



UvA-DARE (Digital Academic Repository)

Enhancing patient participation among older and migrant cancer patients through eHealth

Yilmaz, N.G.

Publication date

2020

Document Version

Other version

License

Other

[Link to publication](#)

Citation for published version (APA):

Yilmaz, N. G. (2020). *Enhancing patient participation among older and migrant cancer patients through eHealth*. [Thesis, fully internal, Universiteit van Amsterdam].

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

CHAPTER 5

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

An adapted version of this chapter has been published as: Yilmaz, N. G., Schouten, B. C., Schinkel, S., & van Weert, J. C. M. (2019). Information and participation preferences and needs of non-Western ethnic minority cancer patients and survivors: A systematic review of the literature. *Patient Educ Couns*, 102(4), 631-650. <https://doi.org/10.1016/j.pec.2018.11.018>

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.

INTRODUCTION

During the past decades, the number of non-Western ethnic minority groups living in Western countries has increased rapidly (Aelbrecht et al., 2016; Arnold et al., 2010). Ethnic minority groups can be defined as numerically smaller, non-dominant groups distinguished by 'shared cultural heritage, including values, traditions, and often language' (Phinney & Ong, 2007, 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 (Mintchev & Moore, 2018; Vertovec, 2007).

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 (Arnold et al., 2010). 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 (Arnold et al., 2010; Reus-Pons et al., 2016), including stomach cancer, liver cancer, and lung cancer (Arnold et al., 2010). As a consequence, encounters between Western healthcare providers and cancer patients from non-Western ethnic minority groups are on the increase (Aelbrecht et al., 2016).

A cancer diagnosis entails a physical and psychological burden for patients, and treatment outcomes are often uncertain (Mazor et al., 2013). 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 (Fujimori & Uchitomi, 2009). 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 (Paternotte et al., 2015; Schouten & Meeuwesen, 2006; Suurmond & Seeleman, 2006). These communication difficulties may contribute to low patient satisfaction, poor treatment adherence and suboptimal health outcomes (Aelbrecht et al., 2016). 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 (Gany et al., 2013). 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 (Aelbrecht et al., 2017).

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 (Ellis & Varner, 2018). Unmet information needs among the general population of cancer patients primarily concern disease and treatment-related information (Hack et al., 2005), 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 (Husson et al., 2011). As for participation preferences and needs of cancer patients, passive, shared, and active participation in decision-making can be distinguished (Palmer et al., 2013). Passive decision-making refers to patients deferring decisions to their healthcare professional and/or caregiver, active decision-making refers to patients making all decisions by themselves, and shared decision-making (SDM) implies that the patient and healthcare professional share knowledge, values, and preferences, ultimately leading to mutual healthcare choices (Godolphin, 2009; Holland et al., 2016; van de Pol et al., 2016). SDM has several benefits over passive and active participation (Durand et al., 2014; Holland et al., 2016; Stacey et al., 2017; van de Pol et al., 2016; Wiering et al., 2016), among which higher healthcare professional and patient satisfaction, increased quality of life, better functional and clinical outcomes, and more adherence to treatment plans (Holland et al., 2016; van de Pol et al., 2016). 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 (Holland et al., 2016; van de Pol et al., 2016; Wiering et al., 2016).

To date, several studies have investigated information and participation preferences and needs of Western cancer patients (Brom et al., 2014; Brown et al., 2012; Fujimori & Uchitomi, 2009; Hack et al., 2005; Mazor et al., 2013; Schmidt et al., 2016; Thorne et al., 2014). 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 (Aelbrecht et al., 2016; Mitchison et al., 2012; Shaw et al., 2015). 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 (Mead et al., 2013). However, this review only focused on behavior instead of preferences and needs. Hence, healthcare professionals 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 (older) non-Western ethnic minority cancer patients living in Western countries. We have a more closely look on preferences and needs of older non-

Western ethnic minority cancer patients because older patients are at higher risk of suboptimal patient participation. Older patients refer to patients aged 65 years or older. 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’ (Phinney & Ong, 2007, 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 professionals 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 professionals to better tailor communication to the individual ethnic minority cancer patient.

METHODS

Search strategy

Literature was retrieved from the four most commonly addressed scientific databases in the field of health communication research (Bélanger et al., 2011; de Graaff, Mistiaen, et al., 2012; Mead et al., 2013): PsycINFO, PubMed, CINAHL, and EMBASE. Search strings were assembled together with an experienced information specialist in order to ensure adequacy in the search process. The primary search terms used were: *communication preferences, migrants, ethnic minority, cancer, information preferences, information needs, decision-making, participation preferences, and participation needs*. Appendix H shows the exact search strings per database. Supplementary manual searches with these search terms were 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.

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 (Barnett, 2006), and/or participation preferences and needs, referring to the patient’s preferred level of involvement in the medical decision-making process (Longtin et al., 2010). 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 9*.

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).

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 *Figure 7* for the flow diagram).

In order to be able to report the information and participation preferences and needs of older ethnic minority patients in particular, and to compare these preferences and needs to the preferences and needs of younger ethnic minority patients, studies that had a sample of only older (i.e. 65 years or older) ethnic minority patients or that explicitly reported the comparisons between younger (i.e. younger than 65 years old) and older ethnic minority patients were selected and additionally analysed. From 24 papers with an on average older sample, three papers specifically reported about the preferences and needs of older ethnic minority patients (Maliski et al., 2006; Muthu Kumar et al., 2004; Walker et al., 2016), and six papers compared the preferences and needs of older and younger patients (Kent et al., 2012; Kreling et al., 2006; Matsuyama et al., 2013; McInnes et al., 2008; Noguera et al., 2014; Obeidat et al., 2012). As these nine studies gave insight into the preferences and needs of older ethnic minority cancer patients, they were analyzed for the paragraphs comparing older and younger patients.

Data extraction, analysis, and synthesis

The methodological quality of studies included in the review was independently assessed by the first two authors by using an instrument that is suitable for assessing the

methodological quality of both qualitative and quantitative studies (Hawker et al., 2002). The instrument consists of nine items: abstract, background, method, sampling, 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 (Dixon-Woods et al., 2005). 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. 137-140). Results concerning participation preferences and needs are reported per decision-making style (p. 141-142). Data concerning the author and year, research design, participants, country and setting, and the (main) results were extracted from the studies included (see *Table 9*). The PRISMA Statement was used to report this review (see *Appendix I*).

Figure 7. Flow diagram.

