# Integrative Review of the Supportive Care Needs of Arab People Affected by Cancer

## Ibrahim Alananzeh<sup>1</sup>, Janelle Levesque<sup>2</sup>, Cannas Kwok<sup>1</sup>, Bronwyn Everett<sup>1</sup>

<sup>1</sup>Centre for Applied Nursing Research, School of Nursing and Midwifery, Ingham Institute for Applied Medical Research, Western Sydney University, Penrith, New South Wales, Australia, <sup>2</sup>Psycho-Oncology Research Group, Centre for Oncology Education and Research Translation, Ingham Institute for Applied Medical Research, UNSW Medicine, The University of New South Wales, Australia



Corresponding author: Ibrahim Alananzeh Research Assistant, Centre for Applied Nursing Research (CANR) Western Sydney University Address: South Western Sydney Local Health District (SWSLHD) Locked Bag 7103 Liverpool BC NSW 1871, Australia

Tel: +61287389351

E-mail: I.Alananzeh@Westernsydney.edu.au

Received: October 28, 2015, Accepted: January 01, 2016

#### ABSTRACT

This review aimed to identify the unmet supportive care needs to conduct an integrative review of the literature, to identify the unmet supportive care needs of Arab people affected by cancer (patients and caregivers), and the impact of these needs on quality of life and psychosocial well-being. In July 2015 databases, search engines and electronic list servers were searched, with no limit on the year of publication. Reference lists of included articles and published reviews were also hand searched. Six studies met the inclusion criteria. Most studies examined the supportive care/unmet needs of Arab cancer patients and their family caregivers. Language, communication, information, and the need to get relief from dependency were the most frequently reported unmet needs among Arab cancer patients. For immigrant Arab

patients, physical unmet needs were higher than other migrant groups and native Anglo-Australians. Arab caregivers' unmet needs included concerns about providing suitable care for their family member, sharing their experience with other caregivers, obtaining information, and, in the case of pediatric cancers, dealing with siblings' emotional reactions. The existing literature exploring the unmet supportive care needs of Arab people affected by cancer is limited suggesting that comprehensive studies are needed to enhance our understanding of these needs and to inform service planning.

Key words: Arab, cancer, caregivers, Middle East, supportive care needs, unmet needs

### Introduction

Cancer is the second leading cause of death worldwide with an estimated global health burden of 193.6 million disability-adjusted life years.<sup>[1]</sup> This presents a particular

Access this article online

Quick Response Code:

Website: www.apjon.org

DOI:
10.4103/2347-5625.177396

challenge for developing nations, which face additional challenges in delivering complex cancer treatments.<sup>[1]</sup> While the incidence of cancer is increasing, so too is the survival

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

Cite this article as: Alananzeh I, Levesque J, Kwok C, Everett B. Integrative review of the supportive care needs of Arab people affected by cancer. Asia Pac J Oncol Nurs 2016;3:148-56.

rate in many countries. For example, worldwide survival rates for breast cancer 2005-2009 were 85% (range 43.1-90.6% based on national registry data from 61 nations). While such statistics are encouraging, they also reveal global discrepancies in survival, with developing countries consistently reporting lower survival rates compared to developed nations. Pecifically, Arab countries included in the study by Allemani *et al.* Peported breast cancer survival rates from 43.1% in Jordan, 59.8% in Algeria, 68.4% in Tunisia, with higher rates around the global average in Saudi Arabia (78.4%) and Qatar (85.3%).

Cancer outcomes differ across population groups, with ethnic minority status being associated with lower participation in screening activities, more advanced disease at diagnosis, differential treatment pathways, poorer survival, and psychosocial outcomes compared to Caucasian members of the same country of residence, although the results are unequivocal.[3-8] This variation may be related to patient factors (e.g., familiarity with the health system, language proficiency, beliefs, and socioeconomic status); health care provider factors (e.g., discrimination, and cultural competence); and structural barriers (e.g., limitations in the health systems).[9] There is an emerging evidence that highlights that within Australia people with Anglo-English heritage have better cancer-related and psychosocial outcomes than people who are from culturally and linguistically diverse (CALD) backgrounds. [3,9-11]

The impact of cancer diagnosis comprises significant physical, emotional, social, and economic burden on individuals, families, and their communities.[12] Overall, cancer patients report a range of unmet needs that impact on multiple areas of their life. [13] Unmet needs are defined as "the requirement for some desirable, necessary or useful action to be taken or some resource to be provided in order for the person to attain optimal well-being."[14,15] A review by Harrison et al.[13] concluded that unmet needs were frequently reported in relation to activities of daily living, psychological, and psychosocial issues, the need for information and physical concerns. Similarly, Fiszer et al.[16] concluded in their review that women with breast cancer had at least one unmet need (range 20%-70%), particularly in the domains of psychological and information needs. Importantly, unmet needs may be particularly problematic for patients with a predisposition to anxiety or depression, with Hodgkinson et al. [17] reporting a 3-fold increase in needs in this subgroup of patients.

