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Yilmaz, N.G.; Schouten, B.C.; Schinkel, S.; van Weert, J.C.M.

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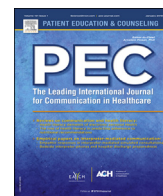
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Review Article

Information and participation preferences and needs of non-Western ethnic minority cancer patients and survivors: A systematic review of the literature

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ABSTRACT

Objective: To provide an overview of information and participation preferences and needs of non-Western ethnic minority cancer patients living in Western countries.

Methods: A systematic literature review was conducted using the databases PsycINFO, PubMed, CINAHL, and EMBASE. Thematic analysis was carried out to synthesize data, allowing for identification of important themes and synthesis of both qualitative and quantitative studies.

Results: Forty-four papers were included. Non-Western ethnic minority cancer patients/survivors have high information preferences and needs regarding topics ranging from diagnosis to treatment and from prevention to the healthcare system. Younger, female, and unmarried patients/survivors, and patients with better language proficiency reported higher information preferences. Latin-American and African-American patients/survivors primarily prefer shared or active participation. Asian and Middle-Eastern patients/survivors prefer primarily passive participation. Younger patients, and those with a higher level of education and acculturation were more likely to prefer active or shared participation.

Conclusion: Further (quantitative) research on factors associated with patients' preferences is needed in order to better understand the underlying reasons of information and participation preferences and needs of diverse non-Western ethnic minority cancer patients.

Practice implications: To better fulfil ethnic minority patients'/survivors' preferences and needs healthcare providers should elaborate upon these and tailor their information-provision accordingly.

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1. Introduction

During the past decades, the number of non-Western ethnic minority groups living in Western countries has increased rapidly [1,2]. Ethnic minority groups can be defined as numerically smaller, non-dominant groups distinguished by ‘shared cultural heritage, including values, traditions, and often language’ [3; p.274]. The current situation in Western countries is best described by the concept of superdiversity. On the one hand, superdiversity refers to the growth of ethnic minority groups from different countries of origin. On the other hand, it refers to the internal fragmentation of ethnic minority groups, leading to differences within these groups [4,5].

As part of their acculturation process, non-Western ethnic minority groups often adapt their lifestyle to the Western lifestyle, which is associated with an increased risk of developing chronic diseases such as hypertension, diabetes, and cancer [2]. For cancer, there is evidence that ethnic minorities from non-Western countries are at higher risk for certain types of cancer compared to the Western population [2,6], including stomach cancer, liver cancer, and lung cancer [2]. As a consequence, encounters between Western healthcare providers and cancer patients from non-Western ethnic minority groups are on the increase [1].

A cancer diagnosis entails a physical and psychological burden for patients, and treatment outcomes are often uncertain [7]. Hence, doctor-patient communication that is tailored to patients’ preferences and needs is vital in oncology, as this has been shown to be associated with lower psychological distress and higher patient satisfaction [8]. However, ethnic minority non-Western cancer patients often experience difficulties in communicating with their doctor, due to cultural, religious, and linguistic differences with their providers [9–11]. These communication difficulties may contribute to low patient satisfaction, poor treatment adherence and suboptimal health outcomes [1]. In order to provide ethnic minority cancer patients with the best quality cancer care, it is of utmost importance to take patients’ preferences and needs regarding information and participation in decision-making (in the remainder of the review referred to as ‘participation’) into account [12]. Superdiversity, in turn, adds another barrier to doctor-patient communication, as in the heterogeneous pattern of ethnic minority groups, both between ethnic minority groups and within ethnic minority groups differences regarding preferences and needs are expected to exist. This heterogeneity, in turn, implies that communication should be tailored to the preferences and needs of individual ethnic minority patients [13].

Information preferences and needs of cancer patients vary from, for example, the preference and need to receive information about diagnosis or treatment options, to the preference and need to receive information about one’s prognosis [14]. Unmet information needs among the general population of cancer patients primarily concern disease and

treatment-related information [15], which is vital for patients to be able to participate in treatment decision-making. Meeting patients’ information preferences and needs results in more positive patient outcomes, such as a better health-related quality of life, and less depression and anxiety [16]. As for participation preferences and needs of cancer patients, passive, shared, and active participation in decision-making can be distinguished [17]. Passive decision-making refers to patients deferring decisions to their physician and/or caregiver, active decision-making refers to patients making all decisions by themselves, and shared decision-making (SDM) implies that the patient and physician share knowledge, values, and preferences, ultimately leading to mutual healthcare choices [18–20]. SDM has several benefits over passive and active participation [19–23], among which higher physician and patient satisfaction, increased quality of life, better functional and clinical outcomes, and more adherence to treatment plans [19,20]. Moreover, SDM is related to a stronger doctor-patient relationship and diminished stress, disbelief and the feeling of loss of control over one’s life [19,20,23].

To date, several studies have investigated information and participation preferences and needs of Western cancer patients [7,8,15,24–27]. However, a systematic overview of the information and participation preferences and needs and underlying associated factors among non-Western ethnic minority cancer patients is lacking [1,28,29]. Insight into the preferences and needs of ethnic minority patients, and the factors that are associated with these preferences and needs, however, is relevant as doctor-patient communication should be tailored to individual patients’ preferences and needs if we want to provide these patients with optimal oncological care. To our knowledge, only one review study investigated SDM among ethnic minority cancer patients [30]. However, this review only focused on behavior instead of preferences and needs. Hence, healthcare providers remain uncertain about ethnic minority patients’ preferences and needs, which possibly leads to suboptimal doctor-patient communication. The aim of our study is to provide a systematic review of research on information and participation preferences and needs of non-Western ethnic minority cancer patients living in Western countries. In accordance with above-mentioned definition of ethnic minorities, in this review ‘ethnic minority’ refers to ‘numerically smaller, non-dominant groups distinguished by shared cultural heritage, including values, traditions, and often language’ [3; p.274]. Furthermore, in this review ‘non-Western’ covers patient populations from African, Asian, Indian-American, Middle-Eastern, and Latin-American descent. Such an overview will help healthcare providers to take these preferences and needs better into account during doctor-patient communication. In addition, it will show which factors are associated with their information and participation preferences and needs. Ultimately, this overview could help healthcare providers to better tailor communication to the individual ethnic minority cancer patient.

Table 1
Study characteristics.

| # | Authors, Year & Country | Design & Method | Sample & Setting | Main findings | Methodological quality |
|---|--|--|---|---|------------------------|
| 1 | Aelbrecht et al. (2016) [1] Belgium | <i>Study design:</i> Qualitative <i>Method:</i> Semi-structured face-to-face interviews <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Hospital <i>Sample:</i> - 30 patients - Female: 70% - Various cancers - Age range: 25–70 - Level of acculturation: 39.1% was living for over 10 years in host country - Ethnicity o Asian: Thai o Middle-Eastern: Iranian, Turkish o African: Congolese, Ethiopian, Ghanaese, Senegalese, Somalian, Tunisian, Moroccan | <i>Topic:</i> Information needs <i>Results:</i> Patients report a vast need for information about general disease-related issues, such as the healthcare system of the host country. | 3 |
| 2 | Ayash et al. (2018) [64] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Community cancer centers <i>Sample:</i> - 309 patients - Female: 100% - Breast cancer - Age range: 47–57 - Level of acculturation: 21.2% was able to speak English language - Ethnicity: o Middle-Eastern: Saudi-Arabian o Carribean immigrants of African descent o Latin-American | <i>Topic:</i> Information needs <i>Results:</i> Arab-American breast cancer patients have significantly lower information needs compared to Latin-American patients. The specific information needs are not mentioned. | 2 |
| 3 | Butow et al. (2013) [51] Australia | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> - Supportive Care Needs - Questionnaire (SCNS) - Cancer Survivors Unmet Needs (CANUS) <i>Focus phase of disease:</i> Survivor | <i>Setting:</i> - <i>Sample:</i> - 596 survivors - Female: 46% - Various cancers - Mean age: 62.5 (SD = 11.0) - Level of acculturation: mean for living in host country = 30 years (SD = 14.6) - Ethnicity: o Asian: Chinese o Middle-Eastern: Saudi-Arabian | <i>Topic:</i> Information needs <i>Results:</i> Survivors report a high need for information about cancer and treatment, alternative medicine, and sexual relationship. | 3 |
| 4 | Costas-Muniz et al. (2013) [59] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Cancer clinics <i>Sample:</i> - 271 patients - Female: 59.5% - Various cancers - Age range : 18 → 80 (M = 55.5; SD = 12.7) - Level of acculturation: 29.8% was able to speak English language fluently - Ethnicity o Latin-American: Dominicans, Puerto Rican, Ecuadorian, Mexican | <i>Topic:</i> Information preferences <i>Results:</i> Patients have a low information preference. Only a minority of cancer patients report to prefer information about their diagnosis and/or treatment. Low English proficiency and being monolingual in Spanish predicted a low preference to receive information. | 2 |
| 5 | Galvan et al. (2009) [60] USA | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups and individual interviews <i>Focus phase of disease:</i> Survivors | <i>Setting:</i> Non-profit cancer support organisation <i>Sample:</i> - 22 survivors - Female: 100% - Breast cancer - Age range : 35–67 (M = 51; SD = 9) (M = 51; SD = 9) - Level of acculturation: low - Ethnicity o Latin-American: South American, Central American, Mexican, Caribbean | <i>Topic:</i> Information needs <i>Results:</i> Survivors report a high need for information about diagnosis, treatment, and procedures after treatment. They believed that this information would help them in coping with the diagnosis, in making better treatment plans and in enhancing their ability to cope with the aftermath of cancer treatment. Limited English proficiency was mentioned to be an important barrier in gathering this information. | 2 |

Table 1 (Continued)

| # | Authors, Year & Country | Design & Method | Sample & Setting | Main findings | Methodological quality |
|----|---------------------------------------|--|---|--|------------------------|
| 6 | Hawley et al. (2008) [66] USA | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> Control Preference Scale <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> Los Angeles metropolitan SEER registries <i>Sample:</i> - 1224 patients - Female (100%) - Ductal Carcinoma in Situ, and invasive breast cancer - Age range: 29 – 79 - Ethnicity: o Latin-American o African-American | <i>Topic:</i> Participation preferences <i>Results:</i> Patients prefer shared decision-making and active decision-making at equal levels. A slight minority prefers passive participation. | 3 |
| 7 | Hodge et al. (2012) [58] USA | <i>Study design:</i> Qualitative <i>Method:</i> Focus group discussions <i>Focus phase of disease:</i> Survivors | <i>Setting:</i> Conference rooms in urban clinics <i>Sample:</i> - 132 survivors - Female: 72% - Various cancers - Ethnicity: o Indian-American | <i>Topic:</i> Information preferences <i>Results:</i> Survivors prefer basic information ranging from cancer diagnosis (how and when) to treatment options (surgery, medication, and radiation). They also prefer to be informed about survivorship (symptoms), and spirituality because they believe that this information will help them in keeping balance in their lives. | 2 |
| 8 | Huang et al. (1999) [46] Australia | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups, telephone interviews <i>Focus phase of disease:</i> - | <i>Setting:</i> Major teaching hospitals, cancer support organization <i>Sample:</i> - 36 patients - Female: 63.8% - Various cancers - Age range: 30 –> 0 - Level of acculturation: low (69%) - Ethnicity: o Asia: Chinese | <i>Topics:</i> Information & Participation preferences <i>Results:</i> Patients prefer as much information as possible about their diagnosis and treatment. Prognostic information – especially if the prognosis is bad – is not preferred by the majority. They believed that negative prognostic information would be too stressful for the patient, resulting in the patient being less able to cope with cancer. A minority would like to know all details of their prognosis, even if it was bad, because they believed that this information would help them in better planning their future. Patients prefer the physician to give a definite recommendation concerning the treatment. Only if the different outcomes per treatment options were very clear, patients felt confident to participate in shared decision-making. However, high-educated patients more often report to prefer active participation, because they believe that the patient should make decisions as it is his/her life that is at stake. Low-educated patients more often report to prefer passive participation, because they believe that the physician is the expert. | 3 |
| 9 | Hyatt et al. (2017) [73] Australia | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> Self-developed <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Australian state Cancer Registries, oncology clinics <i>Sample:</i> - 1441 patients - Female: 53.6% - Various cancers - Mean age: 62.7 - Level of acculturation: mean for living in host country = 20–27 years (<i>SD</i> = 11.1–15.5) - Ethnicity: o Asia: Chinese o Middle-East: Saudi-Arabian | <i>Topic:</i> Participation preferences <i>Results:</i> A vast majority of patients prefer passive participation in decision-making. | 3 |
| 10 | Im et al. (2008) [42] USA | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measures:</i> - Cancer Needs Questionnaire-Short Form - Supportive Care Needs Survey <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Internet settings (MSN.com), cancer clinic, and cancer support group <i>Sample:</i> - 110 patients - Female: 80% - Various cancers - Mean age: 50.7 (<i>SD</i> = 11.8) - Ethnicity: o Asian o African-American o Hispanic | <i>Topic:</i> Information needs <i>Results:</i> Patients have high information needs regarding treatment and prognosis. | 3 |