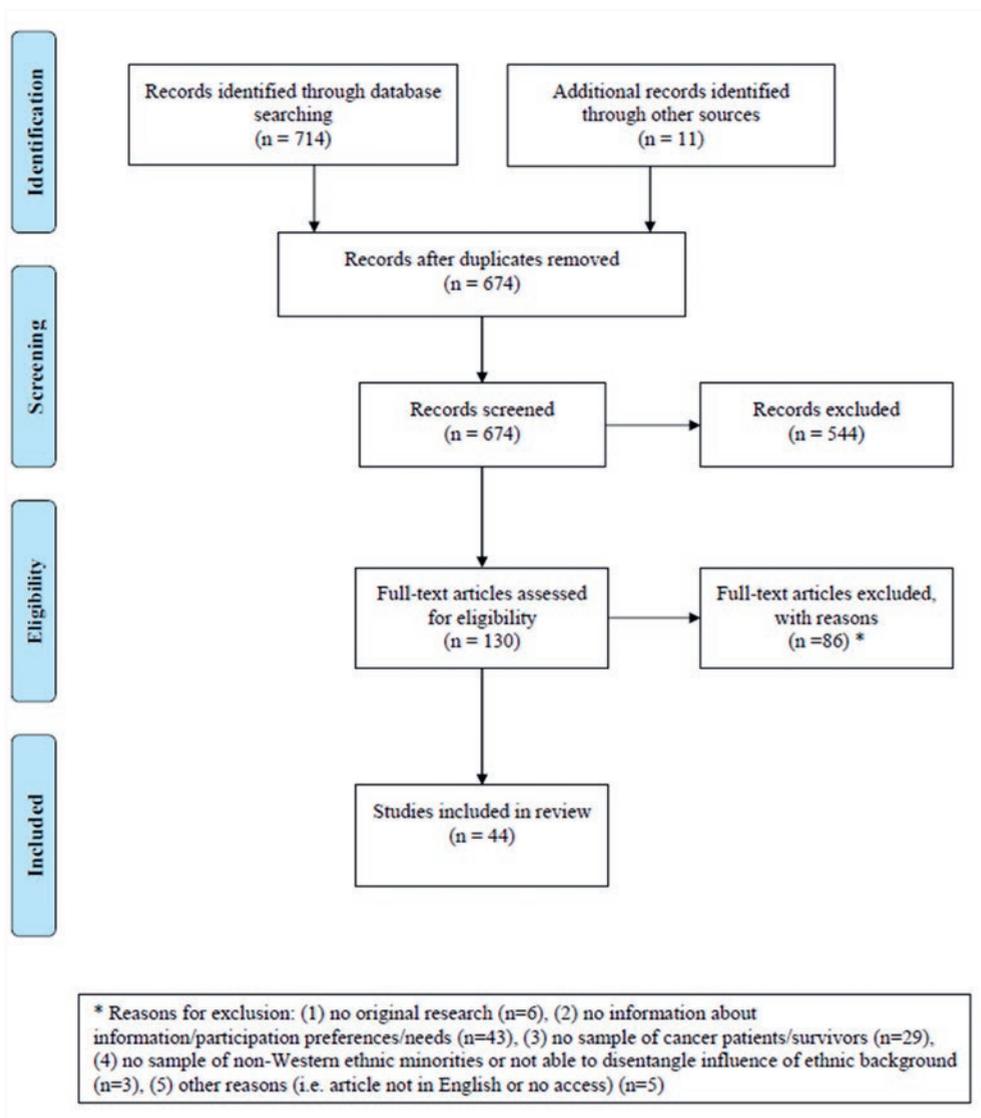


Table 9 Study characteristics.

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
1.	Aelbrecht et al. (2016) 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, Ghanese, 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) 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 Caribbean 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) 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
4.	Costas-Muniz et al. (2013) 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 (<i>M</i> =55.5; <i>SD</i> =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) 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 organization <i>Sample:</i> - 22 survivors - Female: 100% - Breast cancer - Age range: 35 – 67 (<i>M</i> =51; <i>SD</i> =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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
6.	Hawley et al. (2008) 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) 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
8.	Huang et al. (1999) <i>Australia</i>	<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 – >70 - 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 were 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
9.	Hyatt et al. (2017) 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 (SD=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) 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 (SD=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
11.	Janz et al. (2008) 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
12.	Jean-Pierre et al. (2010) 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) 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) 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
15.	Kent et al. (2012) ^b 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) ^b 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
17.	Kwok & White (2014) 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 Kongese	<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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
18.	Lee & Knobf (2016) 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) 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) 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
21.	Leng et al. (2014) 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) 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
23.	Maliski et al. (2006) ^a 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) 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
25.	Matsuyama et al. (2013) ^b 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
26.	Matsuyama et al. (2011) 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 health-care 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
27.	McInnes et al. (2008) ^b 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: - Latin-American - 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
28.	Mitchison et al. (2012) <i>Australia</i>	<i>Study design:</i> Qualitative <i>Method:</i> Structured inter-views <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) - 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) ^a <i>UK</i>	<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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
30.	Napoles-Springer et al. (2017) 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) ^b 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
32.	Obeidat et al. (2012) ^b 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
33.	O'Callaghan et al. (2016) 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) 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 ($M=61.3$; $SD=7.0$) - 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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
35.	Robotin et al. (2017) <i>Australia</i>	<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) <i>USA</i>	<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) <i>Australia</i>	<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

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
38.	Tam Ashing et al. (2003) 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>Topics:</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) ^a USA	<i>Study design:</i> Qualitative <i>Method:</i> Semi-structured interviews and focus groups <i>Focus phase of disease:</i> Multiple stages	<i>Setting:</i> Academic medical center, municipal hospital <i>Sample:</i> - 12 patients - Female: 0% - Prostate cancer - Mean age: 66.4 - Ethnicity: o African-American	<i>Topic:</i> Participation preferences <i>Results:</i> Patients report a preference for active participation in the decision-making process.	2
40.	Wang et al. (2013) USA	<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> Cancer Prevention Institution of California, community centers in San Francisco's Chinatown <i>Sample:</i> - 44 patients and survivors - Female: 100% - Breast cancer - Mean age: M=56.9 (SD=9.2) - Level of acculturation: mean for years in host country = 22.22 (SD=14.67) - Ethnicity: o Asian: Chinese	<i>Topic:</i> Information preferences <i>Results:</i> Patients prefer to be informed about treatment-related issues, such as side effects. Furthermore, patients wanted as much information as possible about their prognosis. Finally, they prefer to receive information about physical symptoms of cancer.	3

