

RESEARCH ARTICLE

Evaluating psychosocial support needs of female cancer patients in the State of Qatar

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ABSTRACT

Patient perceived perceptions of psychosocial support are increasingly important to understanding appropriate holistic patient-centred care. Information is scarce regarding the attitudes of female cancer patients in Arab and Muslim populations. This study was undertaken in the State of Qatar among female cancer patients. The aim of this study was to investigate what extent women undergoing cancer treatment in the State of Qatar view the importance of psychosocial support? Another aim of this study was to determine which demographic indicators, if any, may predict for certain preferences in support. The authors hypothesized that a majority of female cancer patients will perceive psychosocial support as an important aspect. This study used English and Arabic questionnaires to glean data from female cancer patients attending clinics at the National Centre for Cancer Care and Research in Doha, Qatar. For the purpose of this study, psychosocial support was defined under four categories: 1) family support, 2) religious/spiritual support, 3) support groups 4) physician referred support. Results showed that 88% of female respondents rated psychosocial support categories as important. There was no significance between patient demographics and specific preferences for the support categories in the study. This study may provide some areas for future research that may shape guidelines for improving holistic patient care and in assisting the Supreme Health Council in meeting its targets for the Qatar National Cancer strategy, which states that cancer treatment should be patient-centred focusing on both medical and psychosocial needs of patients.

Keywords: cancer, psychosocial, support, women, Arab, Muslim

INTRODUCTION

The State of Qatar has a small population, which is among the richest in the world with a gross domestic product of over US\$80,000 per capita in 2010.¹ Qatar has a relatively young population with only 2% of the population over 60 years of age. Over the next 40 years, this population is expected to increase ten-fold to approximately 20%.² This has huge implications for cancer care (often considered a disease of the aging) in the State of Qatar.

Cancer deaths account for approximately 20% of total deaths in Qatar.³ For example, breast cancer is the most common diagnosis as is the case in many other Gulf Cooperative Council (GCC) countries.¹ The topic as well as the word *cancer* still remains very much a taboo in Qatar, as is the case in many other Arab and Muslim majority societies.⁴⁻⁶ Misconceptions about the disease act as a social and practical barrier to early screening programs.^{1,7,8} This means that women are presenting later, which has resulted in Qatar exhibiting higher breast cancer mortality rates compared to other larger Arab states such as Saudi Arabia and the United Arab Emirates.⁸ Psychological distress amongst female cancer patients has been discussed at length in the literature.^{7,9-13} Female cancer patients tend to exhibit higher psychological support and encouragement needs compared to men.¹⁴ Long-term treatments and subsequent side effects can affect various aspects of a women's daily life and may result in role changes within the family that may exacerbate psychosocial problems such as anxiety and depression.¹⁵⁻¹⁷ In addition, psychosocial distress has been noted to increase steadily even after treatment if left untreated and is found to hinder recovery and physical coping with the disease.¹¹ Literature that explores patients' perceived emotional and psychological needs is currently scarce.^{6,18,19} Even fewer studies exist that evaluate psychosocial support in Arab populations in particular, as most studies have been conducted in Western populations.^{18,19} The literature suggests that unmet support needs of patients differ between cancer populations depending on their geographic location.^{1,14,20,21}

STUDY AIM

Recent recommendations of the Qatar National Cancer Strategy suggest that cancer treatment should be patient-centered, focusing on both medical

and psychosocial needs of patients.¹ The study aims are twofold; to determine to what extent female cancer patients view psychosocial support as an important part of their care strategy and to interrogate what demographic indicators, if any, may predict certain preferences in care. The study will capture the views of all female cancer patients regardless of diagnosis in order to evaluate shared psychosocial issues.

Psychosocial support is a broad term that encompasses many facets. For the purpose of this study, psychosocial support has been divided into four categories: 1) support groups, 2) physician referred support, 3) family support and 4) religious/spiritual support. These categories were chosen according to the literature on Arab and Muslim majority populations where these four items recurred as important areas according to patients' perceptions of psychosocial support.^{5,6}

RESEARCH QUESTIONS AND HYPOTHESIS

The primary research question:

- (a) *To what extent do women undergoing cancer treatment in the State of Qatar, view the importance of psychosocial support?*

Hypothesis 1:

a majority of female cancer patients will perceive psychosocial support as an important aspect.

