Der Onkologe

Psychoonkologie

Onkologe 2021 · 27 (Suppl 2):S133-S144 https://doi.org/10.1007/s00761-020-00872-w Published online: 30 November 2020 © Springer Medizin Verlag GmbH, ein Teil von Springer Nature 2020



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Migrants and ethnic minorities with cancer: an umbrella review on their information and supportive care needs

Electronic supplementary material

The online version of this article (https://doi. org/10.1007/s00761-020-00872-w) contains further information on "Information needs", "Search strategy" and "Quality assessment". The article and supplementary material are available at www.springermedizin.de. Please enter the title of the article in the search field. You will find the supplementary material under "Additional content" in the article.

Approximately half of cancer patients experience distress during or after the disease. Migrants and ethnic minority cancer patients are more affected by poorer healthrelated quality of life and might have specific needs for information and care. Therefore, research on these needs is crucial to inform healthcare providers and to reduce healthcare disparities; however, scientific literature covering the needs of migrants and ethnic minorities for cancer support has focused only on a single minority at a time. The aim

This article is an extended version of Riccetti, N., Werner, A., Ernst, M. et al. Informationsund Unterstützungsbedürfnisse krebskranker Migrant*innen und ethnischer Minderheiten ein Umbrella-Review. Onkologe 26, 957-965 (2020). https://doi.org/10.1007/s00761-020-00827-1

of this umbrella review is thus to provide a comprehensive overview on the needs of migrants and ethnic minority cancer patients, resulting in a practical tool for medical personnel.

Introduction

Migrants and cancer

Several studies have shown that approximately half of all cancer patients suffer at least temporarily from severe psychological stress [7, 9, 12], and one third have a concomitant mental illness [16, 17, 23]. Therefore, the reduction of mental distress at any stage of the disease is a central concern of psycho-oncological care. Previous research has highlighted that migrants (defined as "any person who is moving or has moved across an international border or within a state away from his/her habitual place of residence, regardless of (a) the person's legal status; (b) whether the movement is voluntary or involuntary; (c) what the causes for the movement are or (d) what the length of the stay is." [27]), and ethnic minorities (defined as non-dominant, smaller groups with "shared cultural heritage, including values, traditions, and often language" [19]) represent particularly vulnerable populations [25]. In

fact, when compared to the majority population, they not only present higher death rates [6, 22], more aggressive cancer [6], and later cancer detection [10], but also significantly worse psychological and health-related quality of life cancer outcomes [6, 22]. This is an issue of high social relevance, considering that modern Europe presents the highest number of migrants and refugees since World War II [29]. In 2018, one in four persons in Germany had a migration background [24], meaning they either have experienced migration themselves (first generation migrants) or have at least one parent with a migration history (second generation migrants). Therefore, the investigation of migrants' and ethnic minorities' mental health and its determinants is not only a currently relevant research topic, but is also important for everyday oncological practice.

Psycho-oncological and psychosocial needs

Several studies around the globe investigated how psychosocial interventions could improve the quality of life of migrant or ethnic minority cancer patients and survivors [11, 20, 28]. These studies pointed out that interventions should specifically address the needs of ethnic minority groups; however, to date there

is no overview summarizing what these specific needs look like. The most commonly reviewed needs among migrant and ethnic minority cancer patients and survivors are information needs. According to Rutten et al. [21] information needs are divided into ten categories (with various subcategories: see Supplementary Material A1):

- a) cancer-specific information,
- b) treatment-related information,
- c) prognosis information,
- d) rehabilitation information.
- e) prognosis and health information,
- f) coping information,
- g) interpersonal/social information,
- h) financial/legal information,
- i) medical system information,
- j) body image/sexuality information.

However, as migrant and ethnic minority individuals might face more challenges than the majority population, due to language and cultural differences, their needs for information might differ from the majority group. Beyond information needs, migrant and ethnic minority groups might have particular psychosocial and/or emotional supportive care needs due to cultural differences regarding social norms or spirituality/religion [4, 26]. Regarding seeking psychological support, such as talking to someone about their distress [8], migrants might not receive the help they need due to information, language, and access barriers [13]. Furthermore, general physical needs related to the disease and its therapy might be present (e.g. pain, fatigue, hair loss, etc.) to a different extent.

Objective

Little is known about the specific met and unmet information and supportive care needs of migrant and ethnic minority cancer patients and survivors. As existing systematic reviews often addressed only one specific ethnic minority or migrant group, a synthesis of the existing research was considered necessary. Therefore, the format of an umbrella review was chosen in order to provide a complete and practice-oriented overview for medical and psychological personnel [2].

This umbrella review aims to summarize and discuss the current state of research regarding needs on information and supportive care in cancer patients and survivors of an ethnic minority or with a migration background, driven by the following question:

What are the most commonly reported met and unmet needs in migrants and ethnic minorities cancer patients and survivors?