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
41.	Wen et al. (2014) USA	<i>Study design:</i> Qualitative <i>Method:</i> Telephone semi-structured interviews <i>Focus phase of disease:</i> Survivor	<i>Setting:</i> Community-based organizations <i>Sample:</i> - 16 survivors - Female: 100% - Breast cancer - Age range: 37 – 72 - Ethnicity: o Asian: Chinese	<i>Topic:</i> Information needs <i>Results:</i> Survivors need information about diagnosis, treatment (including information about the side effects of treatment options), recurrence, Chinese medicine, physical activity, and nutrition. Survivors believe that this information will help them in sharing their disease with their family doctors or family members and enable them to be prepared for post treatment side effects. This, in turn, will help them in coping with the side effects of treatment and in reducing anxiety.	2
42.	Williams et al. (2008) USA	<i>Study design:</i> Qualitative <i>Method:</i> Focus group interviews <i>Focus phase of disease:</i> Post-treatment	<i>Setting:</i> Local churches, support groups, hospitals <i>Sample:</i> - 21 survivors - Female (78.6%) - Various cancers - Ethnicity: o African-American	<i>Topic:</i> Participation preferences <i>Results:</i> Survivors report to prefer shared participation in decision-making. Survivors stress the importance of being involved in the decision-making process, which leads to a greater sense of control over treatment choices.	3

#	Authors, Year & Country	Design & Method	Sample & Setting	Main findings	Method. quality
43.	Yennurajalingam et al. (2013) USA	<i>Study design:</i> Quantitative <i>Method:</i> Survey <i>Measure:</i> Control Preference Scale <i>Focus phase of disease:</i> Advanced	<i>Setting:</i> Outpatient specialist palliative care services <i>Sample:</i> - 387 patients - Female: 60.5% - Various cancers - Age: ≥18 - Level of acculturation: high (56%) - Ethnicity: o Latin-American: Bolivian, Colombian, Cuban, Salvadorian, Guatemalan, Mexican, Nicaraguan, Peruvian, Puerto Rican, Venezuelan	<i>Topic:</i> Participation preferences <i>Results:</i> Patients report a preference for shared or active participation. When patients are asked whether they prefer to make the decisions themselves or to leave it to the doctor, they prefer shared participation with their physician. When patients are asked whether they prefer to make the decisions themselves or to leave it to their family, patients prefer shared participation with their family members. When patients are asked whether they prefer to make the decisions themselves or to involve both the doctor and family members in the decision-making process, the majority of patients prefer active participation in which they make all decisions themselves.	3
44.	Zafar et al. (2015) USA	<i>Study design:</i> Quantitative <i>Method:</i> Self-developed survey <i>Focus phase of disease:</i> Treatment	<i>Setting:</i> Comprehensive cancer center, and affiliated, rural, oncology clinics <i>Sample:</i> - 300 patients - Female: 48% - Various cancers - Age range: 27 – 91 - Ethnicity: o African-American o Indian-American	<i>Topic:</i> Information preferences <i>Results:</i> The majority prefers to be informed about treatment-related out-of-pocket costs.	3

Note: ^a studies with a sample of only older ethnic minority patients/survivors

^b studies explicitly reporting comparisons between younger and older ethnic minority patients/survivors

RESULTS

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 9* shows the characteristics of included studies.

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 10* for an overview of the results).

African ethnic minority patients and survivors

Ten studies reported about the information preferences and needs of African ethnic minority patients/survivors (Aelbrecht et al., 2016; Im et al., 2008; Janz et al., 2008; Jean-Pierre et al., 2010; Joseph et al., 2017; Maliski et al., 2006; Matsuyama et al., 2013; Matsuyama et al., 2011; Royak-Schaler et al., 2008; Zafar et al., 2015). African-American (Im et al., 2008; Janz et al., 2008; Jean-Pierre et al., 2010; Joseph et al., 2017; Maliski et al., 2006; Matsuyama et al., 2013; Matsuyama et al., 2011; Royak-Schaler et al., 2008; Zafar et al., 2015) and African-European (Aelbrecht et al., 2016) patients/survivors had high information preferences on all six topics. African-American patients often reported to prefer detailed information about their diagnosis and metastasis (Jean-Pierre et al., 2010; Maliski et al., 2006; Matsuyama et al., 2013; Matsuyama et al., 2011; Royak-Schaler et al., 2008). Besides, African-American patients preferred to be informed about the treatment and its aftermath (Im et al., 2008; Jean-Pierre et al., 2010). 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 (Jean-Pierre et al., 2010). Furthermore, African-American patients preferred to be informed about prognosis and recurrence (Im et al., 2008; Joseph et al., 2017; Maliski et al., 2006; Royak-Schaler et al., 2008), alternative medicine, nutrition, and physical activity (Janz et al., 2008), and causes (Joseph et al., 2017) and prevention of cancer (Maliski et al., 2006; Royak-Schaler et al., 2008). Lastly, African-European (Aelbrecht et al., 2016) and African-American patients (Zafar et al., 2015) wanted to receive information about the healthcare system and services.

Asian ethnic minority patients and survivors

Eighteen studies reported about the information preferences and needs of Asian ethnic minority patients/survivors (Aelbrecht et al., 2016; Butow et al., 2013; Huang et al., 1999; Im et al., 2008; Joseph et al., 2017; Kent et al., 2012; Kwok & White, 2014; Leng et al., 2014; Leng et al., 2012; Maliski et al., 2006; Mitchison et al., 2012; Muthu Kumar et al., 2004; O'Callaghan et al., 2016; Robotin et al., 2017; Shaw et al., 2015; Tam Ashing et al., 2003; Wang et al., 2013; Wen et al., 2014). Asian-European (Aelbrecht et al., 2016; Muthu Kumar et al., 2004), Asian-Australian (Butow et al., 2013; Huang et al., 1999; Kwok & White, 2014; Mitchison et al., 2012; O'Callaghan et al., 2016; Robotin et al., 2017; Shaw et al., 2015), and Asian-American (Im et al., 2008; Joseph et al., 2017; Kent et al., 2012; Leng et al., 2014; Leng et al., 2012; Maliski et al., 2006; Tam Ashing et al., 2003; Wang et al., 2013; Wen et al., 2014) patients/survivors reported to have high information preferences on all topics. The majority of Asian-European (Muthu Kumar et al., 2004), Asian-Australian (Huang et al., 1999; Mitchison et al., 2012; O'Callaghan et al., 2016; Robotin et al., 2017), and Asian-American (Maliski et al., 2006; Wen et al., 2014) patients preferred as much information as possible about diagnosis and metastasis. Besides, Asian-European (Muthu Kumar et al., 2004), Asian-Australian (Butow et al., 2013; O'Callaghan et al., 2016; Robotin et al., 2017), and Asian-American (Huang et al., 1999; Im et al., 2008; Kent et al., 2012; Leng et al., 2014; Leng et al., 2012; Maliski et al., 2006; Tam Ashing et al., 2003; Wang et al., 2013; Wen et al., 2014) patients, except Filipino patients (Muthu Kumar et al., 2004), reported to prefer detailed information about treatment and its aftermath. In addition, in all studies except one (Huang et al., 1999) Asian-Australian (Kwok & White, 2014; Mitchison et al., 2012; O'Callaghan et al., 2016; Robotin et al., 2017; Shaw et al., 2015) and Asian-American (Joseph et al., 2017; Wang et al., 2013; Wen et al., 2014) 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 (Butow et al., 2013; O'Callaghan et al., 2016; Robotin et al., 2017) and Asian-American (Leng et al., 2014; Leng et al., 2012; Wen et al., 2014) patients. Asian-Australian (O'Callaghan et al., 2016) and Asian-American (Joseph et al., 2017; Leng et al., 2012; Wang et al., 2013) patients further preferred information about the risks and symptoms of cancer (Leng et al., 2012), the causes of cancer (Joseph et al., 2017), genetics

