

**TITLE: Cancer beliefs in ethnic minority populations: a review and meta-synthesis of qualitative studies**

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## **Introduction**

Prolonged time to diagnosis is associated with poorer survival for many common cancers (Richards 2009; Tørring et al. 2011). While delays in diagnosis after presentation to health care professionals can negatively impact prognosis (Tørring et al. 2013), patient-related delays are also important factors in cancer treatment success (Walter et al. 2012; Macleod et al. 2009). Patients' decisions about help-seeking relies on their awareness of which symptoms are potentially serious; this can depend on social factors, such as belief systems, health literacy and health care access. Evidence suggests that people from culturally diverse, or ethnic minority, populations tend to have lower participation in screening programs and present with more advanced disease, which negatively impacts their treatment and prognosis (Phillipson et al. 2012).

The World Health Organisation (WHO) acknowledge that social determinants of health make a major contribution to health inequities within and between countries and has recommended a greater focus on social determinants, such as culture, in public health research (CSDH 2008). Culture is considered a social determinant of health that acts at a community and population level. Broadly speaking, culture encompasses ideas, customs, social behaviour, attitudes and characteristics of a particular social group, including ethnic minority groups. Whilst culture has some influence on peoples' cancer beliefs, cultural explanations must also be considered in light of other economic and social determinants (Dein 2004). Ethnic diversity is a characteristic of many high-resource countries including Australia, the United Kingdom (UK) and the United States (US) (Parsons & Walmsley 2011).

The International Cancer Benchmarking Partnership (ICBP) is exploring factors influencing symptom appraisal and help-seeking for cancer, and to determine if these factors influence diagnostic delay. The ICBP has found that global variation in cancer outcomes may be related to population-based differences in cancer awareness and barriers to help-seeking. However, more research needs to be conducted with ethnic minorities to determine if there are culturally-specific factors contributing to cancer disparities in ethnic minorities within developed countries (Forbes et al. 2013).

Existing literature reviews exploring cancer experiences and screening behaviours in ethnic minority groups focus on the patient experience of cancer treatments, health services and survivorship (Harun et al. 2013; Evans et al. 2008; Yoo et al. 2014); screening participation (Lu et al. 2012; Javanparast et al. 2010; Masi et al. 2007a; Khakbazan et al. 2014); and understanding of risk (Lipworth et al. 2010). Diagnostic delays in specific ethnic groups in the United Kingdom (UK) have also been explored (Martins et al. 2013).

The objective of this review is to explore the similarities and differences in cancer beliefs across ethnic minority groups residing in the US, UK and Australia, as reported in primary qualitative research studies.

## **Methods**

The eligibility criteria were qualitative studies published in English reporting primary findings about cancer beliefs in ethnic minority populations in the US, UK and Australia, with participants over 18 years, who may or may not have experienced a cancer diagnosis. Studies focussing on cancer screening participation, health care provision and survivorship were excluded: these topics have already been reviewed and our focus was cancer beliefs that may impact symptom appraisal and help-seeking for a symptomatic cancer diagnosis.

Qualitative studies were chosen because they allow in-depth exploration of the topic. The publication years were limited to the previous ten years to ensure the data were contemporary, considering the changing nature of cultural contexts. The location of the studies was chosen by the research team because of the relevance to a broad audience as well as local relevance, as the researchers are located in Australia and the UK.

The information was sourced from Medline, CINAHL, Cochrane, PsycINFO and Web of Knowledge databases. The search terms used for the respective database searches by two were: cancer OR neoplasms AND culture OR ethnolog\* AND diagnosis AND beliefs OR

health knowledge OR attitudes. The searches were refined using MeSH qualifiers and or/synonyms to focus on qualitative studies, humans and adults. MeSH qualifiers were also applied to exclude screening, quantitative studies, cancer experience and health services. These were excluded because attitudes to screening have been published in previous reviews and our focus was on cancer beliefs impacting diagnosis, not the experience of cancer. Reference lists of included articles were searched by the reviewers for further relevant studies and where possible the authors were contacted to request further information or identify additional papers for review.