Methods

The review was conducted according to the Joanna Briggs Institute guidelines for umbrella reviews [1].

Search strategy

In May 2020, Web of Science Core Collection, PubMed, and PsycINFO were searched. The detailed search strategy is included in the supplementary material

The resulting articles were filtered for article type (reviews) and then exported to a literature software. Two authors (NR, AW) initially screened titles and abstracts of the identified records, applying the exclusion criteria, which were defined in advance. After this screening, the remaining studies underwent a full-text assessment for eligibility. In any phase of the process, in case the two authors did not agree, a third independent author (ME) was consulted. The selection of systematic reviews was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [18].

Inclusion and exclusion criteria

Inclusion criteria for the retrieved articles

- a) being a systematic review,
- b) investigating a study population or at least one subgroup of the study population comprised of migrants or individuals from ethnic minorities,
- c) looking at a study population comprised of cancer patients or survivors, and

d) having the focus of the review on the various needs of the study population in terms of supportive care during and/or after the disease.

Publications which mentioned needs were, however, excluded if their main focus was either on the evaluation of psycho-oncological or psychosocial interventions or on factors impacting cancer screening, primary prevention, or quality of life in cancer patients. Studies testing psychometric properties of needs assessment scales and studies only investigating caregivers or family members of cancer patients were also excluded. As no similar umbrella review on the topic has been published to date, no time limit was considered. Also, due to the paucity of the specific material and in order to provide an internationally relevant overview, neither country-specific nor language-specific restrictions were set.

To ensure the quality of eligible systematic reviews for inclusion, the critical appraisal checklist for systematic reviews and research syntheses was used [2]. As an a priori cut-off value for the inclusion in this umbrella review, it was defined that 6 out of 10 criteria from the checklist had to be met.

Results

The search strategy retrieved n = 445reviews (n = 370 from Web of Science)Core Collection, n = 59 from PubMed, and n = 16 from PsycINFO). controlling for duplicates in EndNote, n=20 records were eliminated. After the inclusion criteria were applied, n = 48 reviews remained for the fulltext assessment for eligibility. Finally, n = 5 reviews were selected for the umbrella review (Fig. 1).

Quality assessment

No systematic review among the five selected scored lower than the defined cutoff, and all could therefore be included (supplementary material A3).

Abstract · Zusammenfassung

Onkologe 2021 · 27 (Suppl 2):S133-S144 https://doi.org/10.1007/s00761-020-00872-w © Springer Medizin Verlag GmbH, ein Teil von Springer Nature 2020

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Migrants and ethnic minorities with cancer: an umbrella review on their information and supportive care needs

Abstract

Objective. The aim of this umbrella review is to summarize and discuss the current state of research on information and other needs among migrant and ethnic minority cancer patients and survivors, as well as to provide a practical and comprehensive overview for medical personnel. In fact, although migrants and ethnic minorities with cancer show worse psychological and health-related quality of life outcomes, little is known about their needs during the different phases of cancer. Methods. Web of Science, PubMed, and PsycINFO databases were searched for systematic reviews on information and supportive care needs of ethnic minority and migrant cancer patients and survivors.

Results. From the 445 articles retrieved, 5 systematic reviews were included. During the diagnosis and therapy phase, almost all ethnic groups showed high needs for "cancerspecific", "treatment-related", and "prognosis" information. During the survivorship phase, high needs for "coping", "rehabilitation", and "prognosis" information were reported. Among mostly all migrant groups and ethnic minorities, information on the "general health care system" were among the most reported needs, especially on the topics of communication with medical personnel. Barriers towards the fulfillment of these needs were often reported in language and cultural differences. Supportive care needs

concerning family and spirituality were not sufficiently met. Information needs on "body image/sexuality" were only present among certain minorities.

Conclusions. Information and other needs are mostly similar among the various ethnic groups, as are the barriers towards them. However, some specific information or other needs are more present in some migrant groups or ethnic minority cancer patients and/or survivors than in others.

Keywords

Psycho-oncology · Psychosocial support · Minority groups · Cancer survivors · Patient preference

Krebskranke Migrant*innen und ethnische Minderheiten: ein Umbrella-Review über ihre Informations- und Unterstützungsbedürfnisse

Zusammenfassung

Zielsetzung. Ziel dieses Reviews ist es, den aktuellen Forschungsstand in Bezug auf Informations- und andere Unterstützungsbedürfnisse von Krebspatienten und -überlebenden mit Migrationshintergrund und/oder Zugehörigkeit zu einer ethnischen Minderheit zusammenzufassen, zu diskutieren und Behandelnden einen praxisnahen, umfassenden Überblick zu bieten. Obwohl Migranten und ethnische Minderheiten mit Krebs häufig eine schlechtere Lebensqualität angeben, ist wenig über ihre Bedürfnisse in verschiedenen Erkrankungsphasen bekannt. Methoden. Die Datenbanken Web of Science, PubMed und PsycINFO wurden nach systematischen Übersichtsarbeiten zu Informationsund Unterstützungsbedürfnissen von

Krebspatienten ethnischer Minderheiten und Migranten durchsucht.

