ABSTRACT: The number of cancer patients in Lebanon is increasing, and patients are living longer due to early detection and enhanced methods of treatment. The purpose of this study was to evaluate the quality of life, symptom management, functional ability, and the quality of palliative care in adult Lebanese cancer patients at the American University of Beirut-Medical Center.

A cross-sectional survey design was used. A number of internationally validated instruments were translated into Arabic. A total of 200 cancer patients participated in the study; the majority was female with breast cancer and mean age 54. The cognitive functioning domain of the Quality of Life scale was found to have the highest score and social functioning the lowest. The most prevalent symptom was lack of energy and the least prevalent was shortness of breath. Nausea and pain were the symptoms mostly treated.

In conclusion, this sample reported a fair quality of life and social functioning with high prevalence of physical and psychological symptoms. Inadequate symptom management was reported especially for the psychological symptoms. Participants reported a satisfactory level with the quality of care. Based on these results, providing adequate symptom management and social support to Lebanese cancer patients is highly recommended.

INTRODUCTION

Despite the improved methods of treatment and early diagnosis which increase the chance of survival of patients with cancer, some of these patients will not be cured. Patients diagnosed with cancer are faced with a chronic, progressive disease that leads to a range of physical, emotional, social, and spiritual challenges [1]. When the chances of a cure decrease, care is shifted to focus on palliation and optimizing quality of life [2].

The number of cancer patients in Lebanon is increasing [3-5], and patients are living longer due to early detection and enhanced methods of treatment; however, the majority is suffering unnecessarily, due to lack of pain relief and palliative care (PC) [3]. It is estimated that 4,224,000 people live in Lebanon [4]. With a death rate of 4-5/1000, and over 22,000 deaths per year, it is estimated that around 12,000 patients are in need of morphine, 60% need pain relief and PC [5]. Although opioids are available, accessibility is poor due to restrictive regulations and lack of training of physicians in prescription and use of opioids. PC is not yet recognized by the Lebanese health authorities as a discipline; there is limited information on the number of teams and programs that provide PC services.
and on the type of care they deliver. Less than 5% of health professionals involved in PC have received formal PC education, most have acquired knowledge and skills after graduation [5-7].

PURPOSE & SPECIFIC AIMS OF THE STUDY

In Lebanon, no studies were found which evaluate the outcomes of palliative care. The purpose of this study was to evaluate the quality of life, symptom management, functional ability, and the quality of palliative care in adult Lebanese cancer patients.

The following specific aims were addressed:

1. To assess the quality of life in cancer patients in the physical, psychological, social, and spiritual domains.
2. To determine symptom prevalence and the effectiveness of symptom management in cancer patients.
3. To explore the level of functional ability among cancer patients.
4. To assess the quality of palliative care as perceived by cancer patients in terms of coordination, continuity, and accessibility of care, and involvement in decision-making.

These aims are based on the factors and domains considered important to measure in palliative care and that have been studied extensively by many authors [8-12].

METHODS

Study Design

The study followed the cross-sectional descriptive survey design with oncology patients as the target population. The American University of Beirut-Medical Center (AUB-MC) cancer registry was the main source for data collection. AUB-MC is a national cancer referring center in Lebanon; it is located in the capital Beirut, and receives patients from all parts of the country.

Sample and Sample Size

The study targeted Lebanese oncology adult patients (age ≥18 years) living in Lebanon during the data collection period. The sampling procedure followed was sequential; patients were approached on daily basis as they come to the center until the sample size was secured. Patients diagnosed for less than one month and those who did not know of their cancer diagnosis were excluded.

The sample size was calculated based on an estimate of 0.5 for prevalence of outcomes (such as symptom prevalence) and a precision of 7% for a 95% confidence interval; the required sample size was calculated to be 197. Sample size calculation was done using the PASS resource part of the NCSS software.