Table 1 (Continued)

| # | Authors, Year & Country | Design & Method | Sample & Setting | Main findings | Methodological quality |
|----|---------------------------------------|--|--|---|------------------------|
| 11 | Janz et al. (2008) [43] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Los Angeles County, SEER registry <i>Sample:</i> - 1137 patients - Female: 100% - Ductal carcinoma in-situ and breast cancer - Mean age: 56.9 - Ethnicity: o Latin-American o African-American | <i>Topic:</i> Information needs <i>Results:</i> Patients have a high need for information about cancer treatment and its aftermath, such as the effect on patients' (sexual) relationships. Furthermore, patients have a high need for information about nutrition. Patients with a higher level of education, a lower level of acculturation, and older patients have higher information needs compared to lower educated, more acculturated, and younger patients, respectively. | 3 |
| 12 | Jean-Pierre et al. (2010) [39] USA | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> Information Needs Assessment questionnaire <i>Focus phase of disease:</i> - | <i>Setting:</i> University of Rochester Cancer Center Community Clinical Oncology Program <i>Sample:</i> - 69 patients - Female: 61.9% - Various cancers - Mean age: 56.6 (SD = 14.6) - Ethnicity: o African-American o Hispanic | <i>Topic:</i> Information needs <i>Results:</i> A significantly higher proportion of African-American and Hispanic cancer patients need more information about their diagnosis and treatment plan, compared to White patients. They believe that this information will help them in understanding their diagnosis and coping with the treatment plan. | 2 |
| 13 | Joseph et al. (2017) [44] USA | <i>Study design:</i> Qualitative <i>Method:</i> Recall interviews <i>Focus phase of disease:</i> - | <i>Setting:</i> Public county hospitals <i>Sample:</i> - 124 patients - Female: 59.3% - Various cancers - Mean age: 48.3 (SD = 13.3) - Level of acculturation: mean for living in host country = 14.8 years (range = 5–37) - Ethnicity: o Asia: Chinese o African-American o Latin-American: Spanish-speaking | <i>Topic:</i> Information needs <i>Results:</i> Patients report a need for information about the causes of cancer, genetics, recurrence, and prevention. | 3 |
| 14 | Katz et al. (2017) [72] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Stage III or IV | <i>Setting:</i> Georgia and Los Angeles County, SEER registry <i>Sample:</i> - 5080 patients - Female: 100% - Breast cancer - Age range: 20–79 - Level of acculturation: low (52.9% among Latin-Americans) - Ethnicity: o Asian o African-American o Latin-American | <i>Topic:</i> Participation preferences <i>Results:</i> Patients report a preference for passive participation. Especially Latin-American and Asian-American patients prefer low autonomy in the decision-making process. | 3 |
| 15 | Kent et al. (2012) [52] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Survivor | <i>Setting:</i> Los Angeles County, SEER registry <i>Sample:</i> - 1197 survivors - Female: 37.9% - Various cancers - Mean age: 68.0 (SD = 11.4) - Ethnicity: o Hispanic o African-American o Asian/Pacific Islanders | <i>Topic:</i> Information needs <i>Results:</i> Survivors report a need for information about treatment, side effects and symptoms. Survivors who are younger, have an ethnic minority background, received less than excellent care or no treatment summary report higher information needs. Colorectal cancer survivors report lower information needs compared to survivors of other types of cancer. | 3 |
| 16 | Kreling et al. (2006) [76] USA | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups <i>Focus phase of disease:</i> Post-treatment | <i>Setting:</i> Local church, Spanish Senior Center, and conference room of Cancer Center <i>Sample:</i> - 34 patients - Female: 100% - Breast cancer - Age: >65 - Ethnicity: o Latin-American o African-American | <i>Topic:</i> Participation preferences <i>Results:</i> Patients report that they do not feel like they are provided a 'choice' in which treatment they want to receive. They are told what to do. However, patients do not mind this and report to prefer passive participation. | 2 |

Table 1 (Continued)

| # | Authors, Year & Country | Design & Method | Sample & Setting | Main findings | Methodological quality |
|----|---------------------------------------|---|--|---|------------------------|
| 17 | Kwok & White (2014) [57] Australia | <i>Study design:</i> Qualitative <i>Method:</i> Semi-structured focus group interviews <i>Focus phase of disease:</i> Post-treatment | <i>Setting:</i> Cancer support group <i>Sample:</i> - 23 patients - Female (100%) - Breast cancer - Mean age: 56 (SD = 2.5) - Level of acculturation: 47.8% was living for 20–29 years in host country - Ethnicity: o Asian: Chinese, Hong Kongers | <i>Topic:</i> Information preferences <i>Results:</i> Patients prefer to receive linguistically appropriate and culturally sensitive cancer information. They prefer to get information about cancer in general, and signs and symptoms of cancer recurrence. | 3 |
| 18 | Lee & Knobf (2016) [70] USA | <i>Study design:</i> Qualitative <i>Method:</i> Semi-structured interviews <i>Focus phase of disease:</i> Post-treatment | <i>Setting:</i> Metropolitan New York area <i>Sample:</i> - 123 patients - Female: 100% - Breast cancer - Mean age: 48.7 - Level of acculturation: median for living in host country = 13.6 years - Ethnicity: o Asian: Chinese | <i>Topic:</i> Participation preferences <i>Results:</i> The majority reports a preference for shared decision-making. They want to compare the treatment choices and treatment outcomes together with family member. In line with this, patients describe treatment choices as 'our decision'. | 2 |
| 19 | Lee et al. (2016) [75] USA | <i>Study design:</i> Qualitative <i>Method:</i> Dyadic, ethnographic interviews <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> Ambulatory oncology clinic within county safety-net hospital system <i>Sample:</i> - 13 patients - Female: 52.9% - Lung cancer - Age range: 46–86 - Ethnicity: o African-American | <i>Topic:</i> Participation preferences <i>Results:</i> Patients prefer passive participation in the decision-making process. Patients perceive the doctor as the expert, and, hence, prefer to leave decisions to the doctor. | 3 |
| 20 | Leng et al. (2012) [53] USA | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> Cancer support organization, surgical oncology clinic of large municipal hospital <i>Sample:</i> - 28 patients - Female: 43% - Various cancers - Age range: 35 – 80 - Level of acculturation: 48% was living for over 20 years in host country - Ethnicity: o Asian: Chinese, Taiwanese, Hong Kongers, Malaysians, Vietnamese | <i>Topic:</i> Information needs <i>Results:</i> Patients report a need for information about cancer in general, treatment and risks, nutrition, and Chinese medicine. | 3 |
| 21 | Leng et al. (2014) [56] USA | <i>Study design:</i> Quantitative <i>Method:</i> Needs assessment survey <i>Measure:</i> Self-developed <i>Focus phase of disease:</i> - | <i>Setting:</i> Hospital-based cancer clinics <i>Sample:</i> - 59 cancer patients - Female: 63% - Various cancers - Level of acculturation: 29% was living for over 15 years in host country - Ethnicity: o Asian: Chinese, Malaysian | <i>Topic:</i> Information needs <i>Results:</i> Patient report a vast need for information about treatment issues, nutrition and exercise, the healthcare system in general, and alternative medicine. | 2 |
| 22 | Lopez et al. (2014) [67] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> - | <i>Setting:</i> California Cancer Registry <i>Sample:</i> - 742 patients - Female: 100% - Ductal carcinoma in-situ - Age range: 18 -> 60 - Level of acculturation: mean for living in host country = 1.4–4.1 years - Ethnicity: o Latin-American | <i>Topic:</i> Participation preferences <i>Results:</i> The majority prefers shared or active participation in the treatment decision-making process. This preference is higher among Spanish-speaking Latin-American patients, than among English-speaking Latin-American patients. | 3 |

Table 1 (Continued)

| # | Authors, Year & Country | Design & Method | Sample & Setting | Main findings | Methodological quality |
|----|--|---|---|---|------------------------|
| 23 | Maliski et al. (2006) [38] USA | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups <i>Focus phase of disease:</i> - | <i>Setting:</i> Local prostate cancer support groups, a previous prostate cancer study, local hospital urology clinics, health fairs, community-based organizations <i>Sample:</i> - 41 patients - Female: 0% - Prostate cancer - Age range: 51–88 - Ethnicity: o Asian: Chinese, Filipinos o African-American | <i>Topics:</i> Information & Participation preferences <i>Results:</i> Patients prefer to be informed about treatment choices, the phase between diagnosis and treatment onset, the phase after treatment, and what patients can do to help themselves. All patients, except Filipino patients, prefer information about treatment options and side effects, and diagnostic and staging procedures. Patients prefer their family members to be involved in treatment decision-making. Patients report that they prefer shared decision-making with their family members, because they believe that their family members will have a better understanding of the disease and how it affects the patient if they are involved. | 2 |
| 24 | Markovic et al. (2004) [74] Australia | <i>Study design:</i> Qualitative <i>Method:</i> Interviews <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> Tertiary, public hospital <i>Sample:</i> - 10 cancer patients - Female: 100% - Gynaecological cancer - Age range: 50 → 70 years - Ethnicity: o Middle-Eastern o Asian-Pacific | <i>Topic:</i> Participation preferences <i>Results:</i> Patients prefer passive participation in treatment decision-making. This preference was influenced by the unavailability of alternative treatment options, and the perception that the hospital is a centre of concentrated clinical expertise in treating gynaecological cancer. | 2 |
| 25 | Matsuyama et al. (2013) [37] USA | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> Toronto Informational Needs Questionnaire <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> Virginia Commonwealth University (VCU) Massey Cancer Center <i>Sample:</i> - 138 patients - Female: 62% - Various cancers - Mean age: 54.7 (SD = 11.8) - Ethnicity: o African-American | <i>Topic:</i> Information needs <i>Results:</i> The majority has high information needs about side effects of diagnostic tests, and about the disease (i.e. cancer in general, expected progression, and prognosis). However, they do not want to know about the chance of getting worse. Female patients, younger patients, African-American patients, less educated patients, and married patients had significantly higher information needs than male patients, older patients, non-Hispanic White patients, higher educated patients, and unmarried patients, respectively. | 3 |
| 26 | Matsuyama et al. (2011) [40] USA | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> Toronto Informational Needs Questionnaire <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> Virginia Commonwealth University (VCU) Massey Cancer Center <i>Sample:</i> - 138 patients - Female: 62.3% - Various cancers - Mean age: 54.7 (SD = 11.8) - Ethnicity: o African-American | <i>Topic:</i> Information needs <i>Results:</i> Patients have high information needs about diagnostic tests (i.e. purpose, method, and side effects of test), and about treatment (i.e. reasons for, admission of, and reactions to treatment). Furthermore, patients report a need for information about physical (i.e. self-care) and psychological (i.e. emotional and psychological wellbeing) topics. Also information about the healthcare system (i.e. transportation to the cancer center, and where to find money to pay medical bills) is needed. The needs are the highest for treatment, and the lowest for physical and psychological topics, and the healthcare system. Factors associated with information needs are ethnic background and education. African-American patients and less educated patients had significantly higher information needs than White patients and higher educated patients, respectively. | 3 |