of cancer (i.e. whether cancer is hereditary) (Joseph et al., 2017; O'Callaghan et al., 2016), and prevention of cancer (Joseph et al., 2017; O'Callaghan et al., 2016). Finally, Asian-European (Aelbrecht et al., 2016) and Asian-Australian (Robotin et al., 2017) patients preferred information about the healthcare system and services in the host country.

Indian-American ethnic minority patients and survivors

Two studies reported about the information preferences and needs of Indian-American (Hodge et al., 2012; Zafar et al., 2015) 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 (Hodge et al., 2012). Besides, Indian-American patients reported to prefer information about treatment and its aftermath (Hodge et al., 2012), and the healthcare system and services (Zafar et al., 2015). 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.

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 (Costas-Muniz et al., 2013; Galván et al., 2009; Im et al., 2008; Janz et al., 2008; Jean-Pierre et al., 2010; Joseph et al., 2017; Kent et al., 2012; Nápoles-Springer et al., 2007; Noguera et al., 2014). In all studies but one (Costas-Muniz et al., 2013) Latin-American (Galván et al., 2009; Janz et al., 2008; Joseph et al., 2017; Nápoles-Springer et al., 2007; Noguera et al., 2014) and Hispanic (Im et al., 2008; Kent et al., 2012; Robotin et al., 2017) patients/survivors had high information preferences on five topics. Latin-American and Hispanic patients/survivors preferred detailed information about their diagnosis and metastasis (Galván et al., 2009; Matsuyama et al., 2013; Noguera et al., 2014), and about the aftermath of cancer treatment (Kent et al., 2012; Nápoles-Springer et al., 2007; Noguera et al., 2014). Besides, patients preferred to know about prognosis and cancer recurrence (Im et al., 2008; Joseph et al., 2017; Noguera et al., 2014). Eventually, Latin-American patients indicated that they would like to be informed about alternative medicine, nutrition, and physical activity (Janz et al., 2008), and about the causes, genetics and prevention of cancer (Joseph et al., 2017). In no study, Latin-American and/or Hispanic ethnic minority patients/survivors reported information preferences and/or needs concerning the healthcare system and services.

Middle-Eastern ethnic minority patients and survivors

Six studies reported about the information preferences and needs of Middle-Eastern ethnic minority patients/survivors (Aelbrecht et al., 2016; Ayash et al., 2018; Butow et al., 2013;

Mitchison et al., 2012; Obeidat et al., 2012; Shaw et al., 2015). Middle-Eastern American (Obeidat et al., 2012), Middle-Eastern Australian (Butow et al., 2013; Mitchison et al., 2012; Shaw et al., 2015), and Middle-Eastern European (Aelbrecht et al., 2016) 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 (Ayash et al., 2018). The majority of Middle-Eastern Australian (Shaw et al., 2015) and Middle-Eastern American (Obeidat et al., 2012) patients preferred to be informed about their diagnosis and the metastatic stage of the cancer. Furthermore, Middle-Eastern American (Obeidat et al., 2012) and Middle-Eastern Australian (Butow et al., 2013) patients wanted detailed information about treatment options and their side effects. Middle-Eastern Australian patients preferred as much information as possible about their prognosis (Shaw et al., 2015), and about alternative medicine, nutrition, and physical activity (Butow et al., 2013). Finally, Middle-Eastern European patients wanted to be informed about the healthcare system and services (Aelbrecht et al., 2016). In no study, Middle-Eastern ethnic minority patients/survivors reported information preferences and/or needs concerning causes, genetics and prevention.

Factors related to information preferences and needs

Apart from ethnic background (Janz et al., 2008; Kent et al., 2012; Matsuyama et al., 2013; Matsuyama et al., 2011), 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 (Galván et al., 2009; Jean-Pierre et al., 2010; Robotin et al., 2017; Wen et al., 2014), and to keep balance in their lives (Hodge et al., 2012). Secondly, several demographic (e.g. younger age and female gender) and socio-cultural factors (e.g. higher level of language proficiency and lower level of acculturation) (Costas-Muniz et al., 2013; Galván et al., 2009; Janz et al., 2008; Kent et al., 2012; Matsuyama et al., 2013; Matsuyama et al., 2011; McInnes et al., 2008), 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 (Kent et al., 2012; Leng et al., 2014; Matsuyama et al., 2013; McInnes et al., 2008). Finally, patients who perceived the quality of care as excellent (Kent et al., 2012), and patients who had limited financial resources to afford healthcare, had low information preferences (Leng et al., 2014; Zafar et al., 2015).

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 (Hawley et al., 2008; López et al., 2014; Noguera et al., 2014; Palmer et al., 2013; Royak-Schaler et al., 2008; Shaw et al., 2015; Williams et al., 2008; Yennurajalingam et al., 2013) and a preference for SDM with family members (Lee & Knobf, 2016; Maliski et al., 2006; Yennurajalingam et al., 2013).