### **Study Selection**

520 records were screened by two reviewers and 55 full-text articles assessed for eligibility using the eligibility criteria and appraised using the Critical Skills Appraisal Program (CASP) Qualitative Checklist (CASP UK 2013). Two experienced qualitative researchers applied the CASP criteria to judge methodological rigour, relevance and credibility and relevance of the study to the aims of the review. The areas where many of the studies did not meet all of the criteria related to transparency of researcher reflexivity. The chosen studies were then forwarded to all authors for consensus agreement. Two studies were excluded on the basis of poor methodological quality. 15 studies were deemed high quality and selected for inclusion in the meta-synthesis.

### **Data extraction and collection**

The study methodology, demographic data (including ethnicity, location of study, tumour type, gender), sample size, recruitment strategy, details of data collection and analysis methods were extracted into a data extraction form. Study findings were then uploaded into Dedoose<sup>®</sup> (Sociocultural Research Consultants (“SCRC”) 2014) software to assist with coding and metasynthesis.

### **Analysis**

Critical Interpretative Synthesis (CIS), as developed and described by Dixon-Woods and colleagues (Dixon-Woods et al. 2006) informed the data analysis. Qualitative synthesis methods are used for the examination, critical comparison and synthesis of qualitative studies

exploring a related topic, and there are numerous methods that can be adopted (Britten et al. 2002; Sandelowski et al. 1997; Barnett-Page & Thomas 2009; Dixon-Woods et al. 2006; Whalley Hammell 2007). The methods provide a systematic and rigorous approach and therefore provide a legitimate source of evidence to inform health policy and practice (Barnett-Page & Thomas 2009). CIS was chosen because it has been applied to the synthesis of qualitative studies exploring health care access by vulnerable groups and can be used to synthesise data collected by different methodologies and disciplines (Barnett-Page & Thomas 2009), which was the case in this review.

Once identified as relevant to the research question, papers were critically assessed for research quality. Primary findings, researcher interpretations of primary findings, and demographic data from the included papers were uploaded into Dedoose qualitative analysis software. (SCRC 2014) Analysis was led by an experienced qualitative researcher via an inductive process of line-by-line coding of the findings extracted from each paper and categorising and a constant comparative method (Dixon-Woods et al. 2006). Demographic data, incorporating cultural or ethnic group, tumour type, gender and location of study were linked to the code excerpts. These data were then linked with the categories and themes from each paper to assist deeper analysis, both primary and by sub-group. Relationships were developed between the categories that synthesised the findings across all the included papers. The findings, emerging categories and themes were discussed between three experienced qualitative researchers engaged in cancer research (SL, PPCC, JDE) and the final categories and themes were peer-reviewed by a further three experienced qualitative researchers in cancer research (LP; FW; JW). The team approach to analysis facilitated a broader understanding of the phenomenon (Tong et al. 2007) and validation of the analysis (Miles & Huberman 1994). The rigour of the analysis was also enhanced by the use of qualitative data analysis software and the coding processes (Tong et al. 2007).

## **Findings**

We screened 520 potentially relevant articles, 15 of which were included in the final analysis (Figure 3; Table 1). Publication dates ranged from 2004-2014. Studies were located in the UK (six), USA (five), Australia (two) and Canada (two). The mean number of study participants was 31.7 (range 20-56), with a total of 476 participants from all 15 studies (429 female; 93 non-specified gender). The minority groups were African, African-American, Asian (South East, Southern and Chinese), Arabic, Hispanic and Latino. Seven studies

explored breast cancer, seven explored cancer in general, and one focussed on prostate cancer. Data were collected via interviews in nine of the studies, and via focus groups in five studies, then transcribed and analysed using thematic and/or content analysis, or narrative analysis (Table 1).

Three major categories; 'Health Service Access Barriers', 'Knowledge' and 'Attitudes' were identified which were present across all the ethnic minority groups. There were differences in the presence of minor themes between the groups. Where the theme is absent, it was either because there insufficient or no data to suggest the theme was present, or the question was not asked specifically (Table 2). Examples of quotations for each category and theme are provided in Table 3.