Ergebnisse. Von 445 abgerufenen Artikeln entsprachen fünf systematische Übersichtsarbeiten den Einschlusskriterien. Während der Diagnose- und Therapiephase berichteten fast alle ethnischen Gruppen großen Bedarf an krebsspezifischen, behandlungsbezogenen und prognostischen Informationen. Während der Nachsorgephase bestand ein großer Informationsbedarf zu "Bewältigung", "Rehabilitation" und "Prognose". Fast alle Gruppen benötigten Informationen über das "Allgemeine Gesundheitssystem", besonders zu Kommunikation mit medizinischem Personal. Barrieren waren sprachliche und kulturelle Unterschiede. Unterstützungsbedürfnisse, die Familie

und Spiritualität betreffen, wurden nicht ausreichend befriedigt. Informationsbedarf zu "Körperbild/Sexualität" gab es nur bei wenigen Gruppen.

Schlussfolgerungen. Informations- und andere Unterstützungsbedürfnisse verschiedener ethnischer Gruppen ähneln sich, ebenso deren Barrieren. Einige spezifische Bedürfnisse sind bei manchen Migrantengruppen und ethnischen Minderheiten stärker ausgeprägt als bei anderen.

Schlüsselwörter

Psychoonkologie · Psychosoziale Unterstützung · Minderheitengruppen · Krebsüberlebende · Patientenpräferenzen

Description of reviews included

A summary of the characteristics of each systematic review included is provided in Table 1.

The systematic review by Alananzeh et al. [3] on supportive care needs of Arabic cancer patients, comprised n = 6 studies, 3 of which among Arab, Greek and Chinese migrant and Anglo-Australian cancer patients in Australia. From the remaining studies, two were conducted in Jordan on Jordanian citizens, and one in USA and Egypt, comparing American and Egyptian cancer patients. Total sample size was 1159 patients (min = 82, max = 596, mean = 193).

The review by Cavanagh et al. [5] on supportive care needs among Indigenous cancer survivors comprised N=17 studies on Native American populations, with a total sample size of 3457 (in 14 studies for which study sample is reported in the review) (min = 7, max = 1445, mean = 247). Of the included articles, 15 focused on one single ethnic minority: 9 considered exclusively Native American, 5 exclusively Native Hawaiian, and one exclusively Native Alaskan cancer survivors. The remaining two articles reported on a mixed sample, comprising Native American and Native Alaskan cancer survivors.

The review by Lim et al. [14] comprised N=26 studies on information needs of Chinese cancer patients from

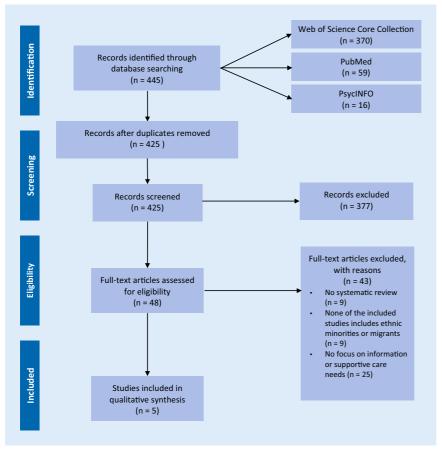


Fig. 1 ▲ Flow diagram (from [18]; for more information visit www.prisma-statement.org)

different countries: Australia (n=4), Hong Kong (n = 11), USA (n = 3), China (n=5), Taiwan (n=2), and Singapore (n=1). Total sample size was 3721 patients (min = 23, max = 649, mean = 117). From the total of 26 studies, 11 (42%) specifically examined breast cancer in women, while the others comprised various cancer types. Survivorship phase was the most frequently included (38%), followed by diagnosis and treatment phase (28%), and then palliative phase (8%).

The review by Maguire et al. [15] on the needs of women with and after cervical cancer, comprised N = 15 studies on women residing in different countries (USA, Canada, UK, Indonesia, South Korea, Nigeria, and Thailand), and with various ethnic background (White Caucasian, Asian, African and Latin American, although just one study focused on ethnic minority groups). Total sample size was 1414 patients and survivors (min = 10, max = 968, grand mean = 50.7). Three in four women were married, one in two had a high school degree, and circa one in three was employed. The majority of women had been diagnosed with stage II cervical cancer, and virtually none presented with metastatic disease.