The majority of Latin-American (Hawley et al., 2008; López et al., 2014; Noguera et al., 2014; Yennurajalingam et al., 2013) and African-American (Hawley et al., 2008; Maliski et al., 2006; Palmer et al., 2013; Royak-Schaler et al., 2008; Walker et al., 2016; Williams et al., 2008) patients preferred shared or active participation at almost equal levels. In contrast, the majority of Asian (Huang et al., 1999; Hyatt et al., 2017; Katz et al., 2017; Markovic et al., 2004; Shaw et al., 2015) and Middle-Eastern (Hyatt et al., 2017; Markovic et al., 2004; Obeidat et al., 2012) ethnic minority patients reported to prefer passive participation in the decision-making process. Only a few studies showed that Asian (Lee & Knobf, 2016; Maliski et al., 2006) and Middle-Eastern (Shaw et al., 2015) ethnic minority cancer patients preferred shared or active participation.

Three studies showed differences in participation preferences within ethnic minority groups (Huang et al., 1999; Nápoles-Springer et al., 2007; Tam Ashing et al., 2003). In one study, higher educated Chinese patients reported more preference for active participation, while lower educated Chinese patients preferred passive participation (Huang et al., 1999). 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 (Tam Ashing et al., 2003). Finally, in one study, some Latin-American cancer patients preferred passive participation, while others preferred active participation (Nápoles-Springer et al., 2007).

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 (Lee et al., 2016; Markovic et al., 2004; Obeidat et al., 2012; Shaw et al., 2015; Tam Ashing et al., 2003; Williams et al., 2008), and healthcare professional's (communicative) behaviour influenced patients' participation self-reported preferences (Kreling et al., 2006; Markovic et al., 2004; Nápoles-Springer et al., 2007; Shaw et al., 2015). Patients who had a paternalistic view on the doctor-patient relationship, and patients who were not offered a choice by their healthcare professional, 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 (Lee & Knobf, 2016; Maliski et al., 2006). Finally, some demographic (e.g. younger age) and socio-cultural (e.g. higher level of education) characteristics of patients seemed to be related to patients' preferences for active or shared

participation (Huang et al., 1999; Katz et al., 2017; Noguera et al., 2014; Tam Ashing et al., 2003).

Table 10 shows an overview of the information and participation preferences and needs, and associated factors per main ethnic minority group.

Information and participation preferences and needs among older patients/survivors

The three papers that studied the information and participation preferences and needs of older ethnic minority cancer patients/survivors (≥ 65 years old) in particular (Maliski et al., 2006; Muthu Kumar et al., 2004; Walker et al., 2016) showed that older Asian patients wanted to be informed about their diagnosis (Muthu Kumar et al., 2004), treatment options, potential side effects of cancer treatment, odds of metastasis, emotional impact of cancer diagnosis and coping strategies, (ethnicity-specific) support groups, and nutrition (Maliski et al., 2006). As for the participation preferences and needs, one study showed that older African-American patients had a high preference to be in control of treatment decisions (i.e. active participation) (Walker et al., 2016).

The six papers that compared the preferences and needs of older ethnic minority cancer patients with those of younger ethnic minority cancer patients showed that older Asian, Latin-American/Hispanic, and African-American cancer patients in general reported a lower need for information (Kent et al., 2012; Matsuyama et al., 2013; McInnes et al., 2008) than younger patients. For instance, older survivors (>50 years old; $M_{age}=68$ years) – compared to younger survivors (<50 years old) – reported a lower need for information about health promotion (Kent et al., 2012). In addition, older patients (>75 years old) reported lower information needs concerning the experiences of other patients, clinical trials, oncology professionals (e.g. oncologists), support groups, and long-term side effects of cancer treatment than younger patients (<55 years old) (McInnes et al., 2008). Three studies also showed that Latin-American, African-American, and Middle-Eastern older cancer patients (≥ 65 years old) often preferred passive participation instead of active or shared participation (Kreling et al., 2006; Noguera et al., 2014; Obeidat et al., 2012) than younger patients.

Table 10. 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> (Huang et al., 1999; Maliski et al., 2006; Muthu Kumar et al., 2004; O'Callaghan et al., 2016; Robotin et al., 2017; Shaw et al., 2015; Wen et al., 2014) <p>Asian-Australian patients wanted to know their diagnosis even if it was already in a severe stage (Huang et al., 1999). Besides Asian-Australian cancer survivors reported to prefer information about where cancer is likely to metastasize after completing treatment (O'Callaghan et al., 2016).</p> <p>In one study, all patients had high information needs concerning diagnosis, except Filipino patients (Maliski et al., 2006).</p> <ul style="list-style-type: none"> - <i>Treatment and its Aftermath</i> (Butow et al., 2013; Huang et al., 1999; Im et al., 2008; Kent et al., 2012; Leng et al., 2014; Leng et al., 2012; Maliski et al., 2006; Muthu Kumar et al., 2004; O'Callaghan et al., 2016; Robotin et al., 2017; Tam Ashing et al., 2003; Wang et al., 2013; Wen et al., 2014) <p>Asian-European (Muthu Kumar et al., 2004), Asian-Australian (Butow et al., 2013; O'Callaghan et al., 2016; Robotin et al., 2017), and Asian-American (Huang et al., 1999; Im et al., 2008; Kent et al., 2012; Leng et al., 2014; Leng et al., 2012; Maliski et al., 2006; Tam Ashing et al., 2003; Wang et al., 2013; Wen et al., 2014) patients, except Filipino patients (Muthu Kumar et al., 2004), 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 (Im et al., 2008). However, this preference was the lowest among Asian-American patients compared to Hispanics and African-Americans (Im et al., 2008).</p> <ul style="list-style-type: none"> - <i>Prognosis and Recurrence</i> (Huang et al., 1999; Im et al., 2008; Joseph et al., 2017; Kwok & White, 2014; Maliski et al., 2006; Mitchison et al., 2012; Muthu Kumar et al., 2004; O'Callaghan et al., 2016; Robotin et al., 2017; Shaw et al., 2015; Wang et al., 2013; Wen et al., 2014) <p>Asian-Australian (Kwok & White, 2014; Mitchison et al., 2012; O'Callaghan et al., 2016; Robotin et al., 2017; Shaw et al., 2015) and Asian-American (Joseph et al., 2017; Wang et al., 2013; Wen et al., 2014) patients reported to need information about cancer recurrence, recurrence statistics, and late effects such as fatigue among survivors.</p>	<p>Information preferences</p> <ul style="list-style-type: none"> - <i>Coping</i> (Huang et al., 1999; Mitchison et al., 2012; Wen et al., 2014) <p>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 (Wen et al., 2014). Furthermore, 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 (Mitchison et al., 2012).</p> <p>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 (Huang et al., 1999).</p> <ul style="list-style-type: none"> - <i>Demographic and socio-cultural factors</i> (Matsuyama et al., 2013) <p>In one study, younger Asian-American patients reported higher information needs than older patients (Matsuyama et al., 2013). Besides, female patients and patients who were married had higher information needs than male patients and unmarried patients (Matsuyama et al., 2013).</p> <ul style="list-style-type: none"> - <i>Cancer-related factors</i> (e.g. type of cancer) (Kent et al., 2012; Leng et al., 2014) <p>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 (Leng et al., 2014).</p> <ul style="list-style-type: none"> - <i>(Perceived) quality of care and financial resources</i> (Kent et al., 2012; Leng et al., 2014) <p>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 (Kent et al., 2012). Furthermore, if Asian-American patients had no health insurance, they were less likely to prefer information about treatment and its related costs (Leng et al., 2014).</p> <p>Participation preferences</p> <ul style="list-style-type: none"> - <i>Beliefs concerning doctor-patient relationship</i> (Markovic et al., 2004; Shaw et al., 2015) <p>Asian-Australian patients perceived the doctor as the expert who is best placed to decide on the treatment (Markovic et al., 2004; Shaw et al., 2015). They also perceived their own understanding about cancer treatment inferior to the doctors' knowledge (Markovic et al., 2004; Shaw et al., 2015). Because of this perceived hierarchical</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 (Huang et al., 1999).