Importantly, there is growing evidence to suggest that unmet needs are associated with or predictive of poorer psychosocial outcomes (e.g., higher anxiety, lower quality of life [QoL]) across a number of cancer types including prostate,<sup>[18]</sup> breast,<sup>[19]</sup> gynecological,<sup>[20]</sup> hematological,<sup>[21]</sup> lung,<sup>[22]</sup> and in studies with mixed diagnoses.<sup>[23,24]</sup> Importantly, unmet needs represent a potentially modifiable

variable that can be addressed through supportive care interventions and, therefore, are one way of improving psychosocial outcomes for cancer patients.

Unfortunately, most unmet needs research has been conducted with Caucasian populations, with few studies examining the needs of cancer patients among CALD backgrounds. Differing aspects pertaining to cancer care delivery, cultural beliefs, and mortality rates are likely to influence the unmet needs of patients with cancer around the world. A recent review by Levesque *et al.*<sup>[25]</sup> concluded that Asian women with breast cancer reported greater needs for information whereas Caucasian women reported a higher prevalence of psychological needs. There is also increasing evidence that, in multicultural societies, immigrants with language difficulties have higher unmet needs which in turn can impact on their health and well-being.<sup>[13]</sup>

It is becoming increasingly accepted that cancer affects not only the patient but also their family caregivers. While reports vary in the literature, there is evidence that family caregivers report elevated levels of anxiety and depression, [26,27] often in excess of patients' levels, [28,29] and that caregivers also report a number of unmet needs. [29,30] In Arab society, family caregivers play a major role in the care of cancer patients due to Arab cultural beliefs.[31] Arab cultures have a strong emphasis on the family unit, with family members expected to look after each other and maintain strong filial relationships.[32] Arabs believe that getting care from family members is a way to maintain confidentiality and avoid the stigma that is associated with a cancer diagnosis. [33-35] To date, little attention has been paid to the exploration of the unmet needs of Arab people affected by cancer; consequently, research examining the unmet needs of this vulnerable group is warranted so that appropriate support can be provided.

The purpose of this review was to synthesize the existing literature to summarize what is known about supportive care needs of Arab people affected by cancer (i.e., patients and their caregivers). Gaining such an insight can assist health professionals to develop and enhance culturally appropriate cancer support services to address the core unmet needs of both patients and family caregivers from Arabic communities. Specifically, the review addressed the following questions:

- a. What are the unmet supportive care needs of Arab cancer patients and their caregivers? and
- b. What is the relationship between supportive care needs, anxiety, depression, and QoL for Arab people affected by cancer?

## Methods

#### Search strategy

In July 2015 databases (Medline, PubMed, PsycInfo, Informit (RMIT)), Web of Science, ProQuest Central, Taylor and Francis Online, Arabic Collections Online), search engines (Google Scholar), and webpages (Western Sydney University Islamic Studies and University of Pennsylvania Arabic Language and Culture) were searched based on the keywords and MeSH terms "unmet needs," "supportive care needs," "psychosocial needs," "cancer" "neoplasm," "Arab," "Arabic" "Middle East." No limit was placed on the time of publication or where the search terms appeared in the article. Each of the Arab countries as listed by Istizada website[37] were included as a search term to ensure any research conducted in or related to these countries was included. Moreover, the search focused on following the relevant cited references of authors, forward in time to find other articles that had cited that author or work. Once the relevant articles were selected, a secondary search of their reference lists was conducted. The search was replicated by a Western Sydney University nursing librarian, with no additional articles being identified.

#### Inclusion and exclusion criteria

To ensure all relevant articles were included, a broad definition of Arab was used and all domains of unmet need and cancer diagnoses were considered. Arab was defined as people who were from any Arab country or if born outside an Arab country, self-identified as having Arabic heritage. [37]

Studies were included if they:

- a. Focused on Arab people diagnosed with cancer or their caregiver;
- Explicitly explored unmet supportive care needs or psychosocial needs;
- c. Used a qualitative, quantitative, or mixed method approach;
- d. Were conducted in countries with multicultural societies, which included Arab people as a subgroup.

#### Studies were excluded if:

- a. The full text was not available or the abstract only had been published;
- b. They were a review article, (however, the reference lists were searched to ensure all possible relevant articles were included);
- c. Participants were not diagnosed with cancer;
- d. Participants' access to supportive services rather than supportive care needs or unmet needs were explored; and
- e. Mixed minority sample included without a defined Arabic group.

### Study selection and data collection

One of the authors (IA) conducted the search and citations were reviewed based on title and abstract by two authors (IA and JL) to identify articles for inclusion. The search yielded 81 documents that were considered for inclusion in the review. There was 90% agreement on papers to include, with the full text of disputed articles (n = 2)read by both IA and JL and discussed until a consensus decision was reached for inclusion or exclusion, resulting in a final number of ten studies for the review. Data were extracted from the published studies using a template covering country of origin, study design, aims, theoretical framework, sample size and characteristics, measures, data analysis, main findings, the significance of findings, and study limitations. As data extraction was conducted, an additional four articles were excluded as they did not meet the inclusion criteria.[11,36,38,39]

Included studies were examined for methodological quality, using the assessment criteria outlined by Kmet *et al.*<sup>[40]</sup> Two authors (IA and JL) reviewed each of the studies, making quality assessments on all eligible criteria for quantitative (10 of the 14 criteria) and qualitative studies (all ten criteria). Each criterion was scored using a 3-point scale, with options of 2 = yes, fulfilled, 1 = partial fulfilment, and 0 = not fulfilled.