The review by Yilmaz et al. [30] focused on information and participation needs among non-Western minorities cancer patients and survivors, and was comprised of N = 44 studies on information and participation needs, conducted in the USA (n=33), Australia (n=9), Belgium (n = 1), and the UK (n = 1). Of the included studies, 18 (41%) considered cancer patients from various ethnic backgrounds. The remaining studies comprised cancer patients from a single ethnic background (Asian, Latin American/Hispanic, African-American and African-European, Middle-Easterner, and Indian-American). Total sample size was 15,685 patients (min = 10, max = 5080, mean = 356).

Findings

Information needs

Cancer-specific, treatment, and prognosis information needs. Information needs concerning "cancer-specific information" were the most commonly reported needs during diagnostic and therapeutic cancer phase, among mostly all observed ethnic groups [14, 30].

Information needs concerning "treatment-related information" ("alternative or complementary medicine") were often reported among Chinese, Asian-American and Asian-Australian, Latin-American/Hispanic, and Middle-Eastern cancer patients and survivors [14, Information needs concerning "treatment-related information" ("side effects of treatments") were often reported among Chinese migrant cancer patients, and Native American, Native Alaskan, and Native Hawaiian cancer survivors

Information needs concerning "prognosis information" (recurrence of cancer) were often reported among Chinese migrant, and Middle-Eastern cancer patients [14, 30].

Asian-European and Middle-Eastern cancer patients also had high information needs regarding "where to get information about treatment" [30].

Coping, rehabilitation, and prognosis information needs. Information needs about "coping information", and especially "emotional reactions, emotional support, coping with cancer" (anxiety and depression) were frequently reported among Asian-American cancer survivors, and African-American cancer patients and survivors [30].

Information needs on "rehabilitation information" ("nutrition") and "prognosis" ("physical activity") were reported by mostly all ethnic groups [5, 14, 30].

Interpersonal and social information needs. Information needs concerning "effect on family, friends, or caregivers" were reported among Latin-American/ Hispanic cancer survivors and African-American cancer patients and survivors [15, 30]. More specifically, Latin-American and African-American women with

Author (year)	Objectives	Number of studies included (N) and total sample size	Places where the included studies were conducted	Patients characteristics
Alananzeh et al. (2016) [3]	Identify the unmet supportive care needs of Arab people affected by cancer, and the impact of these needs on quality of life and psychosocial well-being	6 Total sample size = 1159 (min = 82, max = 596, mean = 193)	Australia (n = 3)	Arabic, Greek and Chinese migrants in Australia;
			Jordan ($n = 2$)	Jordanian citizens in Jordan;
			USA and Egypt (n = 1)	American and Egyptian in USA and Egypt respectively
Cavanagh et al. (2016) [5]	Analyze the experiences and current sup- port services for cancer survivors from Indigenous populations following the cessation of cancer treatment	17 Total sample size = 3843 (and two case studies) (min = 7, max = 1445, mean = 247)	All in the USA	Native American, Native Hawaiian, and Native Alaskan Indigenous groups
Lim et al. (2017) [14]	Gain knowledge on information needs of Chinese cancer patients and their families, as well as assessing whether these needs vary with different health systems, migration status or cultural value	26 Total sample size (patients) = 3721 (min = 23, max = 649, mean = 117)	Hong Kong $(n = 11)$	Chinese community members living in Australia, Hong Kong, United States, China, Taiwan, and Singapore
			China $(n = 5)$	
			Australia ($n = 4$)	
		,	USA $(n=3)$	
			Taiwan $(n=2)$	
			Singapore $(N=1)$	
Maguire	Synthetize the current available evidence	15	USA $(n=5)$	Most studies considered only white Caucasian women. Ethnic minorities mentioned (of one stud in the USA): 10 Asian-American, 10 African-American and 26 Latin American women
et al. (2015) [15]	about social needs in women, which have or have had cervical cancer	Total sample size = 1414 (min = 10, max = 968, median = 33)	Canada (N = 3)	
(2013)[13]			UK(n=2)	
			Indonesia ($n = 1$)	
			Nigeria ($n = 1$)	
			South Korea $(n=1)$	
			Thailand $(n = 1)$	
Yılmaz et al. (2019) [30]	Provide an overview of information and participation preferences and needs of non-Western ethnic minority cancer patients living in Western countries	44 Total sample size = 15,685 (min = 10, max = 5080, mean = 356)	USA (n = 33)	Middle-Eastern, Caribbean, Latin-American, Hispanic, African-American, Indian-American, Asian-Pacific migrants or ethnic minorities in the USA;
			Australia (n = 9)	Asian, Asian-Pacific and Middle-Eastern migrants or ethnic minorities in Australia
			Belgium ($n = 1$)	African, Asian, and Middle-Eastern migrants or ethnic minorities in Belgium;
			UK(n=1)	Asian migrants or minority in the UK

cervical cancer reported being concerned about friends' and neighbors' perceptions of them as well as about the judgment by other people [15]. The same patient groups also reported information needs regarding "effect on employment work life" ("fear of being unable to continue working" and "fear of becoming unable to provide for the family") [15]. Cavanagh et al. [5] reported information needs on "effect on employment work life" (especially about flexible work schedules) among Native American, Native Alaskan, and Native Hawaiian cancer survivors as well. Low

information needs were reported among Chinese cancer patients concerning interpersonal and social information [14].