- *Alternative Medicine, Nutrition, and Physical Activity* (Butow et al., 2013; Leng et al., 2014; Leng et al., 2012; O'Callaghan et al., 2016; Robotin et al., 2017; Wen et al., 2014)

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 (Butow et al., 2013; O'Callaghan et al., 2016; Robotin et al., 2017) and Asian-American (Leng et al., 2014; Leng et al., 2012; Wen et al., 2014) patients.

- *Genetics, Causes and Prevention* (Joseph et al., 2017; Leng et al., 2012; O'Callaghan et al., 2016; Wang et al., 2013)
- Asian-Australian (O'Callaghan et al., 2016) and Asian-American (Joseph et al., 2017; Leng et al., 2012; Wang et al., 2013) patients further preferred information about the risks and symptoms of cancer (Leng et al., 2012), the causes of cancer (Joseph et al., 2017), genetics of cancer (i.e. whether cancer is hereditary) (Joseph et al., 2017; O'Callaghan et al., 2016), and prevention of cancer (Joseph et al., 2017; O'Callaghan et al., 2016).

- *Healthcare System and Cancer in general* (Aelbrecht et al., 2016; Butow et al., 2013; Kwok & White, 2014; Leng et al., 2014; Leng et al., 2012; Robotin et al., 2017)

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 (Aelbrecht et al., 2016). Asian-Australian patients also lacked information about how they could access social services such as interpreters and social workers (Robotin et al., 2017).

Participation preferences

In most studies, Asian patients and survivors prefer passive participation (Hyatt et al., 2017; Katz et al., 2017; Markovic et al., 2004; Shaw et al., 2015) or shared participation (Lee & Knobf, 2016; Maliski et al., 2006; Shaw et al., 2015).

relationship, these patients/survivors preferred passive participation (Markovic et al., 2004). In contrast, patients who preferred shared participation perceived their own opinions as equal to the doctors' opinions (Shaw et al., 2015).

- *Doctor's communicative behaviour* (Markovic et al., 2004; Shaw et al., 2015)
- Asian-Australian patients reported that their doctor did not seek their opinion and provided them with less information than they preferred (Shaw et al., 2015), and that alternative treatment options were not available (Markovic et al., 2004). These patients often reported to think there was no decision to make at all, and preferred passive participation in medical decision-making.

- *Family support* (Lee & Knobf, 2016; Maliski et al., 2006)

Asian-American patients reported that they wish to compare treatment options together with their family members, and often described decisions as 'our' decisions (Lee & Knobf, 2016). 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 (Maliski et al., 2006).

- *Demographic and socio-cultural factors* (Huang et al., 1999; Katz et al., 2017; Tam Ashing et al., 2003)

Asian-Australian (Huang et al., 1999) and Asian-American (Katz et al., 2017) patients with a lower level of acculturation (Katz et al., 2017) or education (Huang et al., 1999) preferred passive participation. Asian-Australian (Huang et al., 1999) patients with a higher level of education preferred active or shared participation in the decision-making process (Huang et al., 1999). Chinese-Australian (Huang et al., 1999) and Asian-American (Tam Ashing et al., 2003) 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 (Huang et al., 1999). 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 (Huang et al., 1999).

Latin-American and Hispanic

Information preferences

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

- *Diagnosis and Metastasis* (Costas-Muniz et al., 2013; Galván et al., 2009; Jean-Pierre et al., 2010; Noguera et al., 2014)

In one study, Latin-American ethnic minority patients show low information preferences regarding diagnosis and treatment (Costas-Muniz et al., 2013). Only 15 percent of these patients reported to prefer additional information about their diagnosis, even though they were not informed about their cancer stage or metastatic stage of the tumour (Costas-Muniz et al., 2013).

- *Treatment and its Aftermath* (Galván et al., 2009; Im et al., 2008; Janz et al., 2008; Jean-Pierre et al., 2010; Kent et al., 2012; Nápoles-Springer et al., 2007; Noguera et al., 2014)

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 (Noguera et al., 2014). Survivors also reported a need for information about the relationship with their partner and sexual functioning after completing cancer treatment (Nápoles-Springer et al., 2007).

- *Prognosis and Recurrence* (Im et al., 2008; Joseph et al., 2017; Noguera et al., 2014)

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 (Im et al., 2008; Joseph et al., 2017; Noguera et al., 2014).

- *Alternative Medicine, Nutrition, and Physical Activity* (Janz et al., 2008)
- Latin-American patients preferred to be informed about the role of nutrition and physical activity in cancer prevention, treatment, recovery, and recurrence (Janz et al., 2008).

- *Genetics, Causes and Prevention* (Joseph et al., 2017)
- Latin-American patients reported to be interested in the causes of cancer, and prevention of cancer (Joseph et al., 2017).

Information preferences

- *Coping* (Galván et al., 2009; Jean-Pierre et al., 2010)
- 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 (Galván et al., 2009; Jean-Pierre et al., 2010).