Table 1 (Continued)

| # | Authors, Year & Country | Design & Method | Sample & Setting | Main findings | Methodological quality |
|----|--|---|---|--|------------------------|
| 27 | McInnes et al. (2008) [65] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Survivor | <i>Setting:</i> Massachusetts Cancer Registry <i>Sample:</i> - 778 survivors - Female: 52.7% - Various cancers - Age range: 18 – >75 - Ethnicity: o Latin-American o African-American | <i>Topic:</i> Information needs <i>Results:</i> Almost half of the survivors need information about long-term side effects of cancer. A younger age at diagnosis is associated with higher information needs. Women who are diagnosed longer ago report a lower need for information than women who are diagnosed more recently. | 3 |
| 28 | Mitchison et al. (2012) [28] Australia | <i>Study design:</i> Qualitative <i>Method:</i> Structured interviews <i>Focus phase of disease:</i> Metastasis | <i>Setting:</i> Oncology clinic <i>Sample:</i> - 73 patients - Female: 64% - Various cancers - Age range: 31 – >60 ($M = 35.5$; $SD = 19.8$) ($M = 35.5$; $SD = 19.8$) - Ethnicity: o Asian: Chinese o Middle-Eastern: Saudi-Arabian | <i>Topic:</i> Information preferences <i>Results:</i> Patients report a preference for full disclosure of their prognosis. They believe this will help them in better planning and preparing for the future. The minority that did not want to know about their prognosis mentioned that they found prognostic statistics inaccurate and unnecessary. Furthermore, knowing bad prognosis would be too stressful for some patients. | 2 |
| 29 | Muthu Kumar et al. (2004) [47] UK | <i>Study design:</i> Qualitative <i>Method:</i> Interviews <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> Oncology Department of a National Health Service hospital <i>Sample:</i> - 82 patients - Female: 57.3% - Various cancers - Age range: 18–77 years - Level of acculturation: mean acculturation score = 12.36 ($SD = 0.96$; range = 8–35) - Ethnicity: o Asian: Indian Pakistani, Bangladeshi | <i>Topic:</i> Information preferences <i>Results:</i> Patients prefer as much information as possible about their diagnosis, prognosis, and treatment (including side effects). | 2 |
| 30 | Napoles-Springer et al. (2017) [52] USA | <i>Study design:</i> Qualitative <i>Method:</i> Semi-structured interviews <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> State wide population-based cancer registry <i>Sample:</i> - 34 patients - Female: 100% - Ductal Carcinoma in Situ - Age range: 40 –> 70 years - Ethnicity: o Latin-American | <i>Topics:</i> Information & Participation preferences <i>Results:</i> Patients report a high preference for information about treatment options. Regarding participation, patients' preferences depend on the communicative behaviour of the physician. If the physician communicates the reasons for a particular decision clearly, patients are satisfied with a passive role in the decision-making process. However, if it is unclear to the patient how the physician arrives at a particular decision or recommendation, patients prefer a more active (i.e. shared) involvement in the decision-making process. | 2 |
| 31 | Noguera et al. (2014) [61] USA | <i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> Control Preference Scale <i>Focus phase of disease:</i> Palliative | <i>Setting:</i> Outpatient specialist palliative care services <i>Sample:</i> - 387 patients - Female: 61% - Various cancers - Age range: 20 – 90 years - Ethnicity: o Latin-American | <i>Topics:</i> Information & Participation preferences <i>Results:</i> A vast majority prefers information about their diagnosis and prognosis. The majority prefers active participation and almost a quarter prefers shared participation. Younger and higher educated patients are more likely to prefer active participation compared to older and lower educated patients. | 3 |
| 32 | Obeidat et al. (2012) [63] USA | <i>Study design:</i> Qualitative <i>Method:</i> In-depth semi-structured interviews <i>Focus phase of disease:</i> Post-treatment | <i>Setting:</i> - <i>Sample:</i> - 10 patients - Female: 100% - Breast cancer - Age range: 42 –84 - Level of acculturation: mean for years in host country = 18.8 (range = 8 – 28) - Ethnicity: o Middle-Eastern: Saudi-Arabian | <i>Topics:</i> Information & Participation preferences <i>Results:</i> Almost all patients prefer to be informed about their diagnosis and available treatment options. Almost all patients prefer to leave the final decision to their doctor, because they believe that the doctor is the expert who has the medical knowledge to make decisions. | 2 |

Table 1 (Continued)

| # | Authors, Year & Country | Design & Method | Sample & Setting | Main findings | Methodological quality |
|----|---|--|--|---|------------------------|
| 33 | O'Callaghan et al. (2016) [48] Australia | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups <i>Focus phase of disease:</i> Survivor | <i>Setting:</i> Community locations <i>Sample:</i> - 39 survivors - Female: 76.9% - Various cancers - Age range: 30 → 61 - Ethnicity: o Asian: Chinese | <i>Topic:</i> Information preferences <i>Results:</i> Survivors prefer information about metastasis, prognosis, recurrence, ongoing effects and late effects (e.g. fatigue, memory problems), genetics, psychological counseling, Chinese and herbal medicine, prevention and diets. | 2 |
| 34 | Palmer et al. (2013) [17] USA | <i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Treatment | <i>Setting:</i> North Carolina Central Cancer Registry <i>Sample:</i> - 181 patients - Female: 0% - Prostate cancer - Age range: 40–75 years ($M = 61.3$; $SD = 7.0$) ($M = 61.3$; $SD = 7.0$) - Ethnicity: o African-American | <i>Topic:</i> Participation preferences <i>Results:</i> Most patients prefer an active or shared role in the treatment decision-making process. | 3 |
| 35 | Robotin et al. (2017) [49] Australia | <i>Study design:</i> Qualitative <i>Method:</i> Focus group discussions and in-depth interviews <i>Focus phase of disease:</i> - | <i>Setting:</i> Liver clinic of major teaching hospital, private consulting room of liver specialist <i>Sample:</i> - 48 patients - Female: 33.3% - Liver cancer - Median age: 64 - Level of acculturation: median for years in host country = 25 years - Ethnicity o Asian: Chinese, Vietnamese | <i>Topic:</i> Information needs <i>Results:</i> Patients report a vast need for information about the healthcare system of the host country, cancer staging, treatment, prognosis, alternative medicine, diet and nutrition. They believe that this information will help them in making sense of their diagnosis, treatment, and outcomes. | 2 |
| 36 | Royak-Schaler et al. (2008) [41] USA | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups <i>Focus phase of disease:</i> Survivor | <i>Setting:</i> Medical centers in the eastern United States <i>Sample:</i> - 39 survivors - Female: 100% - Breast cancer - Mean age: 55 - Ethnicity: o African-American | <i>Topic:</i> Information & Participation preferences <i>Results:</i> Survivors prefer information about diagnosis, treatment, side effects, cancer recurrence and prevention. They think this information will help them in developing plans for follow-up and self-care. As for participation, the vast majority prefers active or shared medical decision-making. | 2 |
| 37 | Shaw et al. (2015) [29] Australia | <i>Study design:</i> Qualitative <i>Method:</i> Focus groups and semi-structured interviews <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Community-based cancer support groups, oncology outpatient clinic <i>Sample:</i> - 73 patients - Female: 70% - Various cancers - Age range: 40 → 70 years - Level of acculturation: 45% was living for over 20 years in host country - Ethnicity: o Asian: Chinese o Middle-Eastern: Saudi-Arabian | <i>Topics:</i> Information & Participation preferences <i>Results:</i> Patients prefer to receive as much information as possible about cancer diagnosis and prognosis. Patients report a preference for shared or active participation. Patients perceive low English language proficiency and cultural factors as barriers to active participation in the decision-making process. | 3 |
| 38 | Tam Ashing et al. (2003) [54] USA | <i>Study design:</i> Qualitative <i>Method:</i> Semi-structured key informant and focus group interviews <i>Focus phase of disease:</i> Multiple stages | <i>Setting:</i> Existing cancer support groups, hospitals, and community health clinics <i>Sample:</i> - 34 survivors - Female (100%) - Breast cancer - Age range: 31–81 years - Ethnicity: o Asian: Korean, Chinese (Cantonese), 'mixed' (i.e. Thai, Chinese (multilingual), Japanese, Filipinos) | <i>Topic:</i> Information & Participation preferences <i>Results:</i> Survivors prefer information about treatment. Although some groups (i.e. 'mixed' group) prefer active participation, and other groups prefer passive participation (i.e. Korean and Chinese), no groups prefer shared participation. | 3 |
| 39 | Walker et al. (2016) [71] USA | <i>Study design:</i> Qualitative <i>Method:</i> Semi-structured interviews and focus groups | <i>Setting:</i> Academic medical center, municipal hospital <i>Sample:</i> - 12 patients - Female: 0% - Prostate cancer | <i>Topic:</i> Participation preferences <i>Results:</i> Patients report a preference for active participation in the decision-making process. | 2 |

performed in the same four databases, without predefined search strings. Furthermore, manual searches were performed by going through the reference lists of articles (snowball method), and through citation tracking in Google Scholar. A bibliographic management software program, EndNote, was used to keep track of the selected literature and to remove duplicates.

2.2. Inclusion and exclusion criteria

Studies were included if they focused on either information preferences and needs, referring to all information patients would like to receive regarding their illness [33], and/or participation preferences and needs, referring to the patient's preferred level of involvement in the medical decision-making process [34]. The study population of all studies had to be non-Western (i.e. African, Asian, Indian-American, Middle- Eastern, and Latin-American) ethnic minority cancer patients and/or survivors (from here 'patients'), living in Western countries (i.e. countries in Europe, Australia, and North America). Patients' ethnic backgrounds varied widely and can be found in Table 1. Both qualitative and quantitative empirical studies were included in the review, as well as comparative studies, which compared information and/or participation preferences and needs of Western and non-Western cancer patients.

In order to retrieve as much eligible publications as possible, no restrictions regarding age of study population, methodology, or publication year were applied. However, the search was limited to publications in English. Studies were excluded if they: (a) did not concern an original research or were not peer-reviewed (i.e. grey literature), (b) did not focus on information and/or participation

preferences and needs of cancer patients (e.g. focused on information-seeking behaviour), (c) were conducted in non-Western countries or only among Western ethnic minority cancer patients, or (d) focussed only on the preferences of others than the patient (e.g. relatives or oncologists).

2.3. Data selection

Based on the search strategy a total of 714 studies were identified. Subsequently, 11 full-text articles gathered through manual searches were included, resulting in 725 titles. After removal of duplicates, 674 abstracts remained. All abstracts were assessed by the first and second author. Based on the inclusion and exclusion criteria 544 studies were excluded, resulting in 130 studies selected for full-text reading. These 130 full-text articles were independently reviewed by the first and second author. Disagreements about inclusion of articles were resolved through discussion. The full-text reading phase resulted in 44 studies being eligible for inclusion in the current review (see Fig. 1 for the flow diagram).

2.4. Data extraction, analysis and synthesis

The methodological quality of studies included in the review was independently assessed by the first two authors by using the instrument developed by Hawker, Payne, Kerr, Hardey and Powell (2002) [35] that is suitable for assessing the methodological quality of both qualitative and quantitative studies. It consists of nine items: abstract, background, method, sampling,

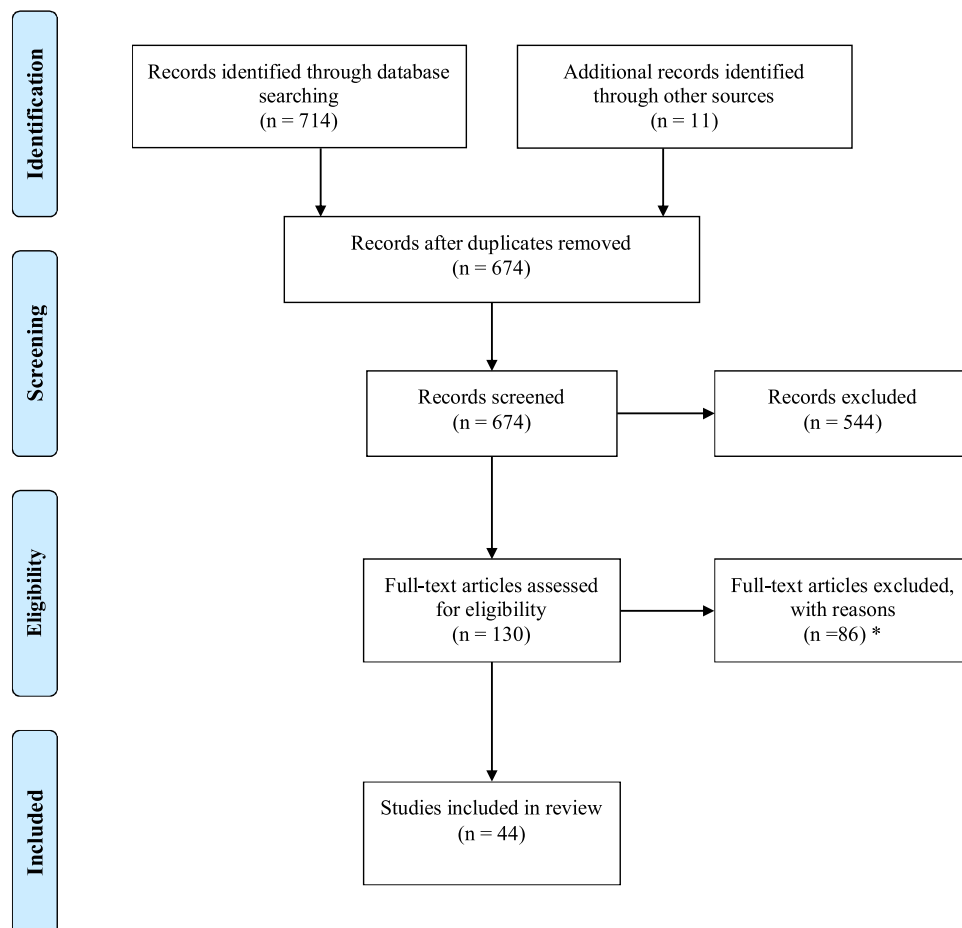


Fig. 1. Flow diagram.

data analysis, ethics, results, transferability and implications. All items are scored on a 4-point Likert scale, with scores ranging from '1 = very poor' to '4 = good'. Total scores could thus range from 9 to 36, with 9 to 18 points considered as 'poor methodological quality' (score 1), 19 to 27 points considered as 'moderate methodological quality' (score 2), and 28 to 36 points considered as 'good quality' (score 3). For three studies, the two coders differed in their assessment. Disagreement about these assessments were discussed and mutual agreement was achieved on the final scores.