Financial and legal information needs.

Latin-American/Hispanic and African-American women with cancer frequently reported having information needs comprising "financial constrain", "not being able to provide for their family", as well as "feeling ashamed for needing financial support" [15]. Indian-American, and African-European cancer patients declared to prefer information on insurance, financial support, and out-ofpocket payments [30]. Lim et al. [14] reported that among Chinese cancer patients, financial and legal needs were rarely mentioned.

Healthcare information needs. Information needs comprising the "healthcare system" were commonly present among all ethnic backgrounds observed, with the exclusion of Latin-American/Hispanic cancer patients [3, 14, 30]. Arabic migrant cancer patients also often reported specific information needs on "interaction with healthcare providers" [3]. Furthermore, Arabic migrant cancer pa-

Table 2 Summary of Domain of needs	Subcategory	Findings	
Information needs	Juneallegory	i maniga	
Cancer-specific	Type of cancer/nature of disease	High information needs among all ethnic minority groups observed [14, 30]	
information needs	Etiology and course of disease	Tilgii ilionnation needs among all etimic milionty groups observed [14, 30]	
	Physical effects of disease		
	Specific diagnosis information	High information needs among mostly all ethnic minority groups observed [14, 30]	
Treatment-related	Alternative or complimentary	High information needs among Chinese, Asian-American or Asian-Australian, Lat-	
information needs	treatments	in-American/Hispanic, and Middle-eastern migrant cancer patients [14, 30]	
		Medium high information needs among African-American and Indian-American ethni minority cancer patients [30]	
		Low information needs among Filipino cancer patients [14]	
	Side effects of treatment/risks and benefits of treatment	High information needs among Chinese cancer patients [14] as well as among Native-American, Native-Hawaiian and Native-Alaskan cancer survivors [5]	
	Where to get information about treatment	High information needs among Asian-European and Middle-eastern ethnic minority cancer patients [30]	
Prognosis information needs	Recurrence of cancer	High information needs among Chinese and Middle-eastern ethnic minority cancer patients [14, 30]	
		Medium information needs among Asian-American, Asian-Australian, Latin-American Hispanic, African-American, and Indian-American ethnic minority cancer patients [30]	
Coping information needs	Emotional reactions, emotional support, coping with cancer	High information needs among Asian-American cancer survivors and African-American cancer patients and survivors, especially for anxiety [30]	
		Medium information needs among Chinese cancer patients [14]	
Rehabilitation information needs	Nutrition during recovery	High information needs in Chinese [14], Native-American, Native-Hawaiian, Native-Alaskan [5], Asian-American, Asian-Australian, and Middle-eastern cancer patient and survivors [30]	
		Medium information needs among African-American an Indian-American cancer patients \cite{Bolton}	
		Low information needs among Latin-American/Hispanic cancer patients [30]	
Prognosis and health information needs	Maintaining physical health or physical activity	High information needs among Chinese [14], Asian-American, Asian-Australian, and Middle-eastern ethnic minority cancer patients [30]	
		Medium information needs among African-American an Indian-American cancer patients ${\bf [30]}$	
		Low information needs among Latin-American/Hispanic cancer patients [30]	
	Prevention and early detection	Medium information needs among African-American, Asian-American, Asian-Australian, Indian-American and Latin-American/Hispanic ethnic minority cancer patients and survivors [30]	
		Low information needs among cancer patients of Middle-eastern ethnic minorities [30]	
Interpersonal/social information needs	Effect on family, friends, or caregivers	High information needs among Latin-American/Hispanic cancer survivors and African-American cancer patients and survivors [15, 30]	
		Low information needs among Chinese migrant cancer patients and survivors [14]	
	Effect on employment or work life	High information needs among Latin-American/Hispanic and African-American cancer patients and survivors [15] and among Native-American, Native-Hawaiian and Native-Alaskan cancer survivors [5]	
		Low information needs among Chinese migrant cancer patients and survivors [14]	
Financial/legal information needs	Cost of treatment, insurance coverage, or other financial issues	High information needs among Latin-American/Hispanic and African-American cancer patients and survivors [15] and among Indian-American and African-European cancer patients [30]	
		Low information needs among Chinese migrant cancer patients and survivors [14]	
Medical system information needs	Interactions with healthcare providers	High information needs among Arabic migrant cancer patients [3]	
	Healthcare systems	High information needs among all ethnic minority groups observed [3, 14, 15, 30] except for Latin-American/Hispanic cancer patients [30]	
		parameter parame	