- *Demographic and socio-cultural factors* (Costas-Muniz et al., 2013; Galván et al., 2009; Janz et al., 2008; Kent et al., 2012; McInnes et al., 2008)

Low English language proficiency and being monolingual in Spanish were reported by Latin-American and Hispanic to be reasons for low information preferences (Costas-Muniz et al., 2013; Galván et al., 2009). 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 (Janz et al., 2008). Furthermore, younger patients reported higher information needs than older patients (Kent et al., 2012; McInnes et al., 2008).

- *Cancer-related factors* (e.g. type of cancer) (Kent et al., 2012; McInnes et al., 2008)

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 (Kent et al., 2012; McInnes et al., 2008).

- *(Perceived) quality of care* (Kent et al., 2012)

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 (Kent et al., 2012).

Participation preferences

- *Doctor's communicative behaviour* (Kreling et al., 2006; Nápoles-Springer et al., 2007)

Latin-American patients reported that they were not provided a choice between treatment options (Kreling et al., 2006). 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 (Nápoles-Springer et al., 2007). If it was

- *Healthcare System and Cancer in general (McImmes et al., 2008)*

Participation preferences

In one study, the majority of Latin-American (Noguera et al., 2014) patients preferred active participation solely. In two studies, shared and active participation were preferred at almost equal levels by Latin-American (Hawley et al., 2008; López et al., 2014) 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 (Katz et al., 2017; Kreling et al., 2006) patients reported to prefer passive participation.

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 (Nápoles-Springer et al., 2007).

- *Demographic and socio-cultural factors (Katz et al., 2017; Noguera et al., 2014)*

Younger Latin-American patients were more likely to prefer active or shared participation in the decision-making process compared to older patients (Noguera et al., 2014). Besides, Latin-American patients with a lower level of acculturation preferred passive participation (Katz et al., 2017). Latin-American (Noguera et al., 2014) patients with a higher level of education preferred active or shared participation in the decision-making process (Noguera et al., 2014).

Ethnic background	Preferences and needs	Factors that are related to preferences and needs
African-American	<p>Information preferences 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> (Jean-Pierre et al., 2010; Maliski et al., 2006; Matsuyama et al., 2013; Matsuyama et al., 2011; Royak-Schaler et al., 2008) - <i>Treatment and its Aftermath</i> (Im et al., 2008; Janz et al., 2008; Jean-Pierre et al., 2010; Kent et al., 2012; Maliski et al., 2006; Matsuyama et al., 2013; Matsuyama et al., 2011; Royak-Schaler et al., 2008) <p>African-Americans preferred to receive information about coping with anxiety/depression, the relationship with their partner and sexual functioning after completing cancer treatment (Im et al., 2008).</p> <ul style="list-style-type: none"> - <i>Prognosis and Recurrence</i> (Im et al., 2008; Joseph et al., 2017; Maliski et al., 2006; Matsuyama et al., 2013; Matsuyama et al., 2011; Royak-Schaler et al., 2008) <p>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 (Im et al., 2008; Joseph et al., 2017; Maliski et al., 2006; Royak-Schaler et al., 2008).</p> <p>In one study, African-American patients showed low information preferences regarding the chances of getting worse (Matsuyama et al., 2013).</p> <ul style="list-style-type: none"> - <i>Alternative Medicine, Nutrition, and Physical Activity</i> (Janz et al., 2008) <p>African-American patients preferred information about the role of nutrition and physical activity in cancer prevention, treatment, recovery, and recurrence (Janz et al., 2008).</p> <ul style="list-style-type: none"> - <i>Genetics, Causes and Prevention</i> (Joseph et al., 2017; Maliski et al., 2006; Royak-Schaler et al., 2008) <p>African-American patients had high information preferences regarding the causes of cancer (Joseph et al., 2017) and prevention of cancer (Maliski et al., 2006; Royak-Schaler et al., 2008).</p>	<p>Information preferences</p> <ul style="list-style-type: none"> - <i>Coping</i> (Jean-Pierre et al., 2010; Royak-Schaler et al., 2008) <p>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 (Jean-Pierre et al., 2010; Royak-Schaler et al., 2008).</p> <ul style="list-style-type: none"> - <i>Demographic and socio-cultural factors</i> (Kent et al., 2012; Matsuyama et al., 2013; Matsuyama et al., 2011; McInnes et al., 2008) <p>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 (Matsuyama et al., 2013). Furthermore, African-American patients with a lower level of education had higher information needs compared to higher educated patients (Matsuyama et al., 2013; Matsuyama et al., 2011). African-American survivors who were diagnosed with colorectal cancer had lower information needs compared to patients who were diagnosed with other types of cancer (Kent et al., 2012; McInnes et al., 2008).</p> <ul style="list-style-type: none"> - <i>(Perceived) quality of care and financial resources</i> (Zafar et al., 2015) <p>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 (Zafar et al., 2015).</p> <p>Participation preferences</p> <ul style="list-style-type: none"> - <i>Beliefs concerning doctor-patient relationship</i> (Lee et al., 2016; Williams et al., 2008) <p>In one study, African-American patients preferred passive participation because of the perceived patriarchal doctor-patient relationship (Lee et al., 2016). In contrast, African-American patients who perceived the physician as responsible for explaining available options and the patient for making the decision (Williams et al., 2008). Patients who preferred shared participation, perceived this as a way to enhance their sense of control over treatment choices (Williams et al., 2008).</p>

- *Healthcare System and Cancer in general (Aelbrecht et al., 2016; Matsuyama et al., 2013; Matsuyama et al., 2011; McInnes et al., 2008; Zafar et al., 2015)*
 African-European patients preferred to be informed about the healthcare system (Aelbrecht et al., 2016), where they could find financial support to pay their medical bills (i.e. health insurance), and out-of-pocket costs of treatment (Zafar et al., 2015).
- *Doctor's communicative behaviour (Kreling et al., 2006)*
 In one study, African-American patients reported that they were not provided a choice between treatment options (Kreling et al., 2006). Hence, they reported to think there was no decision to make at all, and preferred passive participation in medical decision-making.
- *Family support (Maliski et al., 2006)*
 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 (Maliski et al., 2006).
- *Demographic and socio-cultural factors (Katz et al., 2017)*
 African-American patients with a lower level of acculturation preferred passive participation (Katz et al., 2017).

Participation preferences

In most studies, African-American patients and survivors prefer shared (Hawley et al., 2008; Maliski et al., 2006; Palmer et al., 2013; Royak-Schaler et al., 2008; Williams et al., 2008) or active participation (Hawley et al., 2008; Walker et al., 2016). In only a few studies, African-Americans report a preference for passive participation (Katz et al., 2017; Kreling et al., 2006; Lee et al., 2016).

