concerns and should not be generalised to the general population. Although Tawam Hospital is a national referral centre for cancer patients yet; the selected sample size was not fully representative of the entire cancer population in the United Arab Emirates.

6 Conclusion

The study addresses that a considerable portion of the women desire prolonged psychosocial intervention throughout the cancer trajectory. Data also indicates that cancer survivors in the UAE have different dimensions of needs where information, emotional and physical concerns are the highest that require serious attention. The findings provide several opportunities to improve a number of key aspects of cancer care and toward meeting the psychosocial needs of cancer survivors that are usually missed during the routine cancer care. The findings inform that a holistic cancer care model is needed that includes psychosocial and survivorship care as a distinctive part of it. Cancer care facilities should consider establishing a structured survivorship program which should include psychosocial services including all psychosocial domains to meet the needs of all cancer patients which are unique, specific and ongoing. The study findings provide a comprehensive survivorship care road map to address and systematically improve the quality of psychosocial care for cancer patients that may be used across the cancer population in the United Arab Emirates. This study proposes several strategies for healthcare systems, policy, research and cancer survivors aiming to address gaps in knowledge and policy and to implement effective and evidence-based clinical survivorship care that meets the need of cancer patients in the UAE.

6.1 Implications for healthcare systems

- Psychosocial distress screening & survivorship care to be part of routine care;
- Develop survivorship care guidelines for clinical and psychosocial needs;
- Provision of 'Treatment/survivorship Care Plan' to each survivor;
- Coordinated, unfragmented, comprehensive and culturally sensitive patient-centred cancer care;
- Enhance physician patient partnership & patient empowerment;
- Transition from medical paternalism to patient autonomy;
- Develop evidence-based interventions; and
- Education & training of health care professionals.

6.2 Implications for policy

- Reimbursement for essential post-treatment survivorship care;
- Enhance cancer mandate coverage;
- Develop professional guidelines and training on cancer survivorship care;
- Measures to address shared decision making and patients satisfaction in health promotion and disease management; and
- Develop evidence-based, culturally appropriate information and resources to meet the needs of survivors.

6.3 Implications for research

- Funding for survivorship research to increase evidence base;
- Further research on cancer psychosocial care and survivorship care; and
- Education of policy makers to increase awareness of survivorship issues.

6.4 Implications for cancer survivors

- Awareness about psychosocial concerns & survivorship care in general public; and
- Develop models for cancer survivorship to help empower survivors to manage their survivorship care.

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Data availability The datasets generated and/or analyzed during the current study are not publicly available due to the sensitivity of the data and medical information but are available from the corresponding author on approval of the request.

Declarations

Ethics approval and consent to participate This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Tawam Human Research Ethics Committee, Al Ain, Abu Dhabi, UAE. Informed consent was obtained from all individual participants included in the study.

Consent for publication Not applicable.

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