Table 2 (Continued)			
Domain of needs	Subcategory	Findings	
Body image/sexuality information needs	Sexuality	High information needs among Asian-American and African-American cancer patients and survivors and Latin-American/Hispanic cancer survivors [15, 30]	
		Low information needs among Chinese migrant cancer patients and survivors [14]	
	Physical appearance/physical attractiveness	High information needs among Latin-American/Hispanic breast cancer survivors [30]	
		Low information needs among Chinese migrant cancer patients and survivors [14]	
Supportive care needs			
Supportive care needs	Family-related needs	High family-related needs among Native-American, Native-Hawaiian and Native-Alaskan cancer survivors [5]	
	Social needs	High social needs among Native-American, Native-Hawaiian and Native-Alaskan cancer survivors [5] to involve the community to minimize the stigma, possibilities to interact with other indigenous survivors	
	Spiritual/existential needs	High spiritual needs among Native-American, Native-Hawaiian and Native-Alaskan cancer survivors [5]	
Other needs	Physical needs	High physical needs among Arab, Greek, and Chinese migrants with cancer in Australia [3]	

tients often disclosed unmet information needs, as they perceived to obtain less information by healthcare providers, due to language and communication barriers [3].

image/sexuality information needs. Information needs about "body image and sexuality" were highly cited among Latin-American/Hispanic cancer survivors and African-American cancer patients and survivors [15, 30]. More specifically, among Latin-American/Hispanic breast cancer survivors, high information needs regarding reconstruction options, prosthesis and clothing needs were reported [30]. Information needs on "body image and sexuality" were not frequently cited among Chinese cancer patients or survivors [14].

Supportive care needs

Supportive care needs were often reported among Native American, Native Hawaiian and Native Alaskan cancer survivors for the presence and involvement of family and community (including other cancer survivors) during followup care and support group programs [5]. Additionally, in support groups, the need for inclusion of spiritual activities was described, and there were needs of actions towards the education and minimization of stigma associated with cancer [5].

Other needs

Arabic cancer patients reported high physical needs [3]. According to Maguire et al., ethnic minority women with cervical cancer frequently had "fear of being reported to migration officers" [15].

The findings are summarized by the various needs (Table 2) and by migrant group/ethnic minority (Table 3).

Discussion

This umbrella review aimed at summarizing the current state of knowledge about met and unmet information and supportive care needs of cancer patients with migration or ethnic minority background. Web of Science CoreCollection, PubMed, and PsycINFO were searched for systematic reviews on the topic. Five systematic reviews were finally included, covering Arab, Chinese, and Middle-Eastern migrant cancer patients and survivors, and African-American, African-European, Asian-American, Asian-Australian, Latin-American/Hispanic, Indian-American, Native American, Native Alaskan, and Native Hawaiian cancer patients and survivors.

Among all observed ethnic minorities and migrant groups, during the early cancer phases, high information needs for "cancer-specific information" were present, as well as high information needs on "treatment related information" ("alternative therapy"), and "prognosis" (especially "reoccurrence of cancer"), during survivorship [3, 5, 14, 15, 30]; however, few of the studies included in the review also reported patients' wishes not to receive information on "prognosis" in case of negative prognosis [30].

Common information needs among all the observed ethnic minorities and migrant groups concerned "rehabilitation" ("nutrition"), and "prognosis" ("physical activity") [5, 14, 30].

Information needs on "body/image and sexuality" were commonly reported among African-American and Latin-American/Hispanic cancer patients and survivors, but less frequently reported among Asian-American and Chinese cancer patients (except from Chinese cancer patients and survivors who migrated to Hong Kong) [14]. Furthermore, in studies with Arab, Greek and Chinese cancer patients, the patients refused disclosure of information regarding body/ image and sexuality, which might lead to an underestimation of these needs [3]. As body/image and sexuality information needs represent a sensitive topic, albeit it is very relevant for individual quality of life, health professionals should not overlook this domain but seek to introduce information and the possibility of counselling carefully and within a confidential environment. A possibility to inform about body/image and sexuality supportive care beyond a personal face-to-face setting could be to include them within information about