## **Results**

#### **Included studies**

The initial search identified 80 articles across the databases, with an additional article being found through secondary searching. After removal of duplicates and initial screening, ten full-text articles were considered eligible for inclusion, with an additional four articles excluded in the data extraction process, resulting in a six articles included in the review. A summary of the selection process is presented in Figure 1.

Of the six included articles, three were conducted in Australia involving samples of Arab, Greek, and Chinese migrants, [9,10,41] two studies were conducted in Jordan with samples comprised of caregivers<sup>[31,42]</sup> whereas the final study from the USA compared the needs of American and Egyptian cancer patients.<sup>[43]</sup> Four of the studies employed quantitative methodology, with two of the Australian studies using the supportive care needs survey (SCNS), translated into Arabic whereas the Jordanian studies used Arabic translations of the caregiver's need scale, [31] and the family inventory of needs - pediatric - II. [42] Two qualitative studies were conducted; one in Australia, which used focus groups and semi-structured interviews and one in the USA, which used structured interviews.[10,43] Most studies were based on convenience or consecutive sampling, and the Arab sample sizes in these studies ranged from 20 to 91 participants. The included studies are summarized in Table 1.

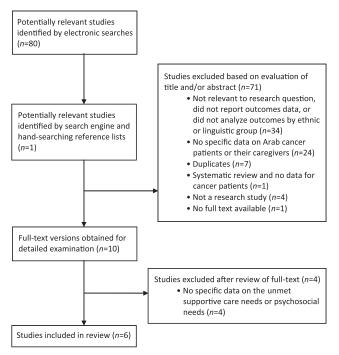


Figure 1: Flow diagram of study selection

# Methodological quality assessment

Cohen's Kappas were calculated for each study to determine inter-rater reliability, with results ranging from 0.38 (strength of agreement = fair) to 0.62 (strength of agreement = good). The authors discussed differences in the quality ratings, which primarily related to the interpretation of criteria pertaining to description of outcome measures and comparison groups, reporting a variance for main results and the connection of qualitative studies to a theoretical framework or wider body of knowledge, leading to a consensus of quality rating. The overall mean quality score was 16.5 (out of a possible 20, standard deviation [SD] = 1.83), indicating that, overall, the studies were of a sound standard. Only one study scored 1 SD below the mean, [43] suggesting a less rigorous methodology was utilized. It is however acknowledged that the paper was written over 25 years ago when methodological standards for qualitative studies were less rigorous. The main flaws with the study by Nagia et al.[43] pertain to limited information presented about sampling strategy, data collection and data analysis, and the absence of researcher reflexivity.

#### Patients' unmet needs

Three papers reported on Arab cancer patients' needs, identifying the areas of information, symptom management, dependency, and communication with health care providers and health care system navigation as unmet. Problems with communication, obtaining information in the patient's home language, and navigating the health care system were unmet needs unique to the Australian context for Arab immigrant patients. [10,43,44]

The first study published by Nagia et al.[43] employed a qualitative design and focused on comparing the similarities and differences between American (n = 61) and Egyptian (n = 66) cancer patients' perceptions of their unmet needs. This study found that Egyptian patients' needs were focused on three themes: Need for information, need to get relief from physical symptoms, and need to get relief from dependency. The information and symptoms needs were common across cultures, with the concept of dependency being unique to the Egyptian sample.[43] Information needs focused on patients, need to know more about cancer, treatment effectiveness, symptoms they experienced, and how to connect with other patients. Physical symptoms needs to be focused on problems with constipation, vomiting, chest pain and heaviness, fatigue, lack of energy, pain, muscular tightness, hair loss, weight loss, lack of appetite, and changes in taste and smell.[43]

The need to obtain relief from dependency was a unique theme identified by Nagia *et al.*<sup>[43]</sup> among Egyptian cancer patients. This theme included being bothered by dependency (e.g., "dependency is my biggest concern in my illness"), perception of self as a burden (e.g., "I am a burden on my family"), uncertainty regarding the duration of dependency (e.g., "uncertain how long I depend on them"), and the need to adjust to being dependent on others (e.g., "I need to learn how to cope with my dependency on others."). <sup>[43]</sup>

In another qualitative study, Butow et al.[10] highlighted the language and communication needs of Arab people affected by cancer living in Australia. The researchers found that some Arab patients perceived that they had received less information as the doctor did not take time to overcome communication barriers, as indicated in the following quote: "I do not know if there is racism in this country. If it is someone who does not speak English then they will not give you a straight answer." Language and communication difficulties relating to understanding communications (e.g., "I just sit there and say yes, yes, but I left his consultation and did not understand most things"), initiating communication (e.g., "because we do not speak good English sometimes, we really want to ask but we do not know how to ask"), and navigating the health care system (e.g., "if you say you can call the cancer association, you must still be able to speak English to be connected to the person you want. Otherwise you do not get through") also emerged. Being provided with English materials was seen as a barrier to communication and strong preferences were expressed for information in the home language, as evidenced by one participant stating: "The doctor brought the nurse and introduced her to me. She spoke English; they gave me a lot of information. I did not know how to read. I did not listen."