### **Category 1: Knowledge**

The themes related to knowledge were low health literacy (LHL) about causes of cancer; LHL about signs and symptoms of cancer; and LHL about treatment and prognosis. All of the groups demonstrated LHL about cancer. Established causes of cancer, such as lifestyle and genetic factors, were mentioned infrequently. LHL about causes of cancer and cancer prevention were present in five of the seven ethnic minority groups. Africans in the UK had particularly poor health literacy about the causes of cancer. The Chinese and Arab Australian and the Arab-American groups mentioned lifestyle, environmental, dietary and hereditary factors as potential causes of cancer. The South Asian people in the UK groups were aware of lifestyle factors that contributed to cancer. Superstitious beliefs about the causes of cancer, for example cancer was caused by 'bad luck', 'curses' or 'black magic', were common in the Chinese Australian and East Asian's in the UK. Some of these beliefs overlapped with faith-based beliefs, for instance attributing cancer to 'bad Karma' or negative Feng Shui.

The African American men believed that prostate cancer was painful and some were "shocked" (Thomas 2004) to hear that it could present asymptotically. They also did not perceive themselves as at risk of prostate cancer unless a close male relative had experienced it. Some had a general awareness, albeit somewhat imprecise understanding, of some prostate cancer symptoms.

LHL about the signs and symptoms of cancer was common in all of the minority groups. For example, some of the East and South Asian women in the UK were aware that a breast lump

may be malignant, whereas others expected that a malignant breast lump would always be painful. There was a strong association between severity and/or escalation of symptoms and decision to seek help, particularly in the Asian women in the UK with breast cancer, who waited until they had pain and/or bleeding before seeking help.

LHL about cancer causes and symptoms – compounded by fear and stigma about cancer - were directly attributed to delays in help-seeking for breast cancer in the people from Southern Asian backgrounds. Three out of the seven ethnic groups had limited awareness/knowledge about cancer treatment and prognosis. The overwhelming perception that cancer is invariably fatal was prevalent in all of the groups, demonstrating a LHL in regard to treatment and prognosis.

### **Category 2: Attitudes**

Themes identified that related to the ‘Attitudes’ category were; pessimism, fear, secrecy, stigma, fatalism, stoicism, pragmatism and optimism. Many of these themes were interrelated and/or co-existed. Attitudes could be powerful motivators for help-seeking, yet they could also be major barriers.

Many of the minority groups had a pessimistic attitude about cancer diagnosis and prognosis. Pessimism and fear was a factor in other groups in delayed help seeking and hiding or ignoring symptoms (e.g. Southern Asians in the UK). All of the minority groups were fearful of a cancer diagnosis and believed that cancer is a ‘death sentence’. The way this fear manifested, in terms of help-seeking, was complex and multi-factorial and interrelated with the other cancer beliefs identified in this review. Fear could either delay help-seeking or motivate help-seeking. All of the minority groups had a nihilistic belief that cancer diagnosis equates to death. Fear was a motivating factor for help-seeking in the Latino women in America. In contrast, fear of finding cancer led to delayed help-seeking in the English African and South Asians as well as African American and Australian Arabic minorities.

Secrecy and/or stigma contributed to people avoiding help-seeking and ignoring their symptoms, particularly in the Asian groups. The Australian Chinese and English South East Asian groups’ beliefs about the contagious nature of cancer contributed to cancer stigma. They would avoid people with cancer for fear of catching it from saliva, clothing, dishes and blankets. Cancer was also a taboo subject and not discussed outside immediate family, for fear of stigma brought upon the family. The American Hispanics were also reluctant to

discuss cancer out of 'respect' for their family. Beliefs around contagion, stigma and taboo, led to some UK South East Asian women hiding symptoms from their family and avoiding help-seeking, for fear of bringing shame on the family and being ostracised from their community.