In one study, the majority of African-American (Walker et al., 2016) patients preferred active participation solely. In three studies, shared and active participation were preferred at almost equal levels by African-American patients (Hawley et al., 2008; Palmer et al., 2013; Royak-Schaler et al., 2008). Furthermore, in two studies African-American patients reported that they preferred shared participation with either their informal caregivers (Maliski et al., 2006) or their physician (Williams et al., 2008). In two studies, African-American (Katz et al., 2017; Lee et al., 2016) patients reported to prefer passive participation.

Ethnic background	Preferences and needs	Factors that are related to preferences and needs
<p>Middle-Eastern</p> <p>Information preferences Middle-Eastern patients and survivors have high information needs. They prefer information about:</p> <ul style="list-style-type: none"> - <i>Diagnosis and Metastasis (Obeidat et al., 2012; Shaw et al., 2015)</i> - <i>Treatment and its Aftermath (Butow et al., 2013; Obeidat et al., 2012)</i> - <i>Prognosis and Recurrence (Mitchison et al., 2012; Shaw et al., 2015)</i> - <i>Alternative Medicine, Nutrition, and Physical Activity (Butow et al., 2013)</i> - <i>Healthcare System and Cancer in general (Aelbrecht et al., 2016; Butow et al., 2013)</i> <p>Middle-Eastern European patients preferred information concerning whom they should address when they experience health problems (Aelbrecht et al., 2016).</p> <p>In one study, Middle-Eastern ethnic minority patients show lower information needs than Latin-American patients (Ayash et al., 2018). However, what type of information is not specified.</p> <p>Participation preferences In most studies, Middle-Eastern American (Obeidat et al., 2012) and Middle-Eastern Australian (Hyatt et al., 2017; Markovic et al., 2004) patients and survivors preferred passive participation. In one study, Middle-Eastern Australian patients reported a preference for shared or active participation (Shaw et al., 2015).</p>		<p>Information preferences</p> <ul style="list-style-type: none"> - <i>Coping (Mitchison et al., 2012)</i> <p>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 (Mitchison et al., 2012).</p> <p>Participation preferences</p> <ul style="list-style-type: none"> - <i>Beliefs concerning doctor-patient relationship (Markovic et al., 2004; Obeidat et al., 2012; Shaw et al., 2015)</i> <p>Middle-Eastern Australian (Markovic et al., 2004; Shaw et al., 2015) and Middle-Eastern American (Obeidat et al., 2012) 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 (Markovic et al., 2004; Obeidat et al., 2012; Shaw et al., 2015). Because of this perceived hierarchical relationship, these patients/survivors preferred passive participation (Markovic et al., 2004; Obeidat et al., 2012). In contrast, patients who preferred shared participation perceived their own opinions as equal to the doctors' opinions (Shaw et al., 2015).</p> <ul style="list-style-type: none"> - <i>Doctor's communicative behaviour (Markovic et al., 2004; Shaw et al., 2015)</i> <p>Middle-Eastern patients reported that their doctor did not seek their opinion and provided them with less information than they preferred (Shaw et al., 2015), and that alternative treatment options were not available (Markovic et al., 2004). These patients often reported to think there was no decision to make at all, and preferred passive participation in medical decision-making.</p>

Ethnic background	Preferences and needs	Factors that are related to preferences and needs
<p>Indian-American</p> <p>Information preferences Indian-American patients and survivors have high information needs. They prefer information about:</p> <ul style="list-style-type: none"> - <i>Diagnosis and Metastasis</i> (Hodge et al., 2012) - <i>Treatment and its Aftermath</i> (Hodge et al., 2012) <p>Indian-American patients wanted to be informed about available treatment options (Hodge et al., 2012). They also wanted to be informed about risks and symptoms of cancer (Hodge et al., 2012).</p> <ul style="list-style-type: none"> - <i>Healthcare System and Cancer in general</i> (Zafar et al., 2015) <p>Indian-American patients preferred information about health insurance, and out-of-pocket costs of treatment (Zafar et al., 2015).</p> <p>Participation preferences</p>		<p>Information preferences</p> <ul style="list-style-type: none"> - <i>Coping</i> (Hodge et al., 2012) - <i>(Perceived) quality of care and financial resources</i> (Zafar et al., 2015) <p>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 (Zafar et al., 2015).</p> <p>Participation preferences</p>

DISCUSSION

The results of this review showed 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 reported to prefer shared or active participation, while Asian and Middle-Eastern patients/survivors tended to prefer passive participation more often. Our analysis about the preferences and needs of older ethnic minority patients/survivors indicated that these findings hold for the specific group of older patients/survivors as well. In two studies, Asian older patients appeared to have high information preferences and another study reported that African-American older patients have high participation needs. However, three studies in which the participation preferences of older ethnic minority patients/survivors were compared with younger ethnic minority patients/survivors reported lower preferences and needs concerning information and active participation among older patients. The results suggested 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 was that the concept of superdiversity was 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 existed between several ethnic minority groups. For example, Latin-American and African-American ethnic minority patients mainly preferred active or shared participation, while Asian and Middle-Eastern ethnic minority patients mainly preferred passive participation. Among the group of non-Western patients, differences in preferences and needs also existed 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 (Aelbrecht et al., 2016). Furthermore, in the traditional Asian culture family-centred care is central (Back & Huak, 2005; Huang et al., 1999). In family-centred care, the spouse or close family fulfil the role of (informal) interpreter and decision-maker, while patients themselves remain less autonomous (de Graaff, Francke, et al., 2012; Maly et al., 2006; Mead et al., 2013; Mitchison et al., 2012). Combined with the hierarchical perceptions of the doctor-patient relation, in which physicians are perceived as authoritative actors (Zea et al., 1994), 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.

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 (Tariman et al., 2014). 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 (Kiesler & Auerbach, 2006). 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 (Hosper et al., 2007). For example, in contrast to many studies, only one study (Huang et al., 1999) 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.

Finally, a general stereotype of 'older migrant patients do not want to know or to participate, but younger migrant patients do' seems not correct. Hence, it is important that preferences and needs of both younger and older patients/survivors are enquired about by healthcare professionals in order to tailor information-provision to individual patients and adequately involve them in the decision-making process. More insight into the unfulfilled needs of the biggest ethnic minority groups in the Europe/the Netherlands, and into ways in which these needs can be fulfilled is needed.

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. No fundamental differences seem to exist between younger and older ethnic minority patients/survivors in their information and participation preferences and needs. However, 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.

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 (Fujimori & Uchitomi, 2009; Gany et al., 2013).