In a quantitative study conducted by Butow *et al.*, [9] the unmet needs of Arabic (n = 57), Greek (n = 79), Chinese (n = 114), and Anglo-Australian patients (n = 319) were

		1		-			a . v	
		Findings	A greater proportion of the immigrant sample reported unmet needs compared to Anglo-Australians Arabic immigrants reported the most severe physical unmet needs (OR: 2.2; 95% CI: 1.3-3.5) Negative correlations between unmet needs and QoL were strongest for the Arabic group Positive correlations between unmet needs and depression and anxiety level Unmet needs are related to worse QoL	The participants' needs focused on three main themes Cultural isolation, alienation, and identification Cultural difference from the treating doctor Being treated differently because of ethnicity Language and communication difficulties Understanding written and verbal communication Initiating communication with the health team Difficulty navigating the health care system Interpreter issues	In the registry study, 26% of Arabic participants' did not complete the FACT-G item, and 18% the SCNS sex items. This is the lowest percentage of all cultural groups for FACT-G and second lowest for SCNS (i.e., the percentage of Greek and Chinese participants' skipping those items was higher)	Caregivers reported experiencing negative impacts of caregiving such as fatigue (78%), sleep disturbance (64.6%), anxiety (60.7%), financial constraints (58.5%), and mood disturbance (43.9%) and for the identified needs were considered very important. The highest ranked needs included being told about symptoms (97.6%), need for home care/public nurse (95%), need to be kept informed about patient's condition (4.7%), help with the patients' emotional needs (87.8%), and help with additional expenses (85.4%) 52 needs were identified as unmet (76.4%) covering all domains (see pages 1093 and 1094 for top 3 unmet needs in each domain)	Most needs were ranked as important, with the highest ranked needs relating to the child's treatment, and lowest ranked needs related to information needs of siblings 78% of needs were rated as met, especially those relating to patient care and information. The need for information regarding outcome, what and how to inform siblings and handling feelings of children were the most commonly cited unmet need. Overall, 78% of the sample had their needs met, suggesting that about 1 in 5 parents still had some level of unmet need. It is suggested that unmet needs may be higher closer to diagnosis liformation needs remain high, suggesting strategies to enhance communication between parents and health care providers are required	Egyptian patient needs were classified into 3 themes: Need for information, need to get relief from physical symptoms and need to get relief from dependency. The information and symptoms need were common across cultures
		Other variables and measures	Demographics and clinical variables HADS: Anxiety and depression QoL: FACT-G	Demographics and disease variables, acculturation scale		Demographics, caregivers chronic medical conditions	Demographic data	
		Needs measure	SCNS: 7 items for physical needs, 3 items for sexual needs 14 items for cancer information and support needs CaSUN: 4 items regarding the future	Focus groups or semi-structured interviews	FACT-G sex item 3 items from SCNS	Caregiver's need scale and structured interview Developed in English and translated into Arabic	FIN-PED II Structured interview	Structured interview
		Sample	n=596 participants: 277 immigrants (57 Arabic participants) and 319 Anglo-Australian All eligibility: Diagnosed in the past 1-6 years, aged between 18-80 at time of dx, had treating doctor assigned to registry esearch immigrant eligibility. Born in a country where Arabic, Chinese or Greek is spoken, family name indicative of this cultural background, language spoken confirmed	n=91, with 20 Arabic patients/carers Eligibility criteria: Diagnosed with cancer in the past 3 years, or carer for such a person, born in a country speaking Arabic, Chinese or Greek	Arabic sample: 55 from registry study and 137 from hospital study	n=82 (64 female) Eligibility criteria: Jordanian nationality, identified by the patient as person most involved in or affected by patient's situation, cohabitating with patient, able to communicate in Arabic and provide written consent	n=98 (79 mothers, 19 fathers) Eligibility criteria: Parents of child diagnosed with any type of cancer, child currently receiving treatment, able to understand Arabic	127 participants (66 Egyptian and 61 American participants)
	Table 1: Study characteristics	Design	Cross-sectional study	Qualitative study	Cross- sectional surveys from 2 studies	Descriptive exploratory study	Descriptive survey	Qualitative cross-cultural
	: Study cl	Country	Australia	Australia	Australia	Jordan	Jordan	USA and Egypt
	Table 1	Author (year)	Shaw et al. (2013) <sup>[9]</sup>	Butow <i>et al.</i> (2010 <sup>[10]</sup>	Bell et al. (2013) <sup>[41]</sup>	Al-Jauissy Jordan (2010) <sup>311</sup>	Arabiat and Al Tamimi (2013) <sup>[42]</sup>	Ali et al. (1993) <sup>[43]</sup>
15	52				Agia	Decific lournel of Once	oay Nursing • Apr. Jun 2016	- Val 2 - las