Fatalistic beliefs about the causation, progression and survival from cancer were present in all the included studies apart from the African-American men. Fatalism, or the notion that cancer is a predetermined condition or destiny, was found in all ethnic groups. American Latino women suggested their 'destiny' could be overcome by self-efficacy, knowledge and optimism about treatment (if cancer is diagnosed early). Motivated by a desire to have their cancer treated, they were active in self-examination and help-seeking. Although they saw it as their 'destiny' rather than God's will to have the disease, they had 'will' to fight it. These women also had a degree of knowledge, self-efficacy and optimism about treatment and prognosis, which stood out in contrast to the other ethnic groups who had lower levels of knowledge, and were pessimistic and fearful about prognosis. The belief that a cancer diagnosis was 'God's will', either a punishment or challenge, predominated in over half of the ethnic groups, with the English South East Asian and Australian Chinese more inclined to believe that cancer was Karmic retribution for past wrongdoing based on their Buddhist or Taoist beliefs. The Chinese Australians were likely to consult a fortune-teller, monks or nuns for healing to address their 'bad luck'. The Australian Chinese and South East Asians, fatalistic, faith-based beliefs engendered a pragmatic attitude towards illness and death.

Stoicism was common in the UK South East, Southern Asian and African, African-American men, US Arabic and Hispanic and Australian Arabic minorities. Stoicism was often related to competing family demands or machismo (for the African-American men). On a more positive note, some US Latino women expressed optimism about breast cancer treatment and awareness of the importance of early detection, which was a facilitator for help-seeking.

### **Category 3: Health Service Barriers**

Themes relating to Health Service Barriers were; language barriers, embarrassment, discrimination, lack of autonomy and use of traditional medicine. All of the ethnic minority groups noted that they had difficulties and reluctance to access health care services due to language barriers. Most of the groups preferred to see health care providers who spoke their native language and, if they were communicating in English, they often had difficulty understanding their health care provider. Embarrassment about physical symptoms and/or

intimate examinations was found to be a barrier to health care access in four out of the seven minority groups. When specifically asked if their Muslim faith can be a barrier to accessing health care, women from Arab backgrounds said that they preferred to be seen by a female physician but they would see a male doctor if they have a ‘problem’. The Hispanic and South Asians also expressed a preference for breast examination by a female practitioner.

The American Arabic people felt discriminated against in New York after the 2001 ‘September 11’ attacks. The men were reluctant to access health care services for fear of being deported and the women expressed concern about assumptions made by health-care workers because they wore a Hijab (Head-covering). The Chinese Australians indicated that it is common to use Traditional Chinese Medicine and consult faith healers for cancer, which may have influenced their decision-making in terms of seeking help from Western medicine practitioners.

## **Discussion**

This is the first systematic review of qualitative studies which explores the effects of cancer beliefs on symptom appraisal and help-seeking for cancer in ethnic minority populations. We found that fatalism, fear, stigma, poor knowledge about cancer causation, symptoms, treatment and prognosis, and attitudes about cancer influence symptom appraisal and help-seeking and could potentially affect timely cancer diagnosis in people from ethnic minority backgrounds. The role of ‘God’s will’, fate or destiny was a significant influence on beliefs around cancer causation, and acceptance of a cancer diagnosis. Fatalism, including the beliefs that an Omnipotent force (i.e God/s, Karma or Heaven) influenced causation and prognosis of cancer, was present in all the minority groups studied. This has not been observed as an important influence in other studies of diagnostic delay in non-minority populations (Tod et al. 2008; Esteva et al. 2013; Almuammar et al. 2010). Similar fatalistic beliefs and acceptance of fate has been found in qualitative studies of cancer beliefs in Hong Kong Chinese (Chan et al. 2009) and Malaysian (Taib et al. 2011) populations. There was variation about these beliefs within the groups: the Latino and Turkish women believed that God would be able to facilitate healing; the Asian groups tended to be more accepting of their ‘fate’ of death from cancer, and Arab groups saw cancer as a punishment from God. Faith-based beliefs have also been identified as influencing cancer screening behaviour in culturally and linguistically diverse populations (Phillipson et al. 2012). Within the broader health literature, these interrelated faith-related beliefs have been conceptualised within the single term ‘fatalism’.