Data synthesis was performed by the first author and results were frequently discussed by the research team to ensure validity of the findings. Thematic analysis was used to synthesize the data, as this approach allows for identification of important themes and synthesis of qualitative and quantitative studies [36]. In this review, the two main themes, i.e. (1) information preferences and needs and (2) participation preferences and needs, were determined a priori. Based on the results, specific subthemes within each main theme were identified (see Results for the specific subthemes). Results concerning information preferences and needs are reported per ethnic minority group (p. 9–12). Results concerning participation preferences and needs are reported per decision-making style (p. 12–14). Data concerning the author and year, research design, participants, country and setting, and the (main) results were extracted from the studies included (see Table 1). The PRISMA Statement was used to report this review (see Appendix B).

3. Results

3.1. Sample characteristics

The included studies were conducted in the United States (n=33), Australia (n=9), Belgium (n=1), and United Kingdom (n=1). In 18 studies the sample consisted of patients from several ethnic backgrounds (e.g. Asian and Middle-Eastern, or Latin-American and African-American). In the other studies, the sample consisted of patients from one ethnic background: Asians (n=11), Latin-Americans/Hispanics (n=6), Africans (i.e. African-American and African-European) (n=7), Middle-Easterners (n=1), and Indian-Americans (n=1). Twenty-five studies contained a qualitative design: interviews (n=10), focus groups (n=8), or a combination of both (n=7). Nineteen studies contained a quantitative design (i.e. survey). Methodologically, no studies were appraised as having 'poor quality', 19 were appraised as having 'moderate quality', and 25 were appraised as having 'good quality'. Twenty-four studies investigated information preferences and needs, 12 studies investigated participation preferences and needs, and eight studies investigated both. Table 1 shows the characteristics of included studies.

3.2. Information preferences and needs

Six different topics regarding information preferences and needs among non-Western ethnic minority patients/survivors emerged, namely: (1) diagnosis and metastasis, (2) treatment and its aftermath, (3) prognosis and cancer recurrence, (4) alternative medicine, nutrition, and physical activity, (5) causes, genetics and prevention, and (6) healthcare system and services. Below, we summarize the results on these six different information needs and preferences per ethnic minority group (see Table 2 for an overview of the results).

3.2.1. African ethnic minority patients and survivors

Ten studies reported about the information preferences and needs of African ethnic minority patients/survivors [1,37–45].

African-American [37–45] and African-European [1] patients/survivors had high information preferences on all six topics. African-American patients often reported to prefer detailed information about their diagnosis and metastasis [37–41]. Besides, African-American patients preferred to be informed about the treatment and its aftermath [39,42]. In a comparative study, African-Americans had a significantly higher preference for information about cancer treatment (i.e. treatment options, and advantages and disadvantages) than White patients [39]. Furthermore, African-American patients preferred to be informed about prognosis and recurrence [38,41,42,44], alternative medicine, nutrition, and physical activity [43], and causes [44] and prevention of cancer [38,41]. Lastly, African-European [1] and African-American patient [45] wanted to receive information about the healthcare system and services.

3.2.2. Asian ethnic minority patients and survivors

Eighteen studies reported about the information preferences and needs of Asian ethnic minority patients/survivors [1,28,29,38,42,44,46–57]. Asian-European [1,47], Asian-Australian [28,29,46,48,49,51,57], and Asian-American [38,42,44,50,52–56] patients/survivors reported to have high information preferences on all topics. The majority of Asian-European [47], Asian-Australian [29,46,48,49], and Asian-American [38,50] patients preferred as much information as possible about diagnosis and metastasis. Besides, Asian-European [47], Asian-Australian [48,49,51], and Asian-American [38,42,46,50,52–56] patients, except Filipino patients [47], reported to prefer detailed information about treatment and its aftermath. In addition, in all studies except one [46] Asian-Australian [28,29,48,49,57] and Asian-American [44,50,55] patients indicated a need for information about prognosis and cancer recurrence. Moreover, information about alternative medicine, nutrition, and physical activity was highly preferred among Asian-Australian [48,49,51] and Asian-American [50,53,56] patients. Asian-Australian [48] and Asian-American [44,53,55] patients further preferred information about the risks and symptoms of cancer [53], the causes of cancer [44], genetics of cancer (i.e. whether cancer is hereditary) [44,48], and prevention of cancer [44,48]. Finally, Asian-European [1] and Asian-Australian [49] patients preferred information about the healthcare system and services in the host country.

3.2.3. Indian-American ethnic minority patients and survivors

Two studies reported about the information preferences and needs of Indian-American [45,58] ethnic minority patients/survivors. Indian-American ethnic minority patients/survivors reported to have high information preferences and needs on three topics. A comparative study showed that Indian-American patients had a significantly higher preference for information about cancer diagnosis than White patients [58]. Besides, Indian-American patients reported to prefer information about treatment and its aftermath [58], and the healthcare system and services [45]. In no study, Indian-American ethnic minority patients/survivors reported information preferences and/or needs concerning prognosis and cancer recurrence, alternative medicine, nutrition, and physical activity, and causes, genetics and prevention.

3.2.4. Latin-American and Hispanic ethnic minority patients and survivors

Nine studies reported about the information preferences and needs of Latin-American and Hispanic ethnic minority patients/survivors [39,42–44,52,59–62]. In all studies but one [59] Latin-American [43,44,60,60,61,62] and Hispanic [42,49,52] patients/survivors had high information preferences on five topics. Latin-American and Hispanic patients/survivors preferred detailed information about their diagnosis and metastasis [39,60,61], and

Table 2
Overview of the main findings per main ethnic minority group.

| Ethnic background | Preferences and needs | Factors that are related to preferences and needs |
|--------------------|---|---|
| Asian | <p>Information preferences Asian patients and survivors have high information needs. They prefer information about:</p> <ul style="list-style-type: none"> - <i>Diagnosis and Metastasis</i> [29,38,46–50] Asian-Australian patients wanted to know their diagnosis even if it was already in a severe stage [46]. Besides Asian-Australian cancer survivors reported to prefer information about where cancer is likely to metastasize after completing treatment [48]. <p>In one study, all patients had high information needs concerning diagnosis, except Filipino patients [38].</p> <ul style="list-style-type: none"> - <i>Treatment and its Aftermath</i> [38,42,46–56] Asian-European [47], Asian-Australian [48,49,51], and Asian-American [38,42,46,50,52–56] patients, except Filipino patients [47], reported to prefer detailed information about treatment options, the odds of success of all options, and surgical recovery in order to be able to adhere to treatment and post-treatment procedures. Asian-American survivors also preferred information about coping with anxiety/depression [42]. However, this preference was the lowest among Asian-American patients compared to Hispanics and African-Americans [42]. - <i>Prognosis and Recurrence</i> [28,29,38,42,44,46–50,55,57] Asian-Australian [28,29,48,49,57] and Asian-American [44,50,55] patients reported to need information about cancer recurrence, recurrence statistics, and late effects such as fatigue among survivors. <p>In one study, the majority of Asian-Australian ethnic minority patients preferred not to be informed about their prognosis if the cancer was incurable or if treatment was not successful [46].</p> <ul style="list-style-type: none"> - <i>Alternative Medicine, Nutrition, and Physical Activity</i> [48–51,53,56] Information about (the usefulness of) Chinese and herbal medicine, and the role of nutrition and physical activity in cancer prevention, treatment, recovery, and recurrence was highly preferred among Asian-Australian [48,49,51] and Asian-American [50,53,56] patients. - <i>Genetics, Causes and Prevention</i> [44,48,53,55] Asian-Australian [48] and Asian-American [44,53,55] patients further preferred information about the risks and symptoms of cancer [53], the causes of cancer [44], genetics of cancer (i.e. whether cancer is hereditary) [44,48], and prevention of cancer [44,48]. - <i>Healthcare System and Cancer in general</i> [1,49,51,53,56,57] Asian-European patients reported not to know where or to whom they should go when they experience health problems, and would like to receive this information [1]. Asian-Australian patients also lacked information about how they could access social services such as interpreters and social workers [49]. | <p>Information preferences</p> <ul style="list-style-type: none"> - <i>Coping</i> [28,46,50] Asian-American survivors reported to believe that being informed will better prepare patients/survivors to cope with unexpected or long-lasting side effects of treatment, ultimately helping them in reducing anxiety [50]. Furthermore, Asian-Australian indicated that information will help them in making better plans (e.g. for treatment, follow-up care, and self-care) and preparing better for their future [28]. - Chinese-Australian patients with low information preferences believed that information, especially about a bad prognosis, would be too stressful for them, leading to being less able to cope with the disease and ultimately resulting in early death [46]. - <i>Demographic and socio-cultural factors</i> [37] In one study, younger Asian-American patients reported higher information needs than older patients [37]. Besides, female patients and patients who were married had higher information needs than male patients and unmarried patients [37]. - <i>Cancer-related factors (e.g. type of cancer)</i> [52,56] Asian-American patients/survivors who were diagnosed longer ago and who did not know their cancer staging reported lower information needs compared to patients who are diagnosed more recently [56]. - <i>(Perceived) quality of care and financial resources</i> [52,56] Asian-American patients who perceived the quality of care as less than excellent or who did not receive a treatment summary, were more likely to have high information needs [52]. Furthermore, if Asian-American patients had no health insurance, they were less likely to prefer information about treatment and its related costs [56]. <p>Participation preferences</p> <ul style="list-style-type: none"> - <i>Beliefs concerning doctor-patient relationship</i> [29,74] Asian-Australian patients perceived the doctor as the expert who is best placed to decide on the treatment [29,74]. They also perceived their own understanding about cancer treatment inferior to the doctors' knowledge [29,74]. Because of this perceived hierarchical relationship, these patients/survivors preferred passive participation [74]. In contrast, patients who preferred shared participation perceived their own opinions as equal to the doctors' opinions [29]. - <i>Doctor's communicative behaviour</i> [29,74] Asian-Australian patients reported that their doctor did not seek their opinion and provided them with less information than they preferred [29], and that alternative treatment options were not available [74]. These patients often reported to think there was no decision to make at all, and preferred passive participation in medical decision-making. - <i>Family support</i> [38,70] Asian-American patients reported that they wish to compare treatment options together with their family members, and often described decisions as 'our' decisions [70]. Asian-American patients with a preference for shared participation reported that this preference is influenced by the belief that their family will better understand the disease and its impact on the patient if they are involved in the decision-making process [38]. - <i>Demographic and socio-cultural factors</i> [46,54,72] Asian-Australian [46] and Asian-American [72] patients with a lower level of acculturation [72] or education [46] preferred passive participation. Asian-Australian [46] patients with a higher level of education preferred active or shared participation in the decision-making process [46]. Chinese-Australian [46] and Asian-American [54] patients with a higher level of education reported to prefer active decision-making, because they perceived the treatment recommended by the physician as 'experimental and risky'. They believed that their life was at stake, and hence wanted to make treatment-related decision themselves [46]. Only if it was clear in what way the outcomes of different treatment options differed, Chinese patients – irrespective of their level of education – indicated to prefer shared participation [46]. |
| Latin-American and | <p>Information preferences Latin-American and Hispanic patients and survivors have high information needs. They prefer information about:</p> <ul style="list-style-type: none"> - <i>Diagnosis and Metastasis</i> [39,59–61] In one study, Latin-American ethnic minority patients show low information preferences regarding diagnosis and treatment [59]. Only 15 percent of these patients reported to | <p>Information preferences</p> <ul style="list-style-type: none"> - <i>Coping</i> [39,60] Latin-American and Hispanic patients reported that information will help them in making better plans (e.g. for treatment, follow-up care, and self-care) and preparing better for their future [39,60]. - <i>Demographic and socio-cultural factors</i> [43,52,59,60,65] |
| Hispanic | | |

