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ORIGINAL ARTICLE

Comparison of perceptions of unmet supportive care needs between cancer patients and their oncologists

Satish Chandrasekhar Nair[1] · **Waleed A. Hassen**[2] · **Jayadevan Sreedharan**[3] · **Khaled Qawasmeh**[4] · **Halah Ibrahim**[5]

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Abstract

Purpose The prevalence of cancer in the Middle East is increasing and predicted to nearly double by 2030. In the United Arab Emirates (UAE), cancer ranks as the third leading cause of death. Yet, there are limited data describing the needs of cancer patients in the region. The purpose of this study is to compare cancer patients' reports of unmet supportive care needs with the perceptions of their oncologists.

Methods A cross-sectional survey of cancer patients and their oncologists, using an Arabic translation of the short form of the Supportive Care Needs Survey (SCNS-SF34), was conducted at a major oncology center in the UAE between December 2014 and March 2017. Descriptive statistics and McNemar test were calculated to determine differences in unmet need responses between oncologists and patients.

Results Nine physicians (100%) and 210 of 268 (78.3%) patients completed the questionnaire. Oncologists accurately assessed the level of unmet physical needs of their patients, but significantly underestimated unmet psychological supportive care needs of the patients. Male patients expressed significantly lower ($p < 0.05$) physical and psychological unmet needs, compared to female patients.

Conclusion Our findings reveal a general concordance between physician and patient perspectives of unmet supportive care needs. This is reassuring as physician perceptions impact the care patients receive. We present multifaceted supportive care strategies for oncology patients in the region.

Keywords Cancer supportive care needs · Middle East · Physician perceptions · Oncology

Introduction

The prevalence of cancer in the Middle East, and the Gulf nations in particular, is increasing and is predicted to nearly double by the year 2030 [1]. In the United Arab Emirates (UAE), after cardiovascular disease and trauma, cancer ranks as the third leading cause of death, with almost 4500 new cases annually [1, 2]. As in other Gulf nations, there have been recent large-scale government efforts in the UAE to increase cancer awareness, screening, and early detection. Specialized cancer units and multidisciplinary oncology teams have been established in tertiary care centers throughout the country. Additional efforts have been made to improve oncology services, including the development of a national cancer registry and funding to support oncology research. Most initiatives have focused on improving clinical modalities and treatment protocols. There is a large and growing literature documenting the importance of supportive care for cancer patients [3–5]. Supportive care in cancer involves the management of physical and psychosocial symptoms across the continuum of the healthcare experience, from diagnosis to post-treatment. Supportive care needs are diverse and include psychological, physical, spiritual, sexual, and health system information-related needs [5]. Studies have documented that identifying and meeting the supportive care needs of oncology patients can improve patient-physician communication, increase

✉ Satish Chandrasekhar Nair
schandra@seha.ae

[1] Department of Academic Affairs, Johns Hopkins Medicine Affiliate-Tawam Hospital and UAE University College of Medicine, PO Box 15258, Al Ain, Abu Dhabi, United Arab Emirates

[2] Cleveland Clinic Lerner College of Medicine, Cleveland, OH, USA

[3] College of Medicine, Gulf Medical University, Ajman, United Arab Emirates

[4] Department of Nursing, Oncology, Tawam Hospital, Al Ain, United Arab Emirates

[5] Johns Hopkins Graduate School of Education, Baltimore, MD, USA

patient perceptions of physician empathy, reduce adverse symptoms of treatment, and help patients and their caregivers better manage the physical and psychological stressors of cancer diagnosis and treatment [3]. This can lead to improved patient satisfaction and enhanced patient engagement in treatment decisions, resulting in decreased health system utilization, decreased costs, and improved patient outcomes [4].