Data Collection Procedures

After receiving Institutional Review Board (IRB) and AUB-MC oncologists’ approval, data collection started. Two trained interviewers and a research assistant were responsible for securing informed consent and for conducting the interviews. Data was collected from the three oncology units at AUB-MC that admit oncology patients from different socioeconomical backgrounds and from all geographical areas in Lebanon. Nurse managers of chosen units assisted in the selection of patients admitted on a daily basis and introduced the study and the interviewer to the participants. Participants’ inclusion criteria were: Lebanese, age ≥18 years; diagnosed more than one month ago; and aware of their cancer diagnosis and willing to be interviewed. Face to face interviews were conducted in a private setting. Data collection took place over a one-year period.

Questionnaire

The questionnaire used “Quality of Palliative Care Questionnaire-Adult” (QPCQ-A) is a combination of four instruments.

The European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire (EORTC QLQ-C30), the most widely used instrument in palliative care research was used to measure quality of life; it is a 30-item core-cancer-specific questionnaire measuring quality of life in cancer patients [13]. The tool incorporates five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), and a global health and quality of life scale. The remaining single items assess additional symptoms commonly reported by cancer patients as well as the perceived financial impact of the disease and treatment. EORTC QLQ-C30 has been found to exhibit adequate levels of reliability and validity in different cancer patient populations and cross-culturally in different countries [14-18].

The Memorial Symptom Assessment Scale (MSAS) was used to measure 32 psychological and physical symptoms in terms of prevalence, frequency, severity, and distress. Adequate reliability and validity have been described by Portenoy et al. in 1994 [19]; an additional section was added by the authors of the study to MSAS to measure symptom management and its effectiveness.

The functional ability was measured using the Barthel Index [20] which evaluates feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers, mobility, and stairs. The reliability and validity of the Barthel Index have been well documented in many studies [21-22].

Quality of palliative care was measured using 22 selected items from the Needs at End of life Screening Tool (NEST). The chosen items cover financial burden (three items), medical care (nine items), spiritual and existential matters (five items), and relationships (five items). Cronbach’s alpha coefficients of the domains ranged from 0.63 to 0.85 [23-24].

The questionnaire included a section addressing the demographic and clinical characteristics of the participants (Tables I & II). Permission was granted by the primary authors to use and translate the instruments (EORTC QLQ-C30; MSAS, and Barthel Index), and in the case of NEST, to use and translate the selected items.
The recommended procedure for translating research instruments which is known as back-translation was followed [25]. Four experts in the field of oncology and research design and instrument development rated the cultural appropriateness of the instrument in Arabic since it contains some sensitive terms related to end-of-life issues. Based on their feedback, negatively worded items were changed to positively worded items and two items from the MSAS were removed: feeling irritable and feeling drowsy because of their respective similarity in the Arabic translation to two items already present in the scale: feeling nervous and dizziness.

The questionnaire was pilot tested on ten oncology patients selected from AUB-MC oncology unit who suggested removing one item related to spiritual and existential matters because it was not easy to comprehend.

Statistical Analysis
Sample characteristics (both demographic and clinical) were analyzed using frequencies (N) and percentages. Age, time since diagnosis, and days lost from work in past six months were reported using means and standard deviations (SD).

For the EORTC QLQ-C30, scores for the Functional scales, Symptom scales, and Global Health Status/QoL scale were computed based on the scoring manual of the instrument [26]. All scales range in score from 0 to 100. A high score for a functional scale and Global Health Status/QoL represents a high/healthy level of functioning and a high QoL, but a high score for a symptom scale re-
represents a high level of symptomatology/problems.

For the MSAS, scores were calculated as described by Porteney et al. [19]. If patients reported a symptom, the symptom score was the mean of the frequency, severity and distress score; the Physical Symptom Subscale score (MSAS-PHYS) was computed as the average of the frequency, severity, and distress associated with 11 most prevalent physical symptoms; the Psychological Symptom Subscale score (MSAS-PSYCH) was computed as the average of the frequency, severity, and distress associated with five most prevalent psychological symptoms [19].