The secondary research questions may provide some insight into the relationship between demographic characteristics and support category preferences presented in the questionnaire:

- (a) What kind of psychosocial support categories presented in the questionnaire do female cancer patients find the most important?
- (b) Are certain demographic indicators correlated with specific support preferences?

H2: *The perceived importance of support is influenced by the patients' nationality*

H3: *The perceived importance of support is influenced by the patients' age*

H4: *The perceived importance of support is influenced by the patients' religious background*

H5: *The perceived importance of support is influenced by patients' marital status*

- H6: *The perceived importance of support is influenced by patients' education level*
- H7: *The perceived importance of support is influenced by the patients' employment status*
- H8: *The perceived importance of support is influenced by the patients' diagnosis*

METHODS/STUDY DESIGN

This descriptive prospective study aimed to measure the importance of four different kinds of psychosocial support categories as perceived by female patients diagnosed with cancer on active treatment at the National Center for Cancer Care and Research (NCCCR) in Qatar. A survey questionnaire was used to gain insight into patients' perceptions of the importance of psychosocial support. This tool was chosen for its ease of use, the feasibility of approaching larger numbers of patients, and confidentiality. This method was selected over alternate methods (such as focus groups) due to the conservative nature of the Qatari society and the taboo still associated with cancer.

PARTICIPANTS AND SAMPLE SIZE

The NCCCR is the only cancer center in the State of Qatar. Nevertheless, NCCCR does not provide surgical interventions for cancer patients. As such, cancer patients who require surgical interventions are treated in other Hamad Medical Corporation (HMC) facilities. This along with the absence of a national cancer registry, made it difficult to predetermine the sample size as there was no accurate patient data available to calculate an appropriate sample size. Accordingly, the researchers opted to set a period of three months to recruit participants who met the inclusion criteria by using non-probability convenience sampling. It was determined that based on the volume of patients seen in clinics, a period of three months would be adequate to recruit a representative, unbiased and large enough sample (minimum 100), since all patients undergoing treatment in Qatar would attend the NCCCR.

INCLUSION/EXCLUSION CRITERIA

All consenting female cancer patients 18 years of age and older that attended clinics or treatment at the NCCCR were invited to participate regardless of diagnosis. Participants were required to be aware of their diagnosis and able to read and write in either

English or Arabic. Those who declined or were unable to self-administer the questionnaire were excluded.

QUESTIONNAIRE

To the knowledge of the researchers, there was no pre-existing bilingual tool for the purpose of this specific study. The questionnaire was designed in English and certain components (such as support, and family and friends) of the questionnaire were adapted from the Self-Assessed Support Needs Scale (SASNS) developed by Lindop and Cannon (2001).²⁸

This questionnaire was found to have good validity/reliability when translated into Turkish by Ecri and Karabulut.²⁰ The final brief questionnaire included descriptors such as age, nationality, religion, education, diagnosis and marital status. A Likert scale was used to grade the degree to which certain aspects of psychosocial care were perceived to be of importance. Participants were questioned on whether they would like to receive any of the psychosocial support categories mentioned in the questionnaire, and were asked to rate the importance of these categories on a scale from 1 to 10, where 1 means "not important", 10 "very important" and 5 to 6 means indifference. Therefore, any rate of 6 or above was considered to be an important support category. A Likert^{22,23} scale was chosen because of the universal ease of use for respondents and ease of analysis for researchers. A 10-point Likert scale was used in order to allow for a more accurate range of responses, given that studies show respondents favor finer scales for expressing their feelings accurately.²⁴ Furthermore, studies indicate that reliability tends to improve for scales with greater response categories.^{24,25} The questionnaire was consisted of 21 questions as follows: Q1-7 for demographics, 8-10 for support groups, 11-13 for physician support, 14-16 for family support, 17-19 for religious support, in addition to two free text questions to allow patients to indicate other kinds of support they perceive to be important.

TRANSLATION AND CONTENT VALIDITY

Questionnaires were provided in English and Arabic. The questionnaire was created in English then professionally translated and back-translated by two independent professional translators in order to avoid discrepancies and to ensure linguistic validity. Three independent bilingual individuals verified the

translated questionnaires to ensure comprehension of the content in both languages.