Despite the evidence that unmet supportive care needs can have detrimental effects on healthcare delivery and patient outcomes, several studies have shown that health care providers do not adequately address them [5]. Multiple barriers to meeting the supportive care needs of cancer patients have been described, including the complexities of physician-patient communication in the cancer setting, lack of physician time to address non-clinical concerns, limited hospital support services, and resources, and the lack of validated tools to assess unmet needs [6]. Physicians often do not address supportive care needs unless raised by their patients, yet studies reveal that patients are reluctant to initiate these conversations [7]. Healthcare providers also defer to their own knowledge and clinical skills to assess unmet needs, rather than formally questioning the patient [8]. However, physician personal beliefs, attitudes, and previous experiences can directly impact their ability to assess patient supportive care needs [7, 8]. This is especially concerning in diverse and multiethnic settings, as cultural beliefs and values can impact clinical outcomes following cancer diagnosis and treatment [9]. To date, there are limited data describing the needs of cancer patients in the Gulf region, and even fewer studies exploring physician perceptions of unmet supportive care needs of their patients. The purpose of this study was to compare oncology patients' reports of unmet supportive care needs with the perceptions of their physicians, in an effort to inform quality improvement and to highlight the need for continuous, formal assessment of the unmet supportive care needs of cancer patients as part of routine care.

Methods

Survey

The short form of the Supportive Care Needs Survey (SCNS-SF34) was used in this study because of its ease of use in clinical practice and coverage of several of the major supportive care domains [5]. The SCNS-SF34 determines cancer-specific perceived needs across five analytically derived domains: psychological (10 items), health systems and information (11 items), patient care and support (5 items), physical and daily living (5 items), and sexuality (3 items) [10]. The SCNS-SF34 was provided by Dr. Allison Boyes (University of New Castel upon Tyne, Australia) [10]. Prior to study commencement, the SCNS-SF34 was translated by a certified legal translator into Arabic, the preferred local language of the patients, and then back-translated into English to ensure the quality of the translation. Survey pre-testing and piloting for reliability and validity have been previously described [11]. Survey questions, if omitted by the participants, were excluded from the paired data analysis (patient and oncologist).

Design

A cross-sectional survey using the SCNS-SF34-Arabic version, or the standard English version, was conducted between December 2014 and March 2017 by a bilingual (Arabic and English) researcher, who was blinded to the study hypothesis. Patient respondents were asked to indicate their level of need for help for each item on the survey on a 5-point Likert scale, with the following response options: 1 = no need, not applicable; 2 = no need, satisfied; 3 = low need; 4 = moderate need; and 5 = high need [10]. Patient and physician survey participants who selected a score of 4 or 5 indicated moderate or high unmet needs that required assistance [10]. The surveys returned by the oncologists were matched with the completed surveys of the patients.

Eligibility criteria

Participating patients were ambulatory patients diagnosed with cancer, who presented to the oncology outpatient clinics of a large tertiary care center that serves as a regional oncology referral center in Abu Dhabi, UAE. Inclusion criteria included men and women aged 18 to 75 with a confirmed new or recurrent cancer diagnosis, who were aware of their cancer diagnosis and were capable of providing informed consent and completing the survey questionnaire based on the European Cooperative Oncology Group (ECOG) status (0–3) [12]. All patients were in the active treatment phase of their disease. In order to minimize challenges related to diminished literacy or poor understandability of the consent, the inclusion criteria limited participant ages between18 and 75.

Eligible physicians from the same oncology referral center where patients were recruited were invited to participate in the study. Physician participants were medical oncologists with a valid medical license, active oncology privileges, engaged in practice in the UAE for at least 2 years, and willing to sign informed consent. Written consents were obtained from all patient and physician participants.

Recruitment

All physicians who met eligibility requirements were asked to participate in the study. Patients were consecutively recruited using the appointment booking module of the hospital electronic medical record. At the conclusion of their oncology appointments, eligible patients were informed about the study by a bilingual (Arabic and English) researcher and were asked to complete a paper-based survey, after signing an informed consent form. Additional information, if required, was obtained from the patient medical record and the hospital's cancer registry.

Data analysis

Data analysis was conducted using SPSS version 24. Descriptive statistics, such as frequency and percentage, were calculated to determine the differences in the unmet need responses between oncologists and patients. Differences in patient and oncologist perception of supportive care needs were determined by comparing the median domain score using the paired Wilcoxon signed rank test. The participants (oncologist and patient) perception of unmet supportive care needs were categorized into two groups, namely (a) low needs and (b) moderate/high needs. The number and percentage of participants with concordance (both the patients and the oncologist agreed) and discordance (disagreement between the patient and the oncologist) pairs were evaluated using the McNemar's test. In both tests, if a value was missing from either the patient or oncologist response, that variable was excluded. Perceptions of "no needs" or "needs not applicable" were separately tabulated, besides missing data. If the oncologist perceived "no need/not applicable" and the patient indicated "moderate/high" need, then that data was excluded from analysis. Wilcoxon rank sum test was used to compare oncologist perceptions of needs for male and female patients. A p value of ≤ 0.05 was considered significant. Data were expressed as mean ± SD, unless otherwise indicated.