The Barthel Index uses a scale of 0–100 to rate the degree of independence in activities of daily living, where 0 is total dependence, and 100 is total independence. There are three categories of functional impairment using the following cut-off values: severe (0–50), moderate (51–75), and mild to no impairment (76–100). A high score on the Barthel Index represents a better functional ability and a higher degree of independence.

The Quality of Palliative Care subscales scores were computed as the mean of means of their corresponding items. All of the scales range in scores from 0 to 10. A high scale score represents a higher/better quality of the subscale.

Ethical Considerations
The study was approved by AUB Institutional Review Board; the primary investigator, co-investigators, research assistant, and interviewers are all CITI certified.

RESULTS

Demographic and Clinical Characteristics
The number of completed interviews was 200; 49 patients refused to participate, reasons were related to being very tired, sleepy, or not having enough time to complete the interview. The majority of the interviews (95%) were conducted with patients in the outpatients units (patients coming for same day treatment).

Table I displays the demographic characteristics of the participants. The majority of the participants were females (N: 126; 63%); mean age was 54 years (Range from 19 to 86; SD: 13.6) with 48% above 55 years of age. The majority was unemployed (N: 120; 60%) and married (N: 156; 78%); 46% had a university level education (N: 92).

As for the clinical characteristics (Table II), the most prevalent type of cancer was breast cancer (N: 89; 44.5%) distributed among 88 (69.8%) females and one male (1.4%), followed by cancer of the gastrointestinal track (N: 36; 18%), blood (N: 20; 10%), and lymphomas (N: 13; 6.5%); 34.5% report cancer metastasis to at least one site (N: 69). When asked about their cancer stage, more than half (N: 126; 63%) reported not knowing. The most common type of treatment received was chemotherapy (N: 120; 60%), followed by surgery (N: 108; 54%), and radiation (N: 49; 24.5%). A total of 79 participants (40%) reported having other medical problems.

European Organization for Research and Treatment of Cancer-Quality of Life Questionnaire (EORTC QLQ-C30)
The majority of patients had EORTC QLQ-C30 function scores above 50 and symptom scores below 50.

The Global Health Status/QoL scale score was 58.46 (SD: 23.86); as for the functional scale, the highest score was for the cognitive functioning (score: 77.02, SD: 20.56) followed by the physical functioning (score: 77.02; SD: 23.22); the lowest score was for the social functioning (score: 56.83; SD: 30.31). For the symptoms scales, fatigue accounted for the highest score (score: 34.67; SD: 29.86) followed by insomnia (score: 32.00; SD: 39.66). Dyspnea had the lowest scores (score: 7.83; SD: 19.76). The score for the financial difficulties scale was 38.53 (SD: 38.65) (Table III).

Memorial Symptom Assessment Scale & Symptom Management
Table IV displays the 13 symptoms that had a prevalence rate greater than 30% on the MSAS. The table also shows the symptom score (mean of the frequency, severity and distress score), treatment received and success of treatment received. The most prevalent symptom was lack of energy (N: 126; 63%) followed by feeling nervous (N: 109; 54.5%), and feeling sad (N: 101; 50.5%). The least prevalent symptom was shortness of breath (N: 32; 6.1%).

The symptoms with the highest scores were: “I don’t look like myself” (score: 2.74; SD: 0.86), pain (score: 2.70; SD: 0.79), worrying (score: 2.69; SD: 0.85), and difficulty sleeping (score: 2.65; SD: 0.79). A high number of those complaining of lack of energy (83.3%), of those complai-