TOOL'S RELIABILITY AND FACE VALIDITY

The questionnaire was cross-checked by both investigators. Bilingual nursing staff were asked to comment and offer suggestions on the English and Arabic versions of the questionnaire to ensure face validity. Cronbach's alpha was calculated for the pilot tested questionnaires to check for internal consistency.^{26,27}

PARTICIPANTS' RECRUITMENT AND DATA PROTECTION

Researchers trained a group of registered nurses who work at NCCCR on how to recruit participants. These nurses were not necessarily responsible for the care of the patients they recruited to eliminate a power inequality in the relationship. All the nurses in this group were bilingual (Arabic and English) in order to explain the scope of the study. Nurses were trained to explain the anonymity and voluntary participation in the study. All participants who agreed to participate signed consent forms as per HMC policy. Participants received information sheets explaining the purpose of the study as well as the contact information of the researchers. All the completed questionnaires were placed in anonymous sealed envelopes and handed over to the co-investigator on a daily basis. Envelopes and signed consent forms were kept in the locked office of the co-investigator. Only the co-investigators had access to the questionnaires and the data was transcribed from the questionnaire to a Microsoft Excel worksheet which was saved in a secured memory disk.

ETHICAL CONSIDERATIONS

This research was approved by the Medical Research Center (MRC) at Hamad Medical Corporation and the dissertation management group at Sheffield Hallam University.

Participants were assured of the anonymity of the questionnaires as well as the voluntary nature of their participation. Participants were informed that the data would be used for research purposes only. Furthermore, participants were informed of their right to refuse participation or to quit at any given time with no consequence. All participants were advised to contact researchers if they had any concerns.

DATA ANALYSIS

Quantitative data values were expressed in terms of proportions, percentages, means, \pm SD, with medians and ranges. Descriptive statistics were used to summarize demographic and all other clinical characteristics of the participants. Associations between two or more categorical variables were assessed using the chi-square test. For small cell frequencies, a chi-square test with continuity correction factor or Fisher's exact test was applied.

Quantitative variables means between two or more independent groups were analysed using unpaired t-test and one-way analysis of variance (ANOVA). Where an overall group difference was found statistically significant, pair-wise comparisons were made using Bonferroni multiple comparison test. A two-sided p-value of < 0.05 was considered to be statistically significant. All statistical analyses were done using Statistical Package for Social Sciences (SPSS), version 19.

RESULTS

Internal consistency

Cronbach's alpha was calculated for each of the four categories of support with a 95% CI. The values were as follows: 1) support group: 0.81, 2) physician/counselling: 0.83, 3) family support: 0.86 and 4) religious/spiritual support: 0.84. The internal consistency was found to be satisfactory and therefore no changes were made as the tool was found to have good reliability.

Sample's demographic characteristics

Only 4 women declined to participate, while 129 women completed the questionnaire giving a response rate of 97%. All patients were able to communicate in either English or Arabic. The ratio of English speaking respondents to Arab speaking respondents was approximately 1:1, with 64 English (46.6%) and 65 Arabic (50.4%). Breast cancer was the most common diagnosis among patients (63.6%) while other diagnoses made up the remaining diagnoses. Diagnoses were subsequently divided into two categories to simplify analysis; (1) breast and (2) other (other consisted of 18 diagnoses). The majority of patients self-identified as being Muslim (59.7%), followed by Christian (37.2%), equaling 96.9% of the total respondents. Table 1 provides more details about the responders' demographic characteristics. Age was

Table 1. Respondents' demographic characteristics.

Demographics	N	(%)
Nationality		
Qatari	14	10.9
Non-Qatari Arab	51	39.8
Non-Arab	64	49.6
Age ranges		
Under 40	24	18.6
40-50	55	42.6
Over 50	48	37.2
Religion		
Muslim	77	59.7
Christian	48	37.2
Hindu	2	1.6
Other	2	1.6
Marital status		
Single	17	13.2
Married	101	78.3
Divorced	4	3.1
Widowed	7	5.4
Employment status		
Full time	59	45.7
Part time	9	7.0
Homemaker	43	33.6
Currently unemployed	17	13.2
Education		
Never went to school	7	5.4
Primary	11	8.5
Secondary	26	20.2
Higher education	85	65.9
Cancer diagnosis		
Breast Cancer	82	63.6
Other	44	34.1%
Total Sample	129	(100)

analyzed on a continuous scale. The average for every question was calculated based on the responses from each individual questionnaire, then converted to percentages to simplify the data. Any averages greater than 60% were categorized as an important category for psychosocial support.^{22,24}