Migrant or ethnic minority cancer patient or sur- vivor group	Domain of needs	Findings
African-American	Information needs	
or African-Australian cancer patients and/or survivors	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [30]
	Treatment-related information needs	Medium information needs on "alternative or complimentary treatments" [30]
	Prognosis information needs	Medium information needs on "recurrence of cancer" [30]
	Coping information needs	High information needs on "emotional reactions, emotional support, coping with cancer" [30]
	Rehabilitation information needs	Medium information needs on "nutrition during recovery" [30]
	Prognosis and health information needs	Medium information needs on "maintaining physical health or physical activity" and on "prevention and early detection" [30]
	Interpersonal/social information needs	High information needs on "effect on family, friends, or caregivers" and on "effect on employment or work life" [15]
	Financial/legal information needs	High information needs on "cost of treatment, insurance coverage, or other financial issues" [15]
	Medical system information needs	High information needs on "healthcare systems" [30]
	Body image/sexuality information needs	High information needs on "sexuality" [30]
Arabic migrant	Information needs	
cancer patients and/or survivors	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [3]
	Medical system information needs	High information needs on "interactions with healthcare providers" and "healthcare systems" [3]
	Other needs	
	Other needs	High physical needs [3]
Asian-American or	Information needs	
Asian-Australian cancer patients and/or survivors	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [30]
aria/or survivors	Treatment-related information needs	High information needs on "alternative or complimentary treatments" [30]
	Prognosis information needs	Medium information needs on "recurrence of cancer" [30]
	Coping information needs	High information needs on "emotional reactions, emotional support, coping with cancer" [30]
	Rehabilitation information needs	High information needs on "nutrition during recovery" [30]
	Prognosis and health information needs	High information needs on "maintaining physical health or physical activity" and medium information needs on "prevention and early detection" [30]
	Medical system information needs	High information needs on "healthcare systems" [30]
	Body image/sexuality information needs	High information needs on "sexuality" [30]

Table 3 (Continue Migrant or ethnic	Domain of needs	Findings	
minority cancer patient or sur- vivor group	Domain of needs	rinuings	
Chinese migrant cancer patients and/or survivors	Information needs		
	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [14]	
	Treatment-related information needs	High information needs on "alternative or complimentary treatments", "side effects of treatment/risks and benefits of treatment" [14]	
	Prognosis information needs	High information needs on "recurrence of cancer" [14]	
	Coping information needs	Medium information needs on "emotional reactions, emotional support, coping with cancer" [14]	
	Rehabilitation information needs	High information needs on "nutrition during recovery" [14]	
	Prognosis and health information needs	High information needs on "maintaining physical health or physical activity" [14]	
	Interpersonal/social information needs	Low information needs on "effect on family, friends, or caregivers" and on "effect on employment or work life" [14]	
	Financial/legal information needs	Low information needs on "cost of treatment, insurance coverage, or other financial issues" [14]	
	Medical system information needs	High information needs on "healthcare systems" [14]	
	Body image/sexuality information needs	Low information needs on "sexuality" and "physical appearance/physical attractiveness" [14]	
Indian-American	Information needs		
cancer patients and/or survivors	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [30]	
	Treatment-related information needs	Medium information needs on "alternative or complimentary treatments" [30]	
	Prognosis information needs	Medium information needs on "recurrence of cancer" [30]	
	Rehabilitation information needs	Medium information needs on "nutrition during recovery" [30]	
	Prognosis and health information needs	Medium information needs on "maintaining physical health or physical activity" and on "prevention and early detection" [30]	
	Financial/legal information needs	High information needs on "cost of treatment, insurance coverage, or other financial issues" [30]	
	Medical system information needs	High information needs on "healthcare systems" [30]	
Latin-American/	Information needs		
Hispanic cancer patients and/or	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [30]	
survivors	Treatment-related information needs	High information needs on "alternative or complimentary treatments" [30]	
	Prognosis information needs	Medium information needs on "recurrence of cancer" [30]	
	Rehabilitation information needs	Low information needs on "nutrition during recovery" [30]	
	Prognosis and health information needs	Low information needs on "maintaining physical health or physical activity" and medium information needs on "prevention and early detection" [30]	
	Interpersonal/social information needs	High information needs on "effect on family, friends, or caregivers" and on "effect on employment or work life" [15]	
	Financial/legal information needs	High information needs on "cost of treatment, insurance coverage, or other financial issues" [15]	
	Body image/sexuality information needs	High information needs on "sexuality" and "physical appearance/physical attractiveness" [15, 30]	

Table 3 (Continue	d)	
Migrant or ethnic minority cancer patient or sur- vivor group	Domain of needs	Findings
Middle-Eastern cancer patients and/or survivors	Information needs	
	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [30]
	Treatment-related information needs	High information needs on "alternative or complimentary treatments" and "where to get information about treatment" [30]
	Prognosis information needs	High information needs on "recurrence of cancer" [30]
	Rehabilitation information needs	High information needs on "nutrition during recovery" [30]
	Prognosis and health information needs	High information needs on "maintaining physical health or physical activity" and low information needs on "prevention and early detection" [30]
	Medical system information needs	High information needs on "healthcare systems" [30]
Native American,	Information needs	
Native Alaskan, Native Hawaiian cancer survivors	Cancer-specific information needs	High information needs on "type of cancer/nature of disease", "etiology and course of disease", "physical effects of disease", and on "specific diagnosis information" [5]
cancer survivors	Treatment-related information needs	High information needs on "side effects of treatment/risks and benefits of treatment" [5]
	Rehabilitation information needs	High information needs on "nutrition during recovery" [5]
	Interpersonal/social information needs	High information needs on "effect on employment or work life" [5]
	Supportive care needs	
	Supportive care needs	High "family-related" needs, high "spiritual" needs, and high "social" needs to involve the community to minimize the stigma, possibilities to interact with other indigenous survivors [5]

other psychosocial needs, for example in brochures on supportive care in cancer.