comparison SCNS: Supportive Care Needs Survey, CaSUN: Cancer Survivors' Unmet Needs measure, FACT-G: Functional Assessment of Cancer Therapy-General, FIN-PED II: Family inventory of needs-Pediatric-II, HADS: Hospital Anxiety and Depression Scale, QoL: Quality of life, OR: Odds ratio, GI: Confidence interval

compared. A greater proportion of the immigrant sample (n=277) reported unmet needs compared to Anglo-Australians. Immigrant unmet needs were primarily related to language and information while Anglo-Australians reported greater needs pertaining to treatment side effects. The Arabic immigrants reported the most severe physical unmet needs (odds ratio 2.2; 95% confidence interval 1.3-3.5) compared with other immigrants.

In a further examination of the data collected by Butow et al., [9] Bell et al. [41] examined the response patterns of immigrants for the functional assessment of cancer therapy-general (FACT-G) and SCNS items to determine if there was any evidence of systematically missing data. They found that 26% of Arabic patients did not answer the FACT-G<sup>[45]</sup> item relating to sexual relationships and 18% skipped the SCNS sexual items. This suggests that the impact of cancer on sexual relationships is a taboo subject that some participants prefer not to comment on, and hence, such issues will be underreported in research examining unmet needs. It is, however, important to acknowledge that in this study, the Chinese and Greek samples also demonstrated a preference to omit these items, suggesting that the underreporting of sexual needs is not unique to Arab patients with cancer.

# Correlation of unmet needs with quality of life, anxiety, and depression

Only one study examined the relationship between unmet needs with psychological outcomes such as anxiety, depression, and QoL<sup>[9]</sup> and, therefore, no conclusions can be determined in this review. The findings from that single study indicated that the Arab migrant group demonstrated a correlation between unmet needs and psychological outcomes, with unmet needs correlated negatively with QoL and positively with depression and anxiety.

#### Arab caregivers unmet needs

Only two papers reported Arab cancer caregivers' needs, with both based on Jordanian samples. [31,42] Overall, these papers found that caregiver reported unmet needs relating to information, health services/patient care, psychological issues (self, patient and other family members), and some financial burden. The magnitude of unmet needs varied widely within the two studies with one study reporting over 76% of needs were unmet[31] compared with 22% of parents caring for children with cancer. [42]

Al-Jauissy<sup>[31]</sup> focused on identifying the unmet needs of the caregivers of cancer patients in Jordan, finding a total of 68 needs across six domains of personal care, activity management, involvement with health care, work, interpersonal interaction, and finance. Around two-thirds of the sample also identified needs as very important, with the highest ranked needs including being told about

symptoms (97.6%), need for home care/public nurse (95%), need to be kept informed about patient's condition (94.7%), help with the patients' emotional needs (87.8%), and help with additional expenses (85.4%). The Jordanian caregivers reported experiencing negative impacts of caregiving such as fatigue (78.0%), sleep disturbance (64.6%), anxiety (60.7%), financial constraints (58.5%), and mood disturbance (43.9%). The caregivers reported that 52 needs were unmet (76.4%) covering all domains. The top unmet needs reported by patient's caregivers were (in order of magnitude):

- a. Personal care (e.g., how they can provide good care for their patient, disease symptoms);
- b. Activity management (e.g., how to encourage patient self-management); and
- c. Interpersonal interactions (e.g., need to talk with other people who have similar experience).

Arabiat and Altamimi<sup>[42]</sup> examined the unmet care needs of parents of children with cancer. Parents reported that the highest ranked needs related to their child's treatment and side effects, sincerity of treatment team in caring for the child, and feeling they could ask questions as needed. The lowest ranked needs related to how and what information to give to other siblings and respond to sibling emotions. Information needs were predicted by level of parental education and type of treatment, with high information needs correlated with low parental education, bone marrow transplantation, or surgery. Encouragingly, 78% of needs were rated as met by the health care providers, with the most frequently unmet needs pertaining to prognosis, obtaining information for siblings, and dealing with their emotional reactions.

### **Discussion**

This is the first review to explore the unmet needs of Arab people affected by cancer, with evidence suggesting that both patients and caregivers have high levels of unmet needs across multiple domains. [9,31,42,43] In particular, Arab patients report high levels of unmet information/communication and physical needs<sup>[9,10,43]</sup> and struggle with the sense of burden they place on their family. [43] For migrant patients, language difficulties and an inability to understand the written and verbal information provided to them was a common issue and has the potential to exacerbate unmet information needs.[9,10] The need for information has consistently been reported as an unmet need in the literature, [13,16] with Levesque et al.[25] highlighting this as the most strongly endorsed domain of need for Asian breast cancer patients. The strong need for additional information about the disease, treatment, and symptoms may be indicative of how information is presented in the care environment, a mismatch in content between patient expectation and information they are provided, and the degree to which high-quality educational materials are available within each Arab country. Furthermore, for multicultural societies such as Australia, United Kingdom, France, Canada, and the USA, there is a need for high-quality information to be made available in Arabic. Importantly, Butow *et al.*<sup>[9]</sup> found that access to an interpreter did not eliminate unmet needs pertaining to information and support, suggesting other forms of intervention are required if we are to fully support Arab migrant cancer patients.