Ethics

The study was approved by the regional research ethics committee (AAMDHREC 12/55).

Results

Every year, approximately 380 to 400 patients with newly diagnosed and recurrent malignancies are treated in the oncology outpatient clinics. Two hundred sixty-eight patients were approached for the study and 210 consented, and successfully completed the survey to yield a response rate of 78.3%. All nine oncologists who met study eligibility requirements agreed to participate. Table 1 shows participant demographic information.

The median values for oncologist versus patient perceptions of unmet supportive care needs were 15 to 16 for the physical and daily living domain; 29 to 37 for the psychological domain; 7 to 5 for the sexuality domain; 14 to 15 in the patient care and support domain; and 29 to 32 for the health system and information domain. With the exception of the psychological domain, there were no significant differences between the patient and the oncologist perceptions of the supportive care needs (data not shown).

The number and percentage of participants with concordance (both the patients and the oncologist agreed) and discordance (disagreement between the patient and the oncologist), pairs, categorized into low and moderate/high care needs, and evaluated using the McNemar's test are shown in Table 2. Total paired responses for the

Table 1 Demographics of patient and oncologist participants (a total of 210 patients consented and participated in the survey)

Categories	Patients, *n* (%)		Oncologists, *n* (%)
Gender			
	Male	66 (31.4)	8 (88.8)
	Female	144 (68.5)	1 (11.2)
Ethnicity			
	Arab	140 (66.6)	8 (88.8)
	Others (Asian, Caucasian, African)	70 (33.3)	1 (11.2)
Age			
	Mean (years)	45 ± 7.2	49 ± 3.1
Cancer type			
	Breast	126 (60.0)	–
	Ovarian	16 (7.6)	
	Endometrial	2 (1.9)	
	Lung	28 (13.0)	
	Prostate	21 (10.0)	
	Testicular	17 (8.0)	–
Average experience (years)			12.6 ± 5.8
Western trained (n)			8 (88.8)
Speak local language			8 (88.8)

Table 2 Concordance and discordance of unmet supportive care needs between the oncologist and the patients. Concordance and discordance of care needs were evaluated across five domains: physical and daily living (*pain*, *tiredness*, *unwellness*), psychological (*anxiety*, *depression*, *sadness*, *uncertainty about treatment* and *future*), sexuality (*sexual feelings* and *relationships*), patient care and support (*choices*, *empathy*, *sensitivity to emotional needs*), and health system and information (*side-effects*, *diagnostic test information*, *availability of test results*, *self-management information*, *counseling access*). *NS* not statistically significant. Expected total number of paired participants ($N = 210$)

Domain	Pair	Low, *n* (%)	Moderate/high, *n* (%)	Total responses each set	Total domain responses	% responses each set	NA/no need responses	Missing data	*p* value
Physical and Daily living	Concordant	42 (43.3)	55 (56.7)	97	175	55.4	35	0	
	Discordant	47 (60.3)	31 (39.7)	78		44.6			NS
Psychological	Concordant	20 (21.3)	74 (78.7)	94	209	45	0	1	
	Discordant	107 (93.0)	8 (7.0)	115		55			0.001
Sexuality	Concordant	21 (100.0)	–	21	37	56.8	164	9	
	Discordant	12 (75.0)	4 (25.0)	16		43.2			NS
Patient care and support	Concordant	44 (56.4)	34 (43.6)	78	163	47.9	34	13	
	Discordant	51 (60.0)	34 (40.0)	85		52.1			NS
Health system and information	Concordant	53 (61.6)	33 (38.4)	86	174	49.4	33	3	
	Discordant	40 (45.5)	48 (54.5)	88		50.6			NS