For example, Shen and colleagues (2010) suggest that fatalism include the concepts of pre-determinism (it doesn't matter what you do), luck (my health is a matter of luck) and pessimism (an expectation of poor health). In this light, whilst faith or religious beliefs may influence the degree or prevalence of fatalism associated with cancer within a particular cultural group (Powe & Finnie 2003; Gullatte et al. 2010), it is possible that fatalism may also be a general attitude that contributes to delayed help seeking, present more or less within different culturally groupings and interacting with specific religious beliefs.

There was a strong sense of stigma and secrecy about cancer across ethnic groups in this review. Secrecy and stigma about cancer have also been identified as contributing to diagnostic delay in Irish (Scanlon et al. 2006) and UK lung cancer patient (Tod et al. 2008). The Irish believed that a cancer diagnosis brought shame on the family and was a sign of weakness (Scanlon et al. 2006), while the UK lung cancer patients felt stigmatised due to the association between smoking and lung cancer and a sense of personal blame (Tod et al. 2008). To reduce cancer-related stigma, there is an emerging consensus that effective interventions must be informed by a more thorough understanding of both the culturally-specific and disease-specific variables that contribute to health related stigma (Chapple et al. 2004; Weiss et al. 2006; Stuber et al. 2014; Scambler 2009; Gregg 2011; Chambers et al. 2012).

This review found that help-seeking motivation was associated with a perceived escalation in severity of symptoms, such as pain or bleeding. This has shown to be a factor motivating help-seeking in general populations, (Almuammar et al. 2010) Mexican women (Hubbell 2006) and colorectal cancer (Esteva et al. 2013). Delays associated with misinterpretation of symptoms, and optimistic beliefs about symptoms have been found in studies of rural Australians (Emery et al. 2013), Irish (Scanlon et al. 2006) and people from the UK with lung cancer (Tod et al. 2008). Stoicism was evident in the South East Asian minority groups in this study, but this is a common theme in research in non-minority populations also. Stoicism has been identified as a factor for delayed help seeking in studies of rural Australians (Emery et al. 2013), Irish (Scanlon et al. 2006) British men (Tod et al. 2008) and Hong Kong Chinese (Chan et al. 2009). Stoicism, like fatalism, therefore may be a general attitude that contributes to delayed help seeking, but may be more prevalent in specific cultural or minority groups.

The ways in which fear and pessimism motivate or de-motivate people to seek help is highlighted in this review. Fear of death from cancer was reported across all the minority

groups, yet fear of cancer is not unique to minority populations. Fear is a factor for poor participation in cancer screening in culturally diverse populations (Phillipson et al. 2012; Ashing-Giwa et al. 2010; Waller et al. 2009) and help-seeking in the general population (Tod et al. 2008; Scanlon et al. 2006; Almuammar et al. 2010; Macleod et al. 2009).

The ICBP survey in the UK, Denmark, Norway, Sweden, Australia and Canada explored barriers to help-seeking for cancer symptoms. Two barriers that were most relevant to this review were 'worry what the doctor may find' (ranging from 19-25% of the populations) and embarrassment (ranging from 5.8%-14.5% of the populations) (Forbes et al. 2013). It is worth noting though that in some minority groups included in this review, fear had the potential to both motivate and delay help-seeking. Whether this is specific to people of ethnic minority alone requires more investigation.