Unfortunately, the second aim of the review to investigate the association between unmet needs, and psychosocial outcomes in Arab people affected by cancer was unable to be explored due to a lack of literature in this area. Only one study was published on Arab migrants in Australia, [44] which suggested that unmet needs are correlated with depression, anxiety, and poorer QoL. While no conclusion should be inferred, this finding is consistent with the published literature across Caucasian and Asian cancer patients, [25,46,47] which suggests that a failure to address needs is associated with poorer psychosocial outcomes. It is strongly recommended that additional studies examining the association between unmet needs and psychosocial outcomes are conducted as a matter of urgency as unmet needs present an avenue for intervention to improve psychosocial outcomes if indeed such an association exists.

While sexuality needs did not emerge as core issues for the Arab cancer patient, it is noted that they were significantly associated with reduced QoL and higher levels of anxiety and depression. It is noteworthy that Bell et al.[41] found that such items may be systematically missed in research questionnaires; however, the link to psychological outcomes suggests that they may be an underreported, yet important aspect of the cancer experience. Levesque et al. [25] found that Asian breast cancer patients are similarly unlikely to rank sexual needs as a high priority; however, they concluded that communication between patients and providers, coupled with cultural beliefs and norms surrounding sex, may exacerbate concerns in this domain. It is therefore recommended that training for health care professionals on the importance of sexual relationships and ways to raise them in a culturally sensitive manner may help to address this potentially hidden need.

The needs of Arab family members were explored by two Jordanian studies, which highlighted the cultural commitment to caregiving, which places high expectations for fulfilling the caregiving role, and unmet needs pertaining to information and support in addressing the physical and emotional needs of the patient, other family members, and dealing with the financial impact of cancer. [31,42] Moreover, Al-Jauissy highlighted the physical and emotional impact of caring on caregivers, suggesting the need to consider the education and support needs of caregivers in care plans for cancer patients and arrange appropriate support services. [31]

#### Future directions and limitations

This review is limited due to the design and methodological quality of the included studies. Specifically, there are no longitudinal studies to explore change in needs over time, the sample sizes were generally low, suggesting that the studies may have been underpowered, and one of the qualitative studies[43] reported minimal information pertaining to their data collection and data analysis. All studies were conducted in a single country, often at a single site, which might limit the generalization of findings. In addition, a variety of measures, with emerging psychometric properties, were used to assess unmet needs, including some scales developed specifically for the study, without adequate reporting of scale development or consideration of psychometric properties and validation. It is therefore recommended that future studies use measures that have been well validated, if not in Arabic, at least in the language they were developed in, having them rigorously translated and pilot tested prior to use. The use of widely-used research tools will also allow inter-study and cross-cultural comparisons to be made so that we may identify needs that are particularly pertinent to the experience of Arabic cancer patients and their caregivers.

The finding that information needs appear to be a core concern of Arabic cancer patients and their carers is not surprising. However, to date, we have very little knowledge of what information they are routinely provided with and how they gather and utilize information through their own independent means, although Shaw *et al.*<sup>[39]</sup> reported many immigrant cancer patients relied on informal sources such as the internet, social networks, and contacting family members in their country of birth to supplement information provided by health professionals.

Specific studies investigating the information needs of Arabic people affected by cancer and their independent information-seeking behaviors are encouraged.

As mentioned previously, this review was unable to fully examine the relationship between unmet needs and psychosocial outcomes such as anxiety, depression, and QoL for Arab cancer patients or their family caregivers. This is a significant limitation as the broader literature has revealed that unmet needs do negatively impact on psychosocial outcomes. It is therefore important that we understand how unmet needs influence both the physical and psychosocial outcomes of Arab cancer patients and caregivers so that relevant and effective interventions can be developed and delivered to address these modifiable variables.

To date, there have been no intervention studies designed to specifically address the needs of Arabic cancer patients and their family caregivers, and this is therefore recommended to determine whether addressing unmet needs can improve the outcomes of anxiety, depression and QoL. As a starting point, greater effort is required to meet the information and psychosocial needs of Arab people affected by cancer, through information provision, communication with health care professionals, and referral to suitable, culturally acceptable support services.

## **Conclusion**

This integrative literature review sought to explore the unmet supportive care needs of Arab people affected by cancer. The supportive care needs of Arab people with cancer cover the known domains of unmet needs, with a particular emphasis on physical, health system, information, and psychological needs. Unmet needs appear to be related to anxiety and depression and poorer QoL suggesting that addressing unmet needs may be a way to improve psychological outcomes for Arab cancer patients. Future research with strong methodological designs involving longitudinal cross-cultural comparisons would greatly enhance our understanding of this group.