physical and daily living domain were 175, out of which 55.4% were concordant, and the remainder (44.6) were discordant. Among the concordant set, 43.3% were concordant for low needs and 56.7% were concordant for moderate or high supportive care unmet needs. On the other hand, discordance was high at 60.3% for low needs and almost 40% (39.7%) were discordant for moderate and high physical and daily living supportive care unmet needs (Table 2). However, the difference between the concordance and discordance pairs was not statistically significant for the physical and daily living needs. Similarly, although differences in the concordance and discordance were observed for the sexuality, patient care and support, and the health system and information domains, the differences were not statistically significant for any of the domains (Table 2). Interestingly, in the case of psychological needs, the overall discordance was more than 50 % (55%) and high, compared to the overall concordance (45%). The concordance was 21.3% and 78.7%, respectively, for the low and moderate/high psychological unmet needs. In comparison, statistically significant ($p < 0.001$) discordance, 93% and 7%, respectively, for the low and moderate/high psychological unmet supportive care needs was noted (Table 2). The no need and not applicable participant responses were limited to less than 17% of the total responses for all the other need domains, except the sexuality need domain, where it was high (78.9%, Table 2). Missing values ranged between 0 and 13 for the various domains (Table 2).

Further, it was also noted that the male oncology patients expressed significantly lower ($p < 0.05$) physical and daily living needs as compared to the female oncology patients. Statistically significant ($p < 0.05$), higher psychological unmet needs were expressed by the female oncology patients as compared with their male counterparts. No other gender differences were noted in other domains.

Discussion

The provision of high quality, patient-centered oncology care transcends beyond medical diagnosis and treatment and involves meeting the supportive care needs of cancer patients. Consistent with previous research, patients in our study revealed a high level of unmet needs across a broad range of domains, primarily in the psychological and health system and information domains [3, 5]. Also consistent with the existing literature, female oncology patients in our study revealed a higher level of unmet psychological needs. This study adds to the supportive care literature in that it reveals that, with the exception of the psychological domain, oncologists accurately recognized and assessed unmet patient needs within a developing country with a large and growing cancer population. This, however, did not hold true for psychological needs, where there was a significant disconnect between physician and patient perspectives of unmet needs. Although oncologists recognized the higher psychological needs of their female patients (Table 3), in general, they significantly underestimated these needs of their patients (Table 2). As physician perceptions can impact the care patients receive, it is essential to develop comprehensive evidence-based strategies to better assess and meet the supportive care needs of cancer patients in the region.

The assessment of unmet needs can direct the redesign of services and improve resources for oncology patients. As such, our findings support the need for formal and continuous

Table 3 Oncologist perceptions of unmet supportive care needs based on patient gender. Male oncology patients expressed significantly lower ($p < 0.05$) physical and daily living needs as compared to the female oncology patients. Statistically significant ($p < 0.05$) higher psychological unmet needs were expressed by the female oncology patients as compared with their male counterparts

Gender		Oncologists perception ($N = 210$)				
		Physical and daily living	Psychological	Sexuality	Patient care and support	Health system and information
Male	Median	14	29	7	14	29
	Minimum	7	21	5	7	13
	Maximum	23	44	11	22	45
	Total (n)	66	66	66	65	65
Female	Median	17	32	7	16	32
	Minimum	5	22	6	5	10
	Maximum	24	43	10	24	47
	Total (*n*)	144	144	144	143	144
	p value	*< 0.05*	*< 0.05*	NS	NS	NS

assessment of supportive care needs to become an integral part of the cancer patients' treatment pathway in the UAE. Western-based guidelines have long encouraged health care providers to assess the needs of oncology patients and their families on a regular basis and throughout the course of their disease. Ristevski and colleagues [4] developed a supportive care kit that included several resources, including screening tools, evidence-based referral protocols, and an information and training guide to facilitate the implementation of supportive care into routine clinical practice, with high levels of feasibility and patient and physician acceptability. In another study of 154 oncology patients in Australia, patients reported that the supportive care needs assessment improved communication with their physicians by encouraging them to reflect on their needs, assisting them in initiating discussion of unmet needs with their health care provider, and validating their needs [13]. However, there is no consensus on how to successfully embed these processes into routine oncology care. This is particularly challenging in diverse and multicultural environments with developing health care systems, such as the Middle East. Richardson et al. [14] reviewed assessment tools used in supportive and palliative care and found only a few instruments that comprehensively assessed health status. To date, there are no published studies on the clinical utility of these tools in non-Western settings.