<table>
<thead>
<tr>
<th>TABLE III</th>
<th>EORTC QLQ-C30 SCALES</th>
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<tbody>
<tr>
<td>Score</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Global Health Status/QoL</td>
<td>58.46 (23.86)</td>
</tr>
<tr>
<td>Functional Scales –</td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>77.37 (23.22)</td>
</tr>
<tr>
<td>Role functioning</td>
<td>72.58 (31.61)</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>71.00 (27.46)</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>87.08 (20.56)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>56.83 (30.31)</td>
</tr>
<tr>
<td>Symptoms Scales –</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>34.67 (29.86)</td>
</tr>
<tr>
<td>Nausea and Vomiting</td>
<td>10.92 (17.73)</td>
</tr>
<tr>
<td>Pain</td>
<td>27.75 (34.29)</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>7.83 (19.76)</td>
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<tr>
<td>Insomnia</td>
<td>32.00 (39.66)</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>23.33 (36.15)</td>
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<tr>
<td>Constipation</td>
<td>15.17 (30.77)</td>
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<tr>
<td>Diarrhea</td>
<td>10.17 (25.28)</td>
</tr>
<tr>
<td>Financial difficulties</td>
<td>38.53 (38.65)</td>
</tr>
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ing of feeling nervous (72.7%), and of those complaining of feeling sad (82.8%) did not receive any treatment. The symptoms that were mostly treated were nausea (64.8%) and pain (62.5%), and the treatments were mostly successful (89.1% and 94.5% respectively).

The MSAS-PSYCH scale score was 2.47 (SD: 0.67); MSAS-PHYS scale score was 2.26 (SD: 0.53); and TMSAS was 2.31 (SD: 0.50).

**Functional Ability, Finances, Medical Care, Spirituality, and Relationships Scores**

The functional ability score was 96.5 (SD: 8.7). The financial burden scale score composed of three items had the lowest score of 4.57 (SD: 2.71); the medical care scale composed of nine items had a score of 7.96 (SD: 1.42) followed by the relationships scale composed of five items (score: 7.37; SD: 1.66) and the spiritual and existential matters scale composed of five items (score: 6.43; SD: 0.99) (Table V). It is worth noting that in the relationship scale, the item: “You try to help those around you prepare for the possibility of losing you” scored a mean of 4.31 (SD: 3.25).

**DISCUSSION**

**Characteristics**

The demographic characteristics of the participants reflect the general situation in Lebanon. Females contributed to 63% of the sample; this can be explained by the increased incidents of cancer cases among females in Lebanon compared to males (57.4% in 2002, 51.3% in 2003, and 50% in 2004) [27-29]. More than half of the participants were unemployed (60%) which can be due to the fact that the majority of the sample was female and usually Lebanese females remain at home to take care of their families and that cancer is considered as an incapacitating disease and once someone is diagnosed with cancer, they are not expected to work.

As for the clinical characteristics, breast cancer was the most common type of cancer seen in females (69.8%) which is comparable to the general population but the prevalence is higher than results found in 2002 and 2003 (29.2% and 42.3% respectively). This high rate can be attributed to better screening as a result of national awareness campaigns leading to earlier diagnosis or possibly to an actual increase in prevalence among Lebanese women.

**Quality of Life**

The majority of the participants reported good functional scores especially for the cognitive function; the Global Health Status/QoL scale score reflects an average perception of the overall health and overall quality of life of the
participants. These results are comparable to other studies conducted in the UK and Germany using EORTC QLQ-C30 with patients diagnosed with colorectal, lung, gastroesophageal cancer, and breast cancer [30-32]; these studies reported a score of 50.00 on the Global Health Status/ QoL scale, a score similar to the Lebanese sample score (58.46). In the Lebanese sample, the lowest score surprisingly was for the social functioning which is different from other studies which reported better social functioning [30-33]. This result may be due to the cancer stigma in the Lebanese society and to the significant interference of the patients’ condition in their family life and social activities as reported by Doumit et al. [34].