Table 2 (Continued)

| Ethnic background | Preferences and needs | Factors that are related to preferences and needs |
|-------------------|---|--|
| | <p>prefer additional information about their diagnosis, even though they were not informed about their cancer stage or metastatic stage of the tumour [59].</p> <ul style="list-style-type: none"> - <i>Treatment and its Aftermath</i> [39,42,43,52,60–62] Latin-American breast cancer survivors wanted to be informed about available breast reconstruction options, coping with a new body image and new clothing needs, and finding breast prostheses [61]. Survivors also reported a need for information about the relationship with their partner and sexual functioning after completing cancer treatment [62]. - <i>Prognosis and Recurrence</i> [42,44,61] Latin-American patients preferred information about cancer remission, cancer recurrence, the possible effects of cancer on the length of one's life, and what to do to get better [42,44,61]. - <i>Alternative Medicine, Nutrition, and Physical Activity</i> [43] Latin-American patients preferred to be informed about the role of nutrition and physical activity in cancer prevention, treatment, recovery, and recurrence [43]. - <i>Genetics, Causes and Prevention</i> [44] Latin-American patients reported to be interested in the causes of cancer, genetics of cancer (i.e. whether cancer is hereditary), and prevention of cancer [4]. - <i>Healthcare System and Cancer in general</i> [65] <p>Participation preferences</p> <p>In one study, the majority of Latin-American [61] patients preferred active participation solely. In two studies, shared and active participation were preferred at almost equal levels by Latin-American [66,67] patients. In one study, Latin-American patients only preferred shared participation if they could involve either their doctor or their informal caregivers in the decision-making process. When they were asked to involve both the doctor and informal caregivers, the majority of patients preferred to make all decisions themselves [69]. In only two studies, Latin-American [72,76] patients reported to prefer passive participation.</p> | <p>Low English language proficiency and being monolingual in Spanish were reported by Latin-American and Hispanic to be reasons for low information preferences [59,60]. Besides, in one study, Latin-American patients with a higher level of education or lower level of acculturation reported higher information needs than patients with a lower level of education or higher level of acculturation [43]. Furthermore, younger patients reported higher information needs than older patients [52,65].</p> <ul style="list-style-type: none"> - <i>Cancer-related factors (e.g. type of cancer)</i> [52,65] Latin-American and Hispanic survivors who were diagnosed with colorectal cancer had lower information needs compared to patients who were diagnosed with other types of cancer [52,65]. - <i>(Perceived) quality of care</i> [52] When Hispanic patients perceived their quality of care as less than excellent or if they did not receive a treatment summary, they were more likely to have high information needs [52]. <p>Participation preferences</p> <ul style="list-style-type: none"> - <i>Doctor's communicative behaviour</i> [62,76] Latin-American patients reported that they were not provided a choice between treatment options [76]. These patients often reported to think there was no decision to make at all, and preferred passive participation in medical decision-making. Furthermore, Latin-American patients' participation preferences depended on how clear the physician explained the treatment options [62]. If it was unclear how the physician arrived at a suggested treatment option or when patients remained ambivalent as to whether other possible treatments might have existed, they preferred a more shared involvement in the decision-making process [62]. - <i>Demographic and socio-cultural factors</i> [61,72] Younger Latin-American patients were more likely to prefer active or shared participation in the decision-making process compared to older patients [61]. Besides, Latin-American patients with a lower level of acculturation preferred passive participation [72]. Latin-American [61] patients with a higher level of education preferred active or shared participation in the decision-making process [61]. |
| African-American | <p>Information preferences</p> <p>African-American patients and survivors have high information needs. They prefer information about:</p> <ul style="list-style-type: none"> - <i>Diagnosis and Metastasis</i> [37–41] - <i>Treatment and its Aftermath</i> [37–43,52] African-Americans preferred to receive information about coping with anxiety/depression, the relationship with their partner and sexual functioning after completing cancer treatment [42]. - <i>Prognosis and Recurrence</i> [37,38,40–42,44] African-American patients wanted to be informed about cancer remission and recurrence, the possible effects of cancer on the length of one's life, and what to do to get better [38,41,42,44]. <p>In one study, African-American patients showed low information preferences regarding the chances of getting worse [37].</p> <ul style="list-style-type: none"> - <i>Alternative Medicine, Nutrition, and Physical Activity</i> [43] African-American patients preferred information about the role of nutrition and physical activity in cancer prevention, treatment, recovery, and recurrence [43]. - <i>Genetics, Causes and Prevention</i> [38,41,44] African-American patients had high information preferences regarding the causes of cancer [44] and prevention of cancer [38,41]. - <i>Healthcare System and Cancer in general</i> [1,37,40,45,65] <p>African-European patients preferred to be informed about the healthcare system [1], where they could find financial support to pay their medical bills (i.e. health insurance), and out-of-pocket costs of treatment [45].</p> | <p>Information preferences</p> <ul style="list-style-type: none"> - <i>Coping</i> [39,41] African-American patients reported that information will help them in making better plans (e.g. for treatment, follow-up care, and self-care) and preparing better for their future [39,41]. - <i>Demographic and socio-cultural factors</i> [37,40,52,65] In one study, younger patients, female patients and patients who were married had higher information needs than older patients, male patients and unmarried patients, respectively [37]. Furthermore, African-American patients with a lower level of education had higher information needs compared to higher educated patients [37,40]. African-American survivors who were diagnosed with colorectal cancer had lower information needs compared to patients who were diagnosed with other types of cancer [52,65]. - <i>(Perceived) quality of care and financial resources</i> [45] If African-American patients had no health insurance or if they had difficulties affording the high out-of-pocket costs for prescribed medication, they were less likely to prefer information about treatment and its related costs [45]. <p>Participation preferences</p> <ul style="list-style-type: none"> - <i>Beliefs concerning doctor-patient relationship</i> [68,75] In one study, African-American patients preferred passive participation because of the perceived patriarchal doctor-patient relationship [75]. In contrast, African-American patients who perceived the physician as responsible for explaining available options and the patient for making the decision [68]. Patients who preferred shared participation, perceived this as a way to enhance their sense of control over treatment choices [68]. - <i>Doctor's communicative behaviour</i> [76] In one study, African-American patients reported that they were not provided a choice between treatment options [76]. Hence, they reported to think there was no decision to make at all, and preferred passive participation in medical decision-making. - <i>Family support</i> [38] |

Participation preferences

In most studies, African-American patients and survivors prefer shared [17,38,41,66,68] or active participation [66,71]. In only a few studies, African-Americans report a preference for passive participation [72,75,76].

In one study, the majority of African-American [71] patients preferred active participation solely. In three studies, shared and active participation were preferred at almost equal levels by African-American patients [17,41,66]. Furthermore, in two studies African-American patients reported that they preferred shared participation with either their informal caregivers [38] or their physician [68]. In two studies, African-American [72,75] patients reported to prefer passive participation.

African-American patients with a preference for shared participation reported that this preference is influenced by the belief that their family will better understand the disease and its impact on the patient if they are involved in the decision-making process [38].

- *Demographic and socio-cultural factors* [72]

African-American patients with a lower level of acculturation preferred passive participation [72].

Middle-Eastern**Information preferences**

Middle-Eastern patients and survivors have high information needs. They prefer information about:

- *Diagnosis and Metastasis* [29,63]
- *Treatment and its Aftermath* [51,63]
- *Prognosis and Recurrence* [28,29]
- *Alternative Medicine, Nutrition, and Physical Activity* [51]
- *Healthcare System and Cancer in general* [1,51]

Middle-Eastern European patients preferred information concerning whom they should address when they experience health problems [1]

In one study, Middle-Eastern ethnic minority patients show lower information needs than Latin-American patients [64]. However, what type of information is not specified.

Participation preferences

In most studies, Middle-Eastern American [63] and Middle-Eastern Australian [73,74] patients and survivors preferred passive participation. In one study, Middle-Eastern Australian patients reported a preference for shared or active participation [29].

Information preferences

- *Coping* [28]

Middle-Eastern Australian patients indicated that information will help them in making better plans (e.g. for treatment, follow-up care, and self-care) and preparing better for their future [28].

Participation preferences

- *Beliefs concerning doctor-patient relationship* [29,63,74]

Middle-Eastern Australian [29,74] and Middle-Eastern American [63] patients perceived the doctor as the expert who is best placed to decide on the treatment. They also perceived their own understanding about cancer treatment inferior to the doctors' knowledge [29,63,74]. Because of this perceived hierarchical relationship, these patients/survivors preferred passive participation [63,74]. In contrast, patients who preferred shared participation perceived their own opinions as equal to the doctors' opinions [29].

- *Doctor's communicative behaviour* [29,74]

Middle-Eastern patients reported that their doctor did not seek their opinion and provided them with less information than they preferred [29], and that alternative treatment options were not available [74]. These patients often reported to think there was no decision to make at all, and preferred passive participation in medical decision-making.

Indian-American**Information preferences**

Indian-American patients and survivors have high information needs. They prefer information about:

- *Diagnosis and Metastasis* [58]
 - *Treatment and its Aftermath* [58]
- Indian-American patients wanted to be informed about available treatment options [58]. They also wanted to be informed about risks and symptoms of cancer [58].
- *Healthcare System and Cancer in general* [45]

Indian-American patients preferred information about health insurance [45], and out-of-pocket costs of treatment [45].

Participation preferences

-

Information preferences

- *Coping* [58]

- *(Perceived) quality of care and financial resources* [45]

If Indian-American patients had no health insurance or if they had difficulties affording the high out-of-pocket costs for prescribed medication, they were less likely to prefer information about treatment and its related costs [45].

Participation preferences

-

about the aftermath of cancer treatment [52,61,62]. Besides, patients preferred to know about prognosis and cancer recurrence [42,44,61]. Eventually, Latin-American patients indicated that they would like to be informed about alternative medicine, nutrition, and physical activity [43], and about the causes, genetics and prevention of cancer [44]. In no study, Latin-American and/or Hispanic ethnic minority patients/survivors reported information preferences and/or needs concerning the healthcare system and services.

3.2.5. Middle-Eastern ethnic minority patients and survivors

Six studies reported about the information preferences and needs of Middle-Eastern ethnic minority patients/survivors [1,28,29,51,63,64]. Middle-Eastern American [63], Middle-Eastern Australian [28,29,51], and Middle-Eastern European [1] patients/survivors showed high information preferences on five

topics. In one study, Middle-Eastern ethnic minority patients had significantly lower information needs than Latin-American patient. However, the specific information needs were not reported [64]. The majority of Middle-Eastern Australian [29] and Middle-Eastern American [63] patients preferred to be informed about their diagnosis and the metastatic stage of the cancer. Furthermore, Middle-Eastern American [63] and Middle-Eastern Australian [51] patients wanted detailed information about treatment options and their side effects. Middle-Eastern Australian patients preferred as much information as possible about their prognosis [29], and about alternative medicine, nutrition, and physical activity [51]. Finally, Middle-Eastern European patients wanted to be informed about the healthcare system and services [1]. In no study, Middle-Eastern ethnic minority patients/survivors reported information preferences and/or needs concerning causes, genetics and prevention.

3.3. Factors related to information preferences and needs

Apart from ethnic background [37,40,43,52], several factors were associated with ethnic minority patients' information preferences and needs. Firstly, ethnic minority patients/survivors with high information preferences and needs believed that information enables them to cope with their diagnosis, treatment, and treatment outcomes [39,49,50,60], and to keep balance in their lives [58]. Secondly, several demographic (e.g. younger age and female gender) and sociocultural factors (e.g. higher level of language proficiency and lower level of acculturation) [37,40,43,52,59,60,65], and cancer-related factors (e.g. being diagnosed more recently and being diagnosed with colorectal cancer) were positively related to patients' information preferences and needs [37,52,56,65]. Finally, patients who perceived the quality of care as excellent [52], and patients who had limited financial resources to afford healthcare, had low information preferences [45,56].

3.4. Participation preferences and needs

The participation preferences and needs found in the literature could be divided into the preference or need for (1) passive participation, (2) shared participation, and (3) active participation. A preference for shared participation, in turn, could be divided into the preference for SDM with the doctor [17,29,41,61,66–69] and a preference for SDM with family members [38,69,70].

The majority of Latin-American [61,66,67,69] and African-American [17,38,41,66,68,71] patients preferred shared or active participation at almost equal levels. In contrast, the majority of Asian [29,46,72–74] and Middle-Eastern [63,73,74] ethnic minority patients reported to prefer passive participation in the decision-making process. Only a few studies showed that Asian [38,70] and Middle-Eastern [29] ethnic minority cancer patients preferred shared or active participation.

Three studies showed differences in participation preferences within ethnic minority groups [46,54,62]. In one study, higher educated Chinese patients reported more preference for active participation, while lower educated Chinese patients preferred passive participation [46]. In another study, Korean and monolingual Chinese ethnic minority cancer survivors preferred passive participation, while Thai, multilingual Chinese, Japanese, and Filipino survivors reported to prefer an active role in decision-making [54]. Finally, in one study, some Latin-American cancer patients preferred passive participation, while others preferred active participation [62].