Most respondents (88.4%) rated the overall importance of support (of all categories) greater than 60% on the 10-point Likert scale. Family support was the most important category (92%) overall indicated by respondents, followed by religious support (86%) and support groups (86%) (see Figure 1). Therefore, hypothesis one was accepted. Muslim patients, Arab patients, and patients diagnosed with breast cancer preferred religious support over support groups whereas Christian patients, non-Arabs and patients

with other diagnoses tended to favour support groups over religious support (see Figures 2 and 3). Physician referred support was consistently the least important type of support regardless of diagnosis, marital status, religion or age. Interestingly, ANOVA test was conducted to measure if there was any significant relationship between demographics- (nationality, age, religion, marital status, education level and employment status)- and the perceived importance of psychosocial support. ANOVA revealed no statistically significant relationship, which means that hypothesis two to seven were rejected. Moreover, independent t-test was conducted to measure if there was a significant relationship between the diagnosis and the perceived importance for support. The test revealed no statistical significance. Accordingly, hypothesis eight was rejected.

The final two questions surveyed the respondents' views on psychosocial support. Ninety-one respondents completed these questions. Question 20 asked, "Do you feel you would like to have any of the support services mentioned above?" Sixty-one out of 91 (67%) indicated yes, while 30 (33%) said no. Language did not seem to affect the response as those who responded positively were 41% English speakers and 59% Arabic speakers. Those that declined were 50% Arabic and 50% English speakers. Respondents that did not indicate a preference for a particular support accounted for 26%. The most common areas of support desired were religious and physician referred support at 20% each, while 13% indicated a desire for all four categories presented in the questionnaire.

DISCUSSION

The study provides some demographic information about patients, which was not available previously and may be very valuable for future studies. There is no cancer registry in Qatar and due to the fact that

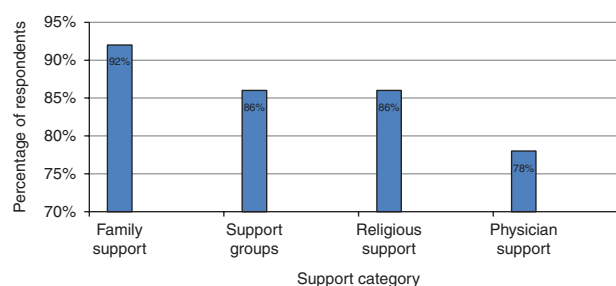


Figure 1. Overall importance of support according to category.

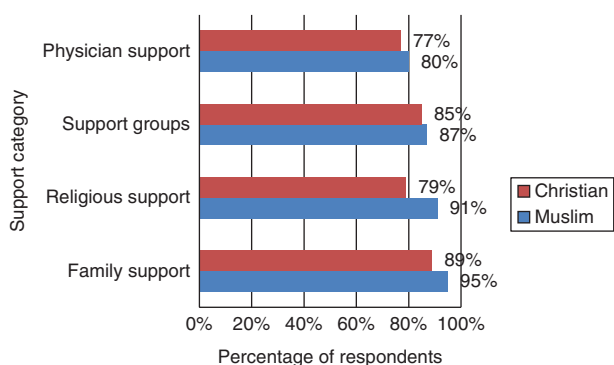


Figure 2. Importance of support category according to religion.

patients’ records are not continuous between surgery, radiotherapy and chemotherapy, each patient visit is registered independently. This made it difficult to ascertain the true demographics of the patient population as well as predetermining a sample size. The high response rate of 97% was unexpected. The researchers expected a higher proportion of women would decline to participate, particularly since Qatar is considered a very conservative society. This high response is significant and may be an indication of patient willingness to share opinions. Further research may be successful in determining more accurate data on patient perceived need for psychosocial support or desire to be involved in the selection of such services. A high proportion of respondents (88%) perceived the psychosocial support as important and 61 patients expressed an interest in receiving one or more of the areas of support categorised in the questionnaire. This result may further highlight a patient desire in supportive care and might potentially allow for new areas of improving patient care.

Contrary to the literature,^{10,15,16} age, education level and marital status had no effect on the importance for psychosocial support as perceived by the patients. This may be explained by the homogeneity of the population in Qatar as the majority of women were over 40 (79.8%), married (78.3%) and had received higher education (65.9%). On the other hand, this may indicate that the need for psychosocial support is important for all female patients regardless of their demographics.