**Symptoms**

The most prevalent symptoms reported by more than 50% of the participants were lack of energy, feeling sad, and feeling nervous. The high prevalence of lack of energy has been seen in two other studies where 92% and 83% of patients with cancer reported having lack of energy [35-36]. On the other hand, in a systematic review of 46 different studies, the five most prevalent symptoms reported by more than 50% of patients were fatigue, pain, lack of energy, weakness, and appetite loss [37]. Pain was reported to be highly prevalent in several studies: 82% by Kutner and colleagues [35], 78% by Trammer and colleagues [36]. In this study, the lower prevalence of pain (44%) may be due to the fact that 95% of participants were recruited from outpatient units and symptoms were evaluated on their occurrence the week before the interview and not post-treatment. The symptom “I don’t look like myself” had the highest score reflecting the highest mean of the frequency, severity and distress of the symptom. This result has not been seen in previous studies and can be due to the fact that the majority of the participants were females with breast cancer. A study describing the Lebanese experience of living with breast cancer reported that the loss of a body part, loss of a normal life, loss of hair, and changes in body image were considered as distressing and upsetting to Lebanese women [38].

As for symptom management, a high number of participants reporting high prevalence of symptoms like lack of energy, feeling nervous and feeling sad did not receive treatment. This is in line with what the National Cancer Institute reported in their review of symptom management research that despite the strong evidence for effective therapies to many symptoms, cancer patients often do not receive these therapies and continue to suffer from needless symptoms; pain and pain management have been well studied but still, pain remains one of the most prevalent symptoms among cancer patients [39].

**Functional Ability; Finances, Medical Care, Spirituality, and Relationships**

Participants showed good functional ability despite high prevalence of lack of energy and is in contrast with the study by Simmonds [40] and other studies [41-44] where cancer patients scored significantly lower on physical function and physical performance than healthy individuals. Results of this study parallel the result reported by Doumit et al. [38] about coping with breast cancer where patients were forcing themselves to continue being functional as usual in order not to be stigmatized as weak cancer patients and in order not to be pitied by others. Most participants in this study were recruited from outpatient units and were mobile which may explain these results.

Financial burden was less than average. This could be related to the fact that all participants had some type of health insurance that covers most of their medical treatment and hospitalizations. In the USA, the situation is different; studies conducted in the US revealed that cancer patients and family caregivers often endure financial hardships as a result of non-reimbursed cancer costs that can reach $ 1,455 per month on average [45-46].

Participants in this study reported good quality of medical care. These results might be related to the healthcare delivery system followed at AUB-MC. It is worth noting that Lebanon is known for being the hospital of the Middle East, for the accessibility of care provided, and for its high standards of medical and nursing care. A study conducted in Canada addressing predictors of cancer patients’ overall perceptions of the quality of care reported that four main predictors were considered as problematic aspects of care: follow-up care after completing treatment, next step in care, person to refer to for questions related to care, and healthcare providers’ awareness of the results [47]. The results of the current study reflect how the Lebanese community accepts and trusts decisions taken by healthcare professionals and more specifically physicians. Some of the field notes reported by the interviewers described how patients consider doctors as the most knowledgeable and that their decisions should not be questioned.

The relationships scale showed that participants had a good and satisfactory support system. However, when it comes to preparing those around them for the possibility of death, participants scored below average which reflects the Lebanese mentality of not wanting to burden the family with stress and despair but to focus on keeping hope and thinking positively, as previously reported by Doumit and Abu-Saad Huijer [48].

Limitations of this study include the potential influence of selection bias; most participants were recruited from the outpatient department as opposed to being hospitalized and very sick. Furthermore, the reasons for nonparticipation suggest another potential source for selection bias; for example, nonparticipation may be due to being sick and experiencing more symptoms. The sample was over represented by females, more specifically females with breast cancer, more than males which might have influenced the results. Data was collected from one medical center in Lebanon where participants were all treated by the same group of healthcare providers meaning the same protocols of treatment and the same methods of follow-up and palliative care which limits the generalizability of the results to the Lebanese population as a whole.
CONCLUSION

In conclusion, this sample of Lebanese adult cancer patients reported a fair quality of life and social functioning with high prevalence of physical and psychological symptoms and their inadequate management that reflects the unavailability of a specialized palliative care team to address symptom management in cancer patients. Participants reported a satisfactory level with the quality of care and minimal concerns with financial difficulties. Based on these results, providing adequate symptom management and social support to Lebanese cancer patients is highly recommended.

ACKNOWLEDGEMENT

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