3.5. Factors related to participation preferences and needs

Apart from ethnic background, several factors seemed to be associated with the participation preferences and needs of ethnic minority patients. Firstly, patients' perceptions about doctor-patient relationships [29,54,63,68,74,75], and physician's (communicative) behaviour influenced patients' participation self-reported preferences [29,62,74,76]. Patients who had a paternalistic view on the doctor-patient relationship, and patients who were not offered a choice by their physician, preferred passive participation. Furthermore, patients who preferred shared participation with their family members seemed to perceive family involvement in the decision-making process as a form of (social) support [38,70]. Finally, some demographic (e.g. younger age) and sociocultural (e.g. higher level of education) characteristics of patients seemed to be related to patients' preferences for active or shared participation [46,54,61,72].

Table 2 shows an overview of the information and participation preferences and needs, and associated factors per main ethnic minority group.

4. Discussion and conclusion

4.1. Discussion

The results of this review show that non-Western ethnic minority cancer patients in general have high information preferences and needs for wide-ranging cancer-related information, from diagnosis to treatment, and from prevention to the healthcare system. As for their participation preferences and needs, a high number of studies reported that ethnic minority cancer patients prefer or need shared or active participation in medical decision-making. Especially Latin-American and African-American patients often report to prefer shared or active participation, while Asian and Middle-Eastern patients/survivors tend to prefer passive participation more often. The results suggest not only differences in preferences and needs between non-Western ethnic minority groups, but also within non-Western ethnic minority groups differences.

An interesting finding is that the concept of superdiversity is supported. The factors that influence ethnic minority patients' information preferences and needs, and participation preferences and needs confirm that the Western healthcare cannot be divided into care for Western patients vs care for non-Western ethnic minority patients. Among the group of non-Western patients, differences in preferences and needs exist between several ethnic minority groups. For example, Latin-American and African-American ethnic minority patients mainly prefer active or shared participation, while Asian and Middle-Eastern ethnic minority patients mainly prefer passive participation. Among the group of non-Western patients, differences in preferences and needs also exist within several ethnic minority groups. For instance, higher educated Chinese patients reported more preference for active participation, while lower educated patients preferred passive participation. Hence, tailoring doctor-patient communication to the preferences and needs of a specific non-Western ethnic minority group is insufficient to provide good quality health care; communication should be tailored to the preferences and needs of individual non-Western ethnic minority patients.

The high preferences for active or shared participation among Latin-American and African-American patients can possibly be explained by their level of acculturation. That is, most have been inhabitants of the United States for relatively long periods of time, and might have become adapted to the American culture. Moreover, African-American and more acculturated Latin-American patients might face relatively few linguistic barriers with their healthcare providers. The high preferences for passive participation among Asian and Middle-Eastern patients, on the other hand, is most probably related to their low level of English language proficiency, high family involvement in their care, and a paternalistic view of the doctor-patient relation. One of the major barriers for non-Western ethnic minority cancer patients in accessing information about the healthcare system or in reaching the level of preferred participation is the language barrier [1]. Furthermore, in the traditional Asian culture family-centred care is central [46,77]. In family-centred care, the spouse or close family fulfil the role of (informal) interpreter and decision-maker, while patients themselves remain less autonomous [28,30,78,79]. Combined with the hierarchical perceptions of the doctor-patient relation, in which physicians are perceived as authoritative actors [80], this might partly explain the preference for passive participation among Asian ethnic minority cancer patients. In addition to patient-related factors, doctors' communicative behaviour that leads to the perception that there is no choice regarding treatment to be made also contributes to a diminished need to participate among non-Western ethnic minority cancer patients.

4.1.1. Study limitations and future research

A limitation of this review is that the majority of studies had a qualitative design. Many factors were derived (e.g. language proficiency and perceived doctor–patient relationship) that seemed to be related to specific preferences. However, due to the study design it was not possible to make any inferences regarding causal relationships between these factors and patients' preferences. It is recommended that future studies focus more on quantitative study designs in order to be able to study such relationships. Moreover, level of acculturation, which is an important factor in studies among ethnic minority populations, was lacking in many studies. It is recommended that future studies take this factor better into account and report on it more accurately.

Secondly, not all studies focussed on the same phase of the disease or used the same methodology or timing to assess patients' information and participation preferences. It is known that cancer patients have changing preferences and needs over time, and cancer stage is a potential factor explaining changing preferences and needs [81]. Furthermore, it can be expected that when preferences are measured retrospectively, the results might be different than when preferences are measured just before or after the medical encounter (e.g. recall bias). As a consequence, the results of different studies were not (always) comparable, which might partly explain the differences in information/participation preferences within and between ethnic minority groups. It is recommended that future studies report accurately when and how information and participation preferences and needs were measured. Also, a longitudinal study design would provide more insight into changes in patients' preferences and needs over time.

Besides, studies often did not report on how they operationalised the concepts 'preferences' and 'needs'. These concepts are often used interchangeably in previous research. Therefore, it was not possible to disentangle between 'needs' and 'preferences' in our reporting. As Kiesler and Auerbach (2006) previously described in their review, various terms and methodologies are used to describe or measure comparable concepts [82]. Hence, there is a need for more clarity concerning the terms and methodologies that are used to measure and report on needs and preferences.

In addition, the studies included did not distinguish between generations of ethnic minority patients, nor did they compare the preferences and needs between ethnic minority patients and ethnic majority patients. Hence, it was not possible to report results separately for different generations in the current review, or to extensively compare the preferences and needs between ethnic minority patients and ethnic majority patients. In many studies, the level of acculturation of the patients was also not assessed. As the second and third generation are more acculturated to the Western culture, it can be assumed that their information and participation preferences and needs are more similar to those of Western patients compared to the first generation ethnic minorities [83]. For example, in contrast to many studies, only one study [46] reported low information preferences regarding prognosis and recurrence among Asian ethnic minority cancer patients. A possible explanation for the difference is that studies reporting high information preferences are conducted more recently (2012–2017). During the time span between the studies, Asian ethnic minority cancer patients might have become more acculturated, leading to higher information preferences among these patients. This also implies that with the recent global international migration flows, acculturation will remain an important factor that influences patient preferences. In future studies, it is recommended that more detailed information is given about the specific sample, including generation and level of acculturation, to be able to gain more insight into reasons for variations within and between ethnic minority groups. It is also recommended that more

comparative studies are conducted, in order to gain more insight into the similarities and differences between ethnic minority and majority cancer patients.

4.2. Conclusion

Non-Western ethnic minority patients exhibit a number of culture-specific factors influencing their information and participation preferences, such as perceptions regarding doctor–patient relationship. However, even within specific ethnic minority groups, patients' preferences might differ. Hence, we should be careful to generalize research results to ethnic minorities in general. It is important that preferences and needs are elaborated upon by healthcare providers in order to tailor information-provision to individual ethnic minority patients and adequately involve patients – and/or their family – in the decision-making process. More (quantitative) research is required in order to gain deeper insight into the (antecedents of) information and participation preferences and needs of individual non-Western ethnic minority cancer patients.

4.3. Practice implications

In order to improve oncological care for non-Western ethnic minority cancer patients, it is crucial that doctors bear in mind that information and participation preferences and needs differ between and within ethnic minority groups. Based on the results, it can be recommended to doctors to inquire about the preferences and needs of patients. In order to enable doctors to make optimal communicators, it is crucial that doctors are taught adequate communicative skills needed during intercultural encounters. On the other hand, it is important that patients become more active in seeking information and getting involved in the decision-making process. Interventions can be implemented to empower patients in SDM. Altogether, these integral actions can contribute to better health outcomes and a higher quality of oncological care for non-Western ethnic minority patients [8,12].

Conflict of interest

The authors declare no conflict of interest.

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Appendix A. Overview of search strings per database

| Database | Search strings |
|--------------------------|--|
| PsycINFO; March 12, 2018 | ((ethnic adj3 group*).ab,id,ti. OR (ethnic adj3 minorit*).ab, id,ti. OR expat*.ab,id,ti. OR expatriates/ OR immigra*.ab, id, ti. OR immigration/ OR migra*.ab,id,ti. OR "racial and ethnic groups"/ OR (racial adj3 group*).ab,id,ti. OR (racial adj3 minorit*).ab,id,ti. OR refugee*.ab,id,ti. OR refugees/) AND (cancer*.ab,id,ti. OR neoplasm*.ab,id,ti. OR Neoplasms/ OR tumor*.ab,id,ti.) AND (communication/ OR (communication adj3 need*).ab,id,ti. OR (communication adj3 preference*).ab,id,ti. OR decision making/ OR decision making.ab,id,ti. OR (information adj3 need*).ab,id,ti. OR (information adj3 preference*).ab,id,ti. OR information seeking/ OR (knowledge adj3 disease*).ab,id,ti. OR (knowledge adj3 health).ab,id,ti. OR needs/ OR (participation adj3 need*.ab,id,ti.) OR (participation adj3 preference*).ab,id,ti. OR preferences/) |

(Continued)

| Database | Search strings |
|------------------------|---|
| PubMed; March 12, 2018 | ("emigrants"[Title/Abstract] OR "emigrants and immigrants"[MeSH Terms] OR "ethnic groups"[MeSH Terms] OR "ethnic group"[Title/Abstract] OR "ethnic groups"[Title/Abstract] OR "expat"[Title/Abstract] OR "expats"[Title/Abstract] OR "expatriates"[Title/Abstract] OR "immigrants"[Title/Abstract] OR "migrants"[Title/Abstract] OR "racial group"[Title/Abstract] OR "racial groups"[Title/Abstract] OR "refugees"[MeSH Terms] OR "refugees"[Title/Abstract] OR "transients and migrants"[MeSH Terms] OR "transients"[Title/Abstract] AND ("neoplasms"[MeSH Terms] OR "neoplasms"[Title/Abstract] OR "cancer"[Title/Abstract] OR "neoplasm"[Title/Abstract] OR "tumor"[Title/Abstract]) AND ("communication preferences"[Title/Abstract] OR "communication needs"[Title/Abstract] OR "decision making"[Title/Abstract] OR "information preferences"[Title/Abstract] OR "information needs"[Title/Abstract] OR "participation preferences"[Title/Abstract] OR "participation needs"[Title/Abstract]) |
| CINAHL; March 12, 2018 | ((MH "emigration and immigration") OR (MH "ethnic groups") OR (MH "immigrants") OR (MH "minority groups") OR (MH "refugees") OR (MH "transient and migrants") OR TI("ethnic group" OR "ethnic minorit*" OR "immigra*" OR "expat*" OR "migra*" OR "racial group*" OR "racial minorit*" OR "transient*" OR AB("ethnic group" OR "ethnic minorit*" OR "immigra*" OR "expat*" OR "migra*" OR "racial group*" OR "racial minorit*" OR "transient*")) AND ((MH "neoplasms") OR TI("cancer*" OR "neoplasm*" OR "tumor*")) OR AB("cancer*" OR "neoplasm*" OR "tumor*")) AND ((MH "communication") OR (MH "decision making") OR (MH "information seeking behavior") OR (MH "health knowledge") OR TI("communication N3 need*" OR "communication N3 preference*" OR "decision making" OR "information N3 need*" OR "information N3 preference*" OR "information N3 seeking OR knowledge N3 disease*" OR "knowledge N3 health OR participation N3 need*" OR "participation N3 preference*" OR AB("communication N3 need*" OR "communication N3 preference*" OR "decision making" OR "information N3 need*" OR "information N3 preference*" OR "information N3 seeking OR knowledge N3 disease*" OR "knowledge N3 health OR participation N3 need*" OR "participation N3 preference*")) |
| EMBASE; March 12, 2018 | (ethnic group/ OR (ethnic adj3 group*).ab,ti. OR (ethnic adj3 minorit*).ab,ti. OR expat*.ab,ti. OR immigrant/ OR immigra*.ab,ti. OR migrant/ OR migra*.ab,ti. OR minority group/ OR (racial adj3 group*).ab,ti. OR (racial adj3 minorit*).ab,ti. OR refugee/ OR refugee*.ab,ti. AND (cancer*.ab,ti. OR malignant neoplasm/ OR neoplasm/ OR neoplasm*.ab,ti. OR tumor*.ab,ti. AND ((communication adj3 need*).ab,ti. OR (communication adj3 preference*).ab,ti. OR decision making/ OR decision making*.ab,ti. OR information seeking/ OR (information adj3 need*).ab,ti. OR (information adj3 preference*).ab,ti. OR interpersonal communication/ OR (knowledge adj3 disease*).ab,ti. OR (knowledge adj3 health).ab,ti. OR (participation adj3 need*).ab,ti. OR (participation adj3 preference*).ab,ti.) |