Knowledge about causes of cancer, symptom awareness, treatment and prognosis were low across all groups. We found variation in health literacy between the groups, however, with Australian Chinese and Arabic, and American Latinos more aware of actual causes of cancer than the other minority groups. This finding has also been reported in other studies of the general populations in the UK and Australia (Waller et al. 2009; Koo et al. 2010). Greater symptom awareness in the American Latino, Australian Arabic and Chinese and South Asians may be due to more effective delivery of health care information in those settings, but may also relate to wider issues of social equality. Gender (i.e. being female), education level and income have also been shown to be associated with awareness of symptoms for colorectal cancer in Malaysian and Chinese (Loh et al. 2013). The observations about symptom awareness in minority populations may at least be in part due to inequalities in education and income (Marmot 2005). Associations between older age, lower socioeconomic status, lower education level and diagnostic delay for symptomatic cancer have been established in general population studies (Macleod et al. 2009; Scanlon et al. 2006; Neal & Allgar 2005). Similarly, poorer cancer symptom awareness has been identified in the general population in the UK. (Simon et al. 2010); (Mitchell et al. 2008) However, pre-hospital diagnostic delays are longer for people from culturally diverse backgrounds in general, compared to the majority population (Ashing-Giwa et al. 2010; Gorin et al. 2006; Gwyn et al. 2004) and therefore probably not entirely related to social deprivation.

A number of methodological processes and strategies were implemented to ensure a rigorous and systematic approach was adopted for this review and meta-synthesis. An experienced

research team comprising people from a diverse range of social science and clinical research backgrounds conducted this study. The studies were appraised for relevance to the question, reporting and methodological rigour, according to established criteria to ensure that included studies were of medium to high quality. 'Critical Interpretative Synthesis' methods were applied to synthesise the studies' findings and develop the categories and themes.

Limitations to meta-synthesis in general are that they 're-interpret' researcher interpretations of original findings. The CIS method, however, is a rigorous approach and the steps can be reproduced by other researchers which engenders more robust findings. The included studies had adequate geographical diversity, considering the paucity of research with adequate representation from people from ethnic minorities. The majority (86%) of the participants in these studies were women and more than half focussed on breast cancer.

None of the studies had comparator groups of the local population to try and disentangle local versus ethnicity specific factors. Furthermore, there may be cancer beliefs of ethnic minorities embedded in studies of general populations and people of ethnic minority may also identify as a member of the 'general population' within the country they reside in. Acknowledging this issue, this synthesis aimed to compare similarities and differences between ethnic minority groups and discuss them in context with findings in the general population.

Whilst recognising the importance of exploring similarities and differences in cancer beliefs in ethnic minority groups, there are limitations to this task that must be explicitly acknowledged. People from ethnic minority groups, and the groups themselves, are heterogeneous in terms of the individual factors that shape their beliefs, i.e. age, gender, socioeconomic background, education, regency of and country of migration (if a migrant at all), country, language proficiency and religious factors. It is well recognised that culture is only one of the social determinants of health that influences health status (CSDH 2008). The large potential for diversity of individual participants' beliefs must be acknowledged and respected. In conducting this review and synthesis, we are not attempting to fuel assumptions and prejudices about and within specific ethnic groups; rather to highlight how the qualitative studies' findings included in this review may be similar or different. Arguably this may seem an impossible task; however we hope this review initiates debate and further research in this field.

Despite initiatives to increase participation in research by ethnic minority groups, barriers remain (Diaz 2012; Durant et al. 2007). Suggestions for increasing participation include establishing trust with individuals, and forming collaborative relationships with health care providers and community leaders who lend their support with both establishing trust and recruitment (Diaz 2012). There are also higher costs associated with interpreting during interviews and translation of materials such as participant information, consent forms and questionnaires and complex issues also arise when using data collected with the assistance of interpreters (Ingvarsdotter et al. 2012). Notwithstanding these complexities, it is essential that culturally diversity is represented in health care research considering the degree of cultural diversity due to migration in many developed countries.

One third of the studies included in this review were conducted with cancer patients of either UK South Asian (2) or South East Asian (2) backgrounds or with men with various cancers from six ethnic groups (1). Analysis focussed on cancer beliefs relating to symptom appraisal and help-seeking for a cancer diagnosis; only relevant data from these studies was coded during analysis. It is impossible to know whether these participants' beliefs were the same if they had not experienced a cancer diagnosis. However, consensus opinion was that including these studies was necessary because of the relevance of the findings to the synthesis.