In fact, Western frameworks of supportive care may not be suited to the cultural values of non-Western countries, an issue which thus far very few studies have addressed. Western health care models cannot be universally adopted by other countries because of the important regional and cultural differences in how illness is perceived and managed. This becomes particularly relevant when discussing serious or life-threatening illness, such as cancer. For example, cultural stigma and biases related to cancer screening and early diagnosis may prevent patients from seeking care, leaving many patients with cancer in the region without treatment until the tumor has progressed to the later stages and is not curable [12, 15]. Also, current models of supportive care center around the Western concept of patient autonomy and include the full disclosure of diagnosis and prognosis. This does not account for the collective approach in Middle Eastern societies, where family and community members are actively involved in the patient's care and provide substantial social support [16]. Previous studies have consistently demonstrated that high levels of perceived social support positively affect cancer patients' coping skills, psychological adjustment, and quality of life [17]. How best to optimize the familial and community support that already exists in the Middle East to better meet the needs of cancer patients is an important area for future research.

Emerging frameworks of integrative oncology may also prove valuable in addressing supportive care needs in Eastern and Middle Eastern settings. In recent years, renowned cancer centers in the United States have inculcated evidence-based complementary medicine services into traditional oncology care [18]. Complementary medicine practices are already widely used by cancer patients in the Middle East [19]. Despite the proven benefits of some complementary medicine treatments in improving well-being during cancer treatment and the high prevalence of its use in the region, a recent study reported that the skepticism and objection of local oncologists served as a significant barrier to integration [19]. Further research is needed for the integration of complementary medicine in cancer care across the Middle East and its potential benefit in improving patient supportive care needs.

With the increasing burden of cancer in the Middle East, long-term sustainability of efforts to meet supportive care needs and generalizability to other emerging healthcare systems will require better strategies for funding and innovative ways to improve care without escalating costs. With the recent advancements in mobile communications and electronic technologies for healthcare, mHealth and eHealth are emerging as viable options for improving health communication and directed support for cancer patients [20, 21]. Early studies using smartphone apps and interactive internet websites have shown promising results [20, 21]. By enabling online communication with their health care team, patients were able to receive direct and confidential guidance regarding symptoms, medication side effects, and planning and follow-up care [20, 21]. This provided patients with a better sense of control and allowed them to treat minor complaints at home or by local physicians, rather than visiting tertiary care centers or traveling to the oncologist [20]. Patients reported that this convenience saved time and increased treatment adherence and overall satisfaction with care [20]. Although smartphones and mobile applications are readily available and popular in the region, UAE physicians and health care centers have been slow to incorporate electronic services into patient care and have instead relied primarily on face-to-face communication. The introduction of these technologies into cancer care in the UAE can offer low-cost, confidential, and patient-centered options to improve cancer patients' access to information and support, thereby enhancing physical and psychological well-being and better meeting supportive care needs.

Our findings must be viewed in light of some limitations. First, patients from only one oncology center were surveyed. The hospital, however, serves as the oncology referral center for the UAE and cares for a large percentage of cancer patients in the country. Also, only outpatients were surveyed. Physicians may have longer contact with patients during inpatient visits and, as such, may be better able to assess their unmet needs. The importance of understanding the needs of the large and growing ambulatory cancer population cannot be overstated. The majority of respondents were women with breast cancer, which may limit generalizability. Finally, a small number of oncologists were surveyed, with only one female physician participant. Larger scale, multicenter studies are needed to further evaluate physician perceptions and factors that affect their recognition and management of cancer patients' supportive care needs.

Conclusion

Oncologists in our study accurately estimated patient perceptions of unmet supportive care needs. However, our findings reveal a disconnect between patient reports of unmet psychological supportive care needs and physician awareness of these needs. This presents an important opportunity to improve oncology care in the region. With the growing cancer burden in the Middle East and the recognition that unmet supportive care needs may persist throughout the disease trajectory, a comprehensive and culturally relevant framework can be developed and implemented to better meet the supportive care needs of oncology patients throughout the region. Understanding and enhancing familial support systems, integrating complementary medicine techniques, and investing in mobile and electronic technology are all feasible options that should be further explored.

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Data availability The data related to the study is stored in the central data repository of the institution and shall be available for the journal upon request.

Compliance with ethical standards

The study was approved by the regional research ethics committee (AAMDHREC 12/55).

Conflict of interest The authors declare that they have no conflicts of interest.

Previous presentations No previous presentations.

Other disclosures None.

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