- [4] N. Mintchev, H.L. Moore, Super-diversity and the prosperous society, *EJST* 21 (1) (2018) 117–134, doi:http://dx.doi.org/10.1177/1368431016678629.
- [5] S. Vertovec, Super-diversity and its implications, *Ethn. Racial Stud.* 30 (6) (2007) 1024–1054, doi:http://dx.doi.org/10.1080/01419870701599465.
- [6] M. Reus-Pons, H. Vandenheede, F. Janssen, E.U. Kibele, Differences in mortality between groups of older migrants and older non-migrants in Belgium, 2001–09, *Eur. J. Public Health* 26 (6) (2016) 992–1000, doi:http://dx.doi.org/10.1093/eurpub/ckw076.
- [7] K.M. Mazor, R.L. Beard, G.L. Alexander, N.K. Arora, C. Firneno, B. Gaglio, S.M. Greene, C.A. Lemay, B.E. Robinson, D.W. Roblin, K. Walsh, R.L. Street Jr., T.H. Gallagher, Patients' and family members' views on patient-centered communication during cancer care, *Psycho-Oncology*. 22 (11) (2013) 2487–2495, doi:http://dx.doi.org/10.1002/pon.3317.
- [8] M. Fujimori, Y. Uchitomi, Preferences of cancer patients regarding communication of bad news: a systematic literature review, *Jpn. J. Clin. Oncol.* 39 (4) (2009) 201–216, doi:http://dx.doi.org/10.1093/jjco/hyn159.
- [9] B.C. Schouten, L. Meeuwesen, Cultural differences in medical communication: a review of the literature, *Patient Educ. Couns.* 64 (1–3) (2006) 21–34, doi:http://dx.doi.org/10.1016/j.pec.2005.11.014.
- [10] E. Paternotte, S. van Dulmen, N. van der Lee, A.J. Scherpier, F. Scheele, Factors influencing intercultural doctor–patient communication: a realist review, *Patient Educ. Couns.* 98 (4) (2015) 420–445, doi:http://dx.doi.org/10.1016/j.pec.2014.11.018.
- [11] J. Suurmond, C. Seeleman, Shared decision-making in an intercultural context: barriers in the interaction between physicians and immigrant patients, *Patient Educ. Couns.* 60 (2) (2006) 253–259, doi:http://dx.doi.org/10.1016/j.pec.2005.01.012.
- [12] F. Gany, L. Yogendran, D. Massie, J. Ramirez, T. Lee, G. Winkel, L. Diamond, J. Leng, Doctor, what do I have? Knowledge of cancer diagnosis among immigrant/migrant minorities, *J. Cancer Educ.* 28 (1) (2013) 165–170, doi:http://dx.doi.org/10.1007/s13187-012-0429-x.
- [13] K. Aelbrecht, S. de Maesschalck, S. Willems, M. Deveugele, P. Pype, How family physicians respond to unpleasant emotions of ethnic minority patients, *Patient Educ. Couns.* 100 (10) (2017) 1867–1873, doi:http://dx.doi.org/10.1016/j.pec.2017.04.001.
- [14] E.M. Ellis, A. Varner, Unpacking cancer patients' preferences for information about their care, *J. Psychosoc. Oncol.* 36 (1) (2018) 1–18, doi:http://dx.doi.org/10.1080/07347332.2017.1357666.
- [15] T.F. Hack, L.F. Degner, P.A. Parker, The communication goals and needs of cancer patients: a review, *Psycho-Oncol.* 14 (10) (2005) 831–845 discussion 846–7.
- [16] O. Husson, F. Mols, L.V. van de Poll-Franse, The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review, *Ann. Oncol.* 22 (4) (2011) 761–772, doi:http://dx.doi.org/10.1093/annonc/mdq413.
- [17] N.R. Palmer, J.A. Toozee, A.R. Turner, J. Xu, N.E. Avis, African American prostate cancer survivors' treatment decision-making and quality of life, *Patient Educ. Couns.* 90 (1) (2013) 61–68, doi:http://dx.doi.org/10.1016/j.pec.2012.08.007.
- [18] W. Godolphin, Shared decision-making, *Healthc. Q.* 12 Spec No Patient, (2009) e186–90.
- [19] W.C. Holland, K.M. Hunold, S.A. Mangipudi, A.M. Rittenberg, N. Yosipovitch, T.F. Platts-Mills, A prospective evaluation of shared decision-making regarding analgesics selection for older emergency department patients with acute musculoskeletal pain, *Acad. Emerg. Med.* 23 (3) (2016) 306–314, doi:http://dx.doi.org/10.1111/acem.12888.
- [20] M.H. van de Pol, C.R. Fluit, J. Lagro, Y.H. Slaats, M.G. Olde Rikkert, A.L. Lagro-Janssen, Expert and patient consensus on a dynamic model for shared decision-making in frail older patients, *Patient Educ. Couns.* 99 (6) (2016) 1069–1077, doi:http://dx.doi.org/10.1016/j.pec.2015.12.014.
- [21] M.A. Durand, L. Carpenter, H. Dolan, P. Bravo, M. Mann, F. Bunn, G. Elwyn, Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis, *PLoS One* 9 (4) (2014) e94670, doi:http://dx.doi.org/10.1371/journal.pone.0094670.
- [22] D. Stacey, F. Legare, K. Lewis, M.J. Barry, C.L. Bennett, K.B. Eden, M. Holmes-Rovner, H. Llewellyn-Thomas, A. Lyddiatt, R. Thomson, L. Trevena, Decision aids for people facing health treatment or screening decisions, *Cochrane Database Syst. Rev.* 4 (2017), doi:http://dx.doi.org/10.1002/14651858.CD001431.pub5 Cd001431.
- [23] B.M. Wiering, J. Noordman, K. Bates, M. Zwaanswijk, G. Elwyn, E.S. De Bont, A. Beishuizen, P.M. Hoogerbrugge, S. Van Dulmen, Sharing decisions during diagnostic consultations: an observational study in pediatric oncology, *Patient Educ. Couns.* 99 (1) (2016) 61–67, doi:http://dx.doi.org/10.1016/j.pec.2015.07.026.
- [24] L. Brom, H.R. Pasman, G.A. Widdershoven, M.J. van der Vorst, J.C. Reijneveld, T.J. Postma, B.D. Onwuteaka-Philipsen, Patients' preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients, *PLoS One* 9 (6) (2014)e100435, doi:http://dx.doi.org/10.1371/journal.pone.0100435.
- [25] R. Brown, P. Butow, M. Wilson-Genderson, J. Bernhard, K. Ribi, I. Juraskova, Meeting the decision-making preferences of patients with breast cancer in oncology consultations: impact on decision-related outcomes, *J. Clin. Oncol.* 30 (8) (2012) 857–862, doi:http://dx.doi.org/10.1200/JCO.2011.37.7952.
- [26] K. Schmidt, K. Damm, A. Prenzler, H. Golpon, T. Welte, Preferences of lung cancer patients for treatment and decision-making: a systematic literature review, *Eur. J. Cancer Care (Engl.)*, 25 (4) (2016) 580–591, doi:http://dx.doi.org/10.1111/ecc.12425.

Appendix B. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2018.11.018>.

References

- [1] K. Aelbrecht, P. Pype, J. Vos, M. Deveugele, Having cancer in a foreign country, *Patient Educ. Couns.* 99 (10) (2016) 1708–1716, doi:http://dx.doi.org/10.1016/j.pec.2016.05.010.
- [2] M. Arnold, O. Razum, J.W. Coebergh, Cancer risk diversity in non-western migrants to Europe: an overview of the literature, *Eur. J. Cancer* 46 (14) (2010) 2647–2659, doi:http://dx.doi.org/10.1016/j.ejca.2010.07.050.
- [3] J.S. Phinney, A.D. Ong, Conceptualization and measurement of ethnic identity: current status and future directions, *J. Couns. Psychol.* 54 (3) (2007) 271, doi:http://dx.doi.org/10.1037/0022-0167.54.3.271.