The paucity of studies exploring the impact of cancer beliefs on timely cancer diagnosis in ethnic minority populations highlights a need to conduct more in-depth studies. The majority of cancer research with minority populations has focussed on participation in cancer screening programs, which tends to be lower than in the general population (Phillipson et al. 2012; Lesjak et al. 1999; Koo et al. 2010; Javanparast et al. 2010; Severino 2009; Aminisani et al. 2012; Tu et al. 2006; Anon 2012). Interventions to increase participation in screening in culturally diverse populations have either not been evaluated, or have had minimal difference on screening uptake (Masi et al. 2007; Lu et al. 2012; Phillipson et al. 2012). Development of community interventions, tailored to the specific beliefs and barriers to help-seeking for each cultural group, are necessary to reduce delays in diagnosing symptomatic cancer. This review may be helpful to inform these interventions, however, may not be applicable for ethnic minority groups where data are not yet available.

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Table 1: Included studies

Authors	Date	location	Participants	Male : Female	Minority Background	Tumour type	Data collection	Data analysis
Ehiwe et al. (2012)	2012	England	29	9:20	African (Ghanaian and Nigerian)	Any	Focus groups	Iterative inductive analysis
Richardson et al. (2004)	2004	North America	15	15:0	African American	Prostate	Focus groups	Inductive thematic analysis
Florez and Flórez et al. (2009)	2009	North America	25	0:25	Latino	Any	Interviews	Coding and conceptual framework
Karbani et al. (2011)	2011	England	24	0:24	South Asian	Breast	Interviews	Thematic and framework analysis
Kwok et al. (2006)	2006	Australia	20	0:20	Chinese	Breast	Interviews	Constructionist thematic
Luquis and Cruz (2006)	2006	North America	56	0:56	Hispanic	Breast	Focus groups	Thematic and content analysis
Saleh et al. (2012)	2012	Australia	38	6:11	Arab	Any	Interviews	Ethnographic thematic analysis
Shah et al. (2008)	2008	North America	36	11:25	Arab	Any	Focus groups	Thematic
Yeo et al. (2005)	2005	Australia	31	6:25	Chinese	Any	Interviews	Ethnographic thematic analysis
Patel et al. (2014)	2014	England	20	0:20	South Asian (Indian, Pakistani) African, Caribbean)	Breast	Interview	Constructivist Thematic analysis

Table 1: Included studies

Kaur et al. (2008)	2008	Canada	20	0:20	South Asian (Punjabi)	Breast	Focus Groups	Thematic analysis
Bottorff et al. (2007)	2007	Canada	25	0:25	South Asian (Punjabi)	Breast	Interviews	Narrative analysis
Randhawa and Owens (2004)	2004	England	48	Not specified	South Asian (Pakistani Punjab, Indian Punjabi, Bangladeshi Sylheti)	Any	Focus groups	Thematic analysis
Banning and Hafeez (2009)	2010	Pakistan and England	44	0:44	South Asian (Pakistani)	Breast	Focus groups	Thematic analysis
Papadopoulos and Lees (2004)	2004	England	45	Not specified	Chinese	Any	Focus groups	

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Table 1: Included studies

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Table 2: Categories and themes by minority group

	African migrant	Arabic migrant	SE Asian migrant	Latino migrant	Hispanic migrant	Chinese Migrant	South Asian migrant	African American
<b>Interactions with health care service</b>								
Discrimination		•						
Lack of autonomy		•						
Language Barrier	•	•	•	•	•	•	•	
Embarrassment		•	•		•		•	•
Preference for/use of 'traditional medicine'						•		
<b>Emotional reactions to cancer</b>								
Fatalism	•	•	•	•	•	•	•	
God's will		•	•			•	•	
Punishment from god		•				•	•	
Superstition		•	•			•		
Cancer is deadly	•	•	•	•	•	•	•	•
Fear delaying help-seeking	•	•					•	•
Fear motivating help-					•		•	