High information needs on coping information and especially coping with emotions (in particular anxiety and depression) were reported from Asian-Australian cancer survivors and African-American cancer patients and survivors, although it was reported also among Chinese migrant cancer patients [14, 30]. The need of family support throughout survivorship was often reported from Native American, Native Alaskan, and Native Hawaiian cancer survivors, and highlighted as more important than support from friends and church/community [5]. Furthermore, in these ethnic minorities, education of family and community to overcome stigma in cancer, was often mentioned as well [5]. This could underline the importance of both involvement and growth through education of the community around the patients.

Common were needs for information regarding the general health system across all observed ethnic minorities and migrant groups (excluding Latin-American/Hispanic cancer patients and survivors). Asian-Australian and Middle-Eastern cancer patients and survivors reported uncertainty to whom to address their information needs about diagnosis, therapy and prognosis, while Indian-American and African-European cancer patients and survivors reported similar uncertainty about needs regarding financial matters, especially insurance and out-of-pocket payment. The mere availability of medical personnel for consultation was not always sufficient, as language/communication differences were perceived and reported as barriers [3]. Language and cultural factors were identified as barriers compounding all domains of information needs [3, 14, 15]. Arab migrant cancer patients felt that they received less information due to linguistic barriers [3]. One potential solution to overcome the necessity for medical personnel to provide information over a broad spectrum of languages could be leaflets and brochures. fact, Chinese migrant cancer patients reported preferring to use these media for information purposes rather than consulting friends or the TV (with the exclusion of Chinese-American cancer patients, who reported using the Internet as main source of information) [14]. Nevertheless, leaflets and brochures should be provided in the language of the patients or survivors affected by cancer, as only providing languages spoken by the majority population was perceived as a barrier, as reported by Alananzeh et al. with respect to Arabic migrant cancer patients [3].

Limitations

The narrow focus of this umbrella review and the paucity of specific material clearly limit the generalization of the findings. More specifically, the review by Maguire et al. [15] only included one study focused on ethnic minorities, while the systematic review from Alananzeh et al. [3] only included three. Therefore, only specific aspects could be reported in this umbrella review. Furthermore, a small percentage (3%) of the observed studies were conducted in Europe, hence the findings were mostly derived from studies conducted in the USA, Canada, and Australia. This detachment from the European settings does not allow the immediate transfer of the results of this umbrella review into the European context. Moreover, the information and supportive care needs of migrants and ethnic minority cancer patients and survivors in Europe should be investigated in detail in future research. This is even more relevant as there are differences within migrant groups and ethnic minorities, which are related to demographic, cultural, and social factors [30], and which could not be disentangled without in-depth analysis of the corresponding majority communities and related health systems.

Practical conclusion

- 1. Ethnic minority cancer patients and survivors have high information needs, especially on diagnosis, alternative therapies, and cancer reoccurrence, as well as on the general functioning of the health system.
- 2. Language differences are perceived by migrant and ethnic minority cancer patients and survivors as a barrier towards the fulfilment of these needs. Therefore, if possible, information material (e.g. leaflets) should be provided in the first languages of the cancer patients and survivors.
- 3. Providers of supportive care in cancer should name concrete personnel who are responsible for the dissemination of specific information needs.
- 4. Information needs regarding sensitive topics of body/image and sexuality should be investigated with caution but not be avoided. Indirect ways to inform on these topics could help to fulfil the information needs in this domain.

5. As differences in information and supportive care needs are present between and within migrant and ethnic minority cancer patients and survivors, medical personnel should never overlook the individual characteristics of a patient.

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Acknowledgements. The authors would like to thank Mrs. L. Cascant-Ortolano of the Bibliothek der Universitätsmedizin Mainz (BUMM) for expert support in developing the search strategy.

Compliance with ethical quidelines

Conflict of interest. N. Riccetti, A. M. Werner, M. Ernst, I. Hempler and S. Singer declare that they have no competing interests.

Ethical standards. For this article no studies with human participants or animals were performed by any of the authors. All studies performed were in accordance with the ethical standards indicated in each case.

The supplement containing this article is not sponsored by industry.

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