- [27] S. Thorne, T.G. Hislop, C. Kim-Sing, V. Oglov, J.L. Oliffe, K.I. Stajduhar, Changing communication needs and preferences across the cancer care trajectory: insights from the patient perspective, *Support. Care Cancer* 22 (4) (2014) 1009–1015, doi:http://dx.doi.org/10.1007/s00520-013-2056-4.
- [28] D. Mitchison, P. Butow, M. Sze, L. Aldridge, R. Hui, J. Vardy, M. Eisenbruch, R. ledema, D. Goldstein, Prognostic communication preferences of migrant patients and their relatives, *PsychoOncology* 21 (5) (2012) 496–504, doi:http://dx.doi.org/10.1002/pon.1923.
- [29] J. Shaw, X. Zou, P. Butow, Treatment decision making experiences of migrant cancer patients and their families in Australia, *Patient Educ. Couns.* 98 (6) (2015) 742–747, doi:http://dx.doi.org/10.1016/j.pec.2015.01.012.
- [30] E.L. Mead, A.Z. Doorenbos, S.H. Javid, E.A. Haozous, L.A. Alvord, D.R. Flum, A.M. Morris, Shared decision-making for cancer care among racial and ethnic minorities: a systematic review, *Am. J. Public Health* 103 (12) (2013) e15–e29, doi:http://dx.doi.org/10.2105/AJPH.2013.301631.
- [31] E. Belanger, C. Rodriguez, D. Groleau, Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis, *Palliat. Med.* 25 (3) (2011) 242–261, doi:http://dx.doi.org/10.1177/0269216310389348.
- [32] F.M. de Graaff, P. Mistiaen, W.L. Deville, A.L. Francke, Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review, *BMC Palliat. Care* 11 (2012) 17, doi:http://dx.doi.org/10.1186/1472-684X-11-17.
- [33] M.M. Barnett, Does it hurt to know the worst? Psychological morbidity, information preferences and understanding of prognosis in patients with advanced cancer, *PsychoOncology* 15 (1) (2006) 44–55.
- [34] Y. Longtin, H. Sax, L.L. Leape, S.E. Sheridan, L. Donaldson, D. Pittet, Patient participation: current knowledge and applicability to patient safety, *Mayo Clin. Proc.* 85 (1) (2010) 53–62, doi:http://dx.doi.org/10.4065/mcp.2009.0248.
- [35] S. Hawker, S. Payne, C. Kerr, M. Hardey, J. Powell, Appraising the evidence: reviewing disparate data systematically, *Qual. Health Res.* 12 (9) (2002) 1284–1299.
- [36] M. Dixon-Woods, S. Agarwal, D. Jones, B. Young, A. Sutton, Synthesising qualitative and quantitative evidence: a review of possible methods, *J. Health Serv. Res. Policy* 10 (1) (2005) 45–53.
- [37] R.K. Matsuyama, L.A. Kuhn, A. Molisani, M.C. Wilson-Genderson, Cancer patients' information needs the first nine months after diagnosis, *Patient Educ. Couns.* 90 (1) (2013) 96–102, doi:http://dx.doi.org/10.1016/j.pec.2012.09.009.
- [38] S.L. Maliski, S. Connor, A. Fink, M.S. Litwin, Information desired and acquired by men with prostate cancer: data from ethnic focus groups, *Health Educ. Behav.* 33 (3) (2006) 393–409.
- [39] P. Jean- Pierre, K. Fiscella, J. Griggs, J.V. Joseph, G. Morrow, J. Carroll, S. Hendren, J. Purnell, C. Figueroa-Moseley, P. Kuebler, T.K. Banerjee, J.J. Kirshner, Race/ethnicity-based concerns over understanding cancer diagnosis and treatment plan, *J. Med. Assoc.* 102 (3) (2010) 184–189.
- [40] R.K. Matsuyama, M. Wilson-Genderson, L. Kuhn, D. Moghanaki, H. Vachhani, M. Paasche-Orlow, Education level, not health literacy, associated with information needs for patients with cancer, *Patient Educ. Couns.* 85 (3) (2011), doi:http://dx.doi.org/10.1016/j.pec.2011.03.022 e229–36.
- [41] R. Royak-Schaler, S.R. Passmore, S. Gadalla, M.K. Hoy, M. Zhan, K. Tkaczuk, L.M. Harper, P.D. Nicholson, A.P. Hutchison, Exploring patient-physician communication in breast cancer care for African American women following primary treatment, *Oncol. Nurs. Forum* 35 (5) (2008) 836–843, doi:http://dx.doi.org/10.1188/08.ONF.836-843.
- [42] E.O. Im, W. Chee, E. Guevara, H.J. Lim, Y. Liu, H. Shin, Gender and ethnic differences in cancer patients' needs for help: an Internet survey, *Int. J. Nurs. Stud.* 45 (8) (2008) 1192–1204.
- [43] N.K. Janz, M.S. Mujahid, S.T. Hawley, J.J. Griggs, A.S. Hamilton, S.J. Katz, Racial/ethnic differences in adequacy of information and support for women with breast cancer, *Cancer* 113 (5) (2008) 1058–1067, doi:http://dx.doi.org/10.1002/cncr.23660.
- [44] G. Joseph, R.J. Pasick, D. Schillinger, J. Luce, C. Guerra, J.K.Y. Cheng, Information mismatch: cancer risk counseling with diverse underserved patients, *J. Genet. Couns.* 26 (5) (2017) 1090–1104, doi:http://dx.doi.org/10.1007/s10897-017-0089-4.
- [45] S.Y. Zafar, F. Chino, P.A. Ubel, C. Rushing, G. Samsa, I. Altomare, J. Nicolla, D. Schrag, J.A. Tulskey, A.P. Abernethy, J.M. Peppercorn, The utility of cost discussions between patients with cancer and oncologists, *Am. J. Manag. Care* 21 (9) (2015) 607–615.
- [46] X. Huang, P. Butow, B. Meiser, D. Goldstein, Attitudes and information needs of Chinese migrant cancer patients and their relatives, *Aust. N. Z. J. Med.* 29 (2) (1999) 207–213.
- [47] D. Muthu Kumar, R.P. Symonds, S. Sundar, K. Ibrahim, B.S. Savelyich, E. Miller, Information needs of Asian and White British cancer patients and their families in Leicestershire: a cross-sectional survey, *Br. J. Cancer* 90 (8) (2004) 1474–1478.
- [48] C. O'Callaghan, P. Schofield, P. Butow, L. Nolte, M. Price, S. Tsintziras, M. Sze, T. Thein, D. Yiu, S. Mireskandari, D. Goldstein, M. Jefford, I might not have cancer if you didn't mention it": a qualitative study on information needed by culturally diverse cancer survivors, *Support. Care Cancer* 24 (1) (2016) 409–418, doi:http://dx.doi.org/10.1007/s00520-015-2811-9.
- [49] M.C. Robotin, M. Porwal, M. Hopwood, D. Nguyen, M. Sze, C. Treloar, J. George, Listening to the consumer voice: developing multilingual cancer information resources for people affected by liver cancer, *Health Expect.* 20 (1) (2017) 171–182, doi:http://dx.doi.org/10.1111/hex.12449.
- [50] K.Y. Wen, A. Hu, G.X. Ma, C.Y. Fang, M.B. Daly, Information and communication needs of Chinese American breast cancer patients: perspectives on survivorship care planning, *J. Commun. Support. Oncol.* 12 (12) (2014) 439–445.
- [51] P.N. Butow, M.L. Bell, L.J. Aldridge, M. Sze, M. Eisenbruch, M. Jefford, P. Schofield, A. Girgis, M. King, P.S. Duggal, J. McGrane, D. Goldstein, Unmet needs in immigrant cancer survivors: a cross-sectional population-based study, *Support. Care Cancer* 21 (9) (2013) 2509–2520, doi:http://dx.doi.org/10.1007/s00520-013-1819-2.
- [52] E.E. Kent, N.K. Arora, J.H. Rowland, K.M. Bellizzi, L.P. Forsythe, A.S. Hamilton, I. Oakley-Girvan, E.B. Beckjord, N.M. Aziz, Health information needs and health-related quality of life in a diverse population of long-term cancer survivors, *Patient Educ. Couns.* 89 (2) (2012) 345–352, doi:http://dx.doi.org/10.1016/j.pec.2012.08.014.
- [53] J. Leng, T. Lee, U. Sarpel, J. Lau, Y. Li, C. Cheng, M.D. Chang, F. Gany, Identifying the informational and psychosocial needs of Chinese immigrant cancer patients: a focus group study, *Support. Care Cancer* 20 (12) (2012) 3221–3229, doi:http://dx.doi.org/10.1007/s00520-012-1464-1.
- [54] K. Tam Ashing, G. Padilla, J. Tejero, M. Kagawa-Singer, Understanding the breast cancer experience of Asian American women, *PsychoOncology* 12 (1) (2003) 38–58.
- [55] J.H. Wang, I.F. Adams, R.J. Pasick, S.L. Gomez, L. Allen, G.X. Ma, M.X. Lee, E. Huang, Perceptions, expectations, and attitudes about communication with physicians among Chinese American and non-Hispanic white women with early stage breast cancer, *Support. Care Cancer* 21 (12) (2013) 3315–3325, doi:http://dx.doi.org/10.1007/s00520-013-1902-8.
- [56] J. Leng, T. Lee, Y. Li, C. Stern, M.H. Chen, G. Winkel, F. Gany, Support needs of Chinese immigrant cancer patients, *Support. Care Cancer* 22 (1) (2014) 33–42, doi:http://dx.doi.org/10.1007/s00520-013-1950-0.
- [57] C. Kwok, K. White, Perceived information needs and social support of Chinese-Australian breast cancer survivors, *Support. Care Cancer* 22 (10) (2014) 2651–2659, doi:http://dx.doi.org/10.1007/s00520-014-2252-x.
- [58] F.S. Hodge, T.L. Itty, M.P. Cadogan, F. Martinez, Weaving balance into life: Development and cultural adaptation of a cancer symptom management toolkit for Southwest American Indians, *J. Cancer Surviv.* 6 (2) (2012) 182–188, doi:http://dx.doi.org/10.1007/s11764-011-0209-3.
- [59] R. Costas-Muniz, R. Sen, J. Leng, A. Aragonés, J. Ramirez, F. Gany, Cancer stage knowledge and desire for information: mismatch in Latino cancer patients?, *J. Cancer Educ.* 28 (3) (2013) 458–465, doi:http://dx.doi.org/10.1007/s13187-013-0487-8.
- [60] N. Galvan, L.P. Buki, D.M. Garces, Suddenly, a carriage appears: social support needs of Latina breast cancer survivors, *J. Psychosoc. Oncol.* 27 (3) (2009) 361–382, doi:http://dx.doi.org/10.1080/07347330902979283.
- [61] A. Noguera, S. Yennurajalingam, I. Torres-Vigil, H.A. Parsons, E.R. Duarte, A. Palma, S. Bunge, J.L. Palmer, E. Bruera, Decisional control preferences, disclosure of information preferences, and satisfaction among Hispanic patients with advanced cancer, *J. Pain Symptom Manage.* 47 (5) (2014) 896–905, doi:http://dx.doi.org/10.1016/j.jpainsymman.2013.06.010.
- [62] A.M. Napoles-Springer, J.C. Livaudais, J. Bloom, S. Hwang, C.P. Kaplan, Information exchange and decision making in the treatment of Latina and white women with ductal carcinoma in situ, *J. Psychosoc. Oncol.* 25 (4) (2007) 19–36.
- [63] R.F. Obeidat, R.M. Lally, S.S. Dickerson, Arab American women's lived experience with early-stage breast cancer diagnosis and surgical treatment, *Cancer Nurs.* 35 (4) (2012) 302–311, doi:http://dx.doi.org/10.1097/NCC.0b013e318231db09.
- [64] C. Ayash, R. Costas-Muniz, D. Badreddine, J. Ramirez, F. Gany, An investigation of unmet socio-economic needs among Arab American breast cancer patients compared with other immigrant and migrant patients, *J. Community Health* 43 (1) (2018) 89–95, doi:http://dx.doi.org/10.1007/s10900-017-0391-y.
- [65] D.K. McInnes, P.D. Cleary, K.D. Stein, L. Ding, C.C. Mehta, J.Z. Ayanian, Perceptions of cancer-related information among cancer survivors: a report from the American Cancer society's Studies of Cancer survivors, *Cancer* 113 (6) (2008) 1471–1479, doi:http://dx.doi.org/10.1002/cncr.23713.
- [66] S.T. Hawley, N.K. Janz, A. Hamilton, J.J. Griggs, A.K. Alderman, M. Mujahid, S.J. Katz, Latina patient perspectives about informed treatment decision making for breast cancer, *Patient Educ. Couns.* 73 (2) (2008) 363–370, doi:http://dx.doi.org/10.1016/j.pec.2008.07.036.
- [67] M.E. Lopez, C.P. Kaplan, A.M. Napoles, E.S. Hwang, J.C. Livaudais, L.S. Karliner, Satisfaction with treatment decision-making and treatment regret among Latinas and non-Latina whites with DCIS, *Patient Educ. Couns.* 94 (1) (2014) 83–89, doi:http://dx.doi.org/10.1016/j.pec.2013.09.005.
- [68] S.W. Williams, L.C. Hanson, C. Boyd, M. Green, M. Goldman, G. Wright, G. Corbie-Smith, Communication, decision making, and cancer: what African Americans want physicians to know, *J. Palliat. Med.* 11 (9) (2008) 1221–1226, doi:http://dx.doi.org/10.1089/jpm.2008.0057.
- [69] S. Yennurajalingam, H.A. Parsons, E.R. Duarte, A. Palma, S. Bunge, J.L. Palmer, M. O. Delgado-Guay, J. Allo, E. Bruera, Decisional control preferences of Hispanic patients with advanced cancer from the United States and Latin America, *J. Pain Symptom Manage.* 46 (3) (2013) 376–385, doi:http://dx.doi.org/10.1016/j.jpainsymman.2012.08.015.
- [70] S.K. Lee, M.T. Knobf, Family involvement for breast cancer decision making among Chinese-American women, *PsychoOncology* 25 (12) (2016) 1493–1499, doi:http://dx.doi.org/10.1002/pon.3989.
- [71] D.M. Walker, A.S. McAlearney, L.N. Sova, J.J. Lin, S. Abramson, N.A. Bickell, Comparing prostate cancer treatment decision making in a resource-rich and a resource-poor environment: a tale of two hospitals, *J. Med. Assoc.* 108 (4) (2016) 211–219, doi:http://dx.doi.org/10.1016/j.jma.2016.08.002.
- [72] S.J. Katz, L.P. Wallner, P.H. Abrahamse, N.K. Janz, K.A. Martinez, D.A. Shumway, A.S. Hamilton, K.C. Ward, K.A. Resnicow, S.T. Hawley, Treatment experiences of

- Latinas after diagnosis of breast cancer, *Cancer* 123 (16) (2017) 3022–3030, doi:<http://dx.doi.org/10.1002/cncr.30702>.
- [73] A. Hyatt, R. Lipson-Smith, P. Schofield, K. Gough, M. Sze, L. Aldridge, D. Goldstein, M. Jefford, M.L. Bell, P. Butow, Communication challenges experienced by migrants with cancer: a comparison of migrant and English-speaking Australian-born cancer patients, *Health Expect.* 20 (5) (2017) 886–895, doi:<http://dx.doi.org/10.1111/hex.12529>.
- [74] M. Markovic, L. Manderson, N. Wray, M. Quinn, He's telling us something, *Anthropol. Med.* 11 (3) (2004) 327–341, doi:<http://dx.doi.org/10.1080/1364847042000296590>.
- [75] S.C. Lee, E.G. Marks, J.M. Sanders, D.J. Wiebe, Elucidating patient-perceived role in "decision-making" among African Americans receiving lung cancer care through a county safety-net system, *J. Cancer Surviv.* 10 (1) (2016) 153–163, doi:<http://dx.doi.org/10.1007/s11764-015-0461-z>.
- [76] B. Kreling, M.I. Figueiredo, V.L. Sheppard, J.S. Mandelblatt, A qualitative study of factors affecting chemotherapy use in older women with breast cancer: barriers, promoters, and implications for intervention, *Psychooncology* 15 (12) (2006) 1065–1076.
- [77] M.F. Back, C.Y. Huak, Family centred decision making and non-disclosure of diagnosis in a South East Asian oncology practice, *PsychoOncology* 14 (12) (2005) 1052–1059.
- [78] F.M. De Graaff, A.L. Francke, M.E. Van den Muijsenbergh, S. van der Geest, Talking in triads: communication with Turkish and Moroccan immigrants in the palliative phase of cancer, *J. Clin. Nurs.* 21 (21–22) (2012) 3143–3152, doi:<http://dx.doi.org/10.1111/j.1365-2702.2012.04289.x>.
- [79] R.C. Maly, Y. Umezawa, C.T. Ratliff, B. Leake, Racial/ethnic group differences in treatment decision-making and treatment received among older breast carcinoma patients, *Cancer* 106 (4) (2006) 957–965.
- [80] M.C. Zea, T. Quezada, F.Z. Belgrave, Latino cultural values: their role in adjustment to disability, *J. Soc. Behav. Pers.* 9 (5) (1994) 185–200.
- [81] J.D. Tariman, A. Doorenbos, K.G. Schepp, S. Singhal, D.L. Berry, Information needs priorities in patients diagnosed with cancer: a systematic review, *J. Adv. Pract. Oncol.* 2014 (5) (2014) 115–122.
- [82] D.J. Kiesler, S.M. Auerbach, Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions, *Patient Educ. Couns.* 61 (3) (2006) 319–341, doi:<http://dx.doi.org/10.1016/j.pec.2005.08.002>.
- [83] K. Hosper, V. Nierkens, M. Nicolaou, K. Stronks, Behavioural risk factors in two generations of non-Western migrants: do trends converge towards the host population? *Eur. J. Epidemiol.* 22 (3) (2007) 163–172.