Family support was important to 92% of the respondents. This finding is in line with the literature and would be interesting to investigate further to compare Qatari culture with other populations.

This may provide some further insight into the

relationship between female cancer patients and their families and whether the perceived importance would translate into a desire for family involvement in support.

The second most popular area of support was religion. This finding is not particularly surprising as the literature suggests that cancer patients often find solace in religious practices.^{5,6,19} Corroborating this literature with evidence from the Qatari population highlights a possible area for future collaboration between pastoral care and healthcare professionals. This study would recommend that future research investigate further the role of religious practices in implementing psychosocial support services. Interestingly, more Muslim patients preferred this type of support than Christian patients, perhaps indicating that differences in religious practices can affect psychosocial support coping mechanisms. Perhaps the inclusion of the five daily prayers (as routinely practiced by many Muslims) provides an effective coping mechanism and consequently inspires a stronger reliance on religion. Implementation of psychosocial support services would also require sensitivity to the needs and perceptions of both Christian and Muslim patients. Further research is recommended to determine the specific needs of these two groups.

A lack in patient perceived importance for physician referred support may be explained by a preference for the privacy offered within the family setting, or perhaps it indicates a disconnect between patients and their physicians. However, in the free-text questions, a desire for physician-referred support was indicated by 20% of respondents. This might represent the portion of patients that are presently in need of support or are more willing to actively

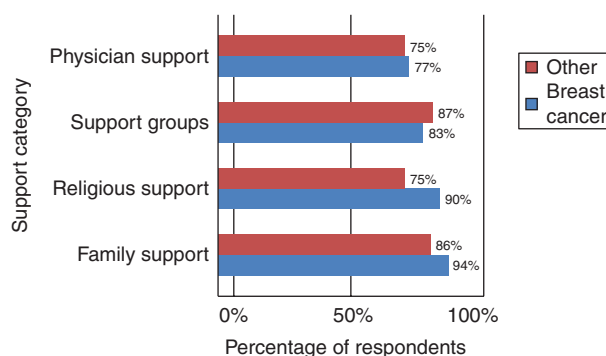


Figure 3. Importance of support categories according to diagnosis.

seek help. It might be interesting to examine patients' views on involving family members in formal counselling or group therapy as well as patients' understanding of possible avenues of physician support. The respondents were equally identified as either English or Arabic speakers. This highlights the need to have bilingual support services and healthcare workers that are able to communicate in both languages competently.

LIMITATIONS

The researchers acknowledge that psychosocial support is a very broad notion and encompasses many complex areas and themes with relation to cancer care. This research serves as only a glimpse into this multifaceted area of patient care and should be considered as a pilot project for much more detailed and in-depth examination. The questionnaire did not cover all the possible areas of psychosocial support (such as nutritional support, exercise, financial support or support for housework). Further research may be required to identify additional areas of psychosocial support not included in this study, and how they can be studied and implemented. Interviewing methods may yield more specific results; however, respondents might not have been willing to participate due to the lack of anonymity associated with interviews. The questionnaire included patients at different points in the treatment pathway, as all patients that attended day-care and outpatient clinics were approached. This may have had some effect on the responses of patients. The point in the treatment pathway was not recorded in the questionnaire and could be something to examine in future. Finally, due to the small size of the population of Qatar and the subsequent sample size of the study, it is acknowledged that these results may not apply to the larger GCC population and findings would need to be validated by a larger sample.¹

CONCLUSION

Psychosocial support is becoming increasingly important in holistic cancer care. The psychological and social stressors of cancer diagnoses have been discussed, and the impact of leaving distress untreated has been shown to have negative effects on treatment compliance and recovery.¹¹ This study provided new information for Arab and Muslim populations living in Qatar. This study also highlights possible areas of future research and development that may improve patient care and help meet Qatar's National Cancer Strategy goals. This includes evidence that highlights the importance of studying the engagement of patients' families in the support process and examining the inclusion of religious support. Several areas of future research have been indicated that would be of value to the State of Qatar and that may be studied in other Arab countries in the region. These include recommendations for further research into different points in the treatment pathway and the preference for support, further research into religious support, and integrating pastoral care into the traditional healthcare setting.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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