# Financial support and sponsorship Nil.

#### **Conflicts of interest**

There are no conflicts of interest.

# References

- Global Burden of Disease Cancer Collaboration, Fitzmaurice C, Dicker D, Pain A, Hamavid H, Moradi-Lakeh M, et al. The Global Burden of Cancer 2013. JAMA Oncol 2015;1:505-27.
- Allemani C, Weir HK, Carreira H, Harewood R, Spika D, Wang XS, et al. Global surveillance of cancer survival 1995-2009: Analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries (CONCORD-2). Lancet 2015;385:977-1010.
- Federation of Ethnic Communities' Councils of Australia. Cancer and Culturally and Linguistically Diverse Communities. Australia; 2010. Available from: http://www.fecca.org.au/images/stories/pdfs/cancer\_cald\_communities\_report2010.pdf. [Last accessed on 2016 Jan 01].
- Moadel AB, Morgan C, Dutcher J. Psychosocial needs assessment among an underserved, ethnically diverse cancer patient population. Cancer 2007;109 (2 Suppl):446-54.
- Kent EE, Arora NK, Rowland JH, Bellizzi KM, Forsythe LP, Hamilton AS, et al. Health information needs and health-related quality of life in a diverse population of long-term cancer survivors. Patient Educ Couns 2012;89:345-52.
- Lim SH, Delaney GP, Descallar J, Sayaloune P, Papadatos G, de Souza P. Outcomes of ethnic minority groups with node-positive, non-metastatic breast cancer in two tertiary referral centers in Sydney, Australia. PLoS One 2014;9:e95852.
- Kwok W, Bhuvanakrishna T. The relationship between ethnicity and the pain experience of cancer patients: A systematic review. Indian J Palliat Care 2014;20:194-200.

- Maly RC, Stein JA, Umezawa Y, Leake B, Anglin MD. Racial/ ethnic differences in breast cancer outcomes among older patients: Effects of physician communication and patient empowerment. Health Psychol 2008;27:728-36.
- 9. Shaw J, Butow P, Sze M, Young J, Goldstein D. Reducing disparity in outcomes for immigrants with cancer: A qualitative assessment of the feasibility and acceptability of a culturally targeted telephone-based supportive care intervention. Support Care Cancer 2013;21:2297-301.
- Butow PN, Sze M, Dugal-Beri P, Mikhail M, Eisenbruch M, Jefford M, et al. From inside the bubble: Migrants' perceptions of communication with the cancer team. Support Care Cancer 2010;19:281-90.
- McGrane JA, Butow PN, Sze M, Eisenbruch M, Goldstein D, King MT. Assessing the invariance of a culturally competent multilingual unmet needs survey for immigrant and Australian-born cancer patients: A Rasch analysis. Qual Life Res 2014;23:2819-30.
- Australia Institute of Health and Welfare. Cancer in Australia: An Overview; 2014. Available from: http://www.aihw.gov. au/WorkArea/DownloadAsset.aspx?id=60129550202. [Last accessed on 2016 Jan 01].
- Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. Support Care Cancer 2009;17:1117-28.
- Lattimore-Foot GG. Needs Assessment in Tertiary and Secondary Oncology Practice: A Conceptual and Methodological Exposition. University of Newcastle; 1996.
- Campbell HS, Sanson-Fisher R, Taylor-Brown J, Hayward L, Wang XS, Turner D. The cancer support person's unmet needs survey: Psychometric properties. Cancer 2009;115:3351-9.
- Fiszer C, Dolbeault S, Sultan S, Brédart A. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: A systematic review. Psychooncology 2014;23:361-74.
- Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, et al. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: The CaSUN (Cancer Survivors' Unmet Needs measure). Psychooncology 2007:16:796-804.
- Ream E, Quennell A, Fincham L, Faithfull S, Khoo V, Wilson-Barnett J, et al. Supportive care needs of men living with prostate cancer in England: A survey. Br J Cancer 2008;98:1903-9.
- Park BW, Hwang SY. Unmet needs and their relationship with quality of life among women with recurrent breast cancer. J Breast Cancer 2012;15:454-61.
- Urbaniec OA, Collins K, Denson LA, Whitford HS. Gynecological cancer survivors: Assessment of psychological distress and unmet supportive care needs. J Psychosoc Oncol 2011;29:534-51.
- 21. Swash B, Bramwell R, Hulbert-Williams N. Unmet psychosocial needs and their impact upon psychological outcomes in long-term haematological cancer survivors. Psychonocology 2014;23:142.
- Davies JM. Determining the Unmet Needs of Outpatients with Lung Cancer and the Relationship between Unmet Needs and Quality of Life. Department of Community Health Science: University of Calgary; 2000.
- Snyder CF, Garrett-Mayer E, Brahmer JR, Carducci MA, Pili R, Stearns V, et al. Symptoms, supportive care needs, and function in cancer patients: How are they related? Qual Life Res 2008;17:665-77.
- Hansen DG, Larsen PV, Holm LV, Rottmann N, Bergholdt SH, Søndergaard J. Association between unmet needs and quality of life of cancer patients: A population-based study. Acta Oncol 2013;52:391-9.
- Levesque JV, Girgis A, Koczwara B, Kwok C, Singh-Carlson S, Lambert S. Integrative review of the supportive care needs of asian and caucasian women with breast cancer. Curr Breast Cancer Rep 2015;7:127-42.
- Lambert SD, Jones BL, Girgis A, Lecathelinais C. Distressed partners and caregivers do not recover easily: Adjustment trajectories among partners and caregivers of cancer survivors. Ann Behav Med 2012;44:225-35.

- Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: A review. Eur J Cancer 2003;39:1517-24.
- Couper JW, Bloch S, Love A, Duchesne G, Macvean M, Kissane DW. The psychosocial impact of prostate cancer on patients and their partners. Med J Aust 2006;185:428-32.
- Chambers SK, Girgis A, Occhipinti S, Hutchison S, Turner J, Morris B, et al. Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. Eur J Cancer Care (Engl) 2012;21:213-23.
- Armoogum J, Richardson A, Armes J. A survey of the supportive care needs of informal caregivers of adult bone marrow transplant patients. Support Care Cancer 2013;21:977-86.
- Al-Jauissy MS. Health care needs of Jordanian caregivers of patients with cancer receiving chemotherapy on an outpatient basis. East Mediterr Health J 2010;16:1091-7.
- 32. Bener A, Denic S, Alwash R. Screening for cervical cancer among Arab women. Int J Gynaecol Obstet 2001;74:305-7.
- 33. Saleh M, Barlow-Stewart K, Meiser B, Tucker K, Eisenbruch M, Kirk J. Knowledge, attitudes and beliefs of Arabic-Australians concerning cancer. Psychooncology 2012;21:195-202.
- Baron-Epel O, Granot M, Badarna S, Avrami S. Perceptions of breast cancer among Arab Israeli women. Women Health 2004;40:101-16.
- Merry J, Robinson J. Review CALD Cancer Information and Support Groups in South Western Sydney Local Health District; 2014. Available from: http://intranet.sswahs.nsw.gov.au/sswahs/ cancer/PDF/CALD%20Cancer%20Information%20and%20 Support%20Project%20Report%202014%20.pd. [Last accessed on 2016 Jan 01].
- Butow P, Bell M, Goldstein D, Sze M, Aldridge L, Abdo S, et al. Grappling with cultural differences; communication between oncologists and immigrant cancer patients with and without interpreters. Patient Educ Couns 2011;84:398-405.
- 37. Istiza da. Complete List of Arabic Speaking Countries; 2014. Available from: http://www.istizada.com/complete-list-of-arabic-speaking-countries-2014/. [Last accessed on 2016 Jan 01].

- 38. Goldstein D, Bell ML, Butow P, Sze M, Vaccaro L, Dong S, *et al.* Immigrants' perceptions of the quality of their cancer care: An Australian comparative study, identifying potentially modifiable factors. Ann Oncol 2014;25:1643-9.
- Shaw J, Zou X, Butow P. Treatment decision making experiences of migrant cancer patients and their families in Australia. Patient Educ Couns 2015;98:742-7.
- Kmet L, Lee R, Cook L. Standard Quality Assessment Criteria for Evaluating Primary Research Papers From a Variety of Fields, 2004. Alberta, Canada: Alberta Heritage Foundation for Medical Research; 2011.
- 41. Bell ML, Butow PN, Goldstein D. Informatively missing quality of life and unmet needs sex data for immigrant and Anglo-Australian cancer patients and survivors. Qual Life Res 2013;22:2757-60.
- 42. Arabiat DH, Altamimi A. Unmet care needs of parents of children with cancer in Jordan: Implications for bed-side practice. J Clin Nurs 2013;22:531-9.
- Ali NS, Khalil HZ, Yousef W. A comparison of American and Egyptian cancer patients' attitudes and unmet needs. Cancer Nurs 1993;16:193-203.
- Butow PN, Bell ML, Aldridge LJ, Sze M, Eisenbruch M, Jefford M, et al. Unmet needs in immigrant cancer survivors: A cross-sectional population-based study. Support Care Cancer 2013;21:2509-20.
- 45. Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, et al. The Functional Assessment of Cancer Therapy scale: Development and validation of the general measure. J Clin Oncol 1993;11:570-9.
- Dyson GJ, Thompson K, Palmer S, Thomas DM, Schofield P. The relationship between unmet needs and distress amongst young people with cancer. Support Care Cancer 2012;20: 75-85.
- Luutonen S, Vahlberg T, Eloranta S, Hyväri H, Salminen E. Breast cancer patients receiving postoperative radiotherapy: Distress, depressive symptoms and unmet needs of psychosocial support. Radiother Oncol 2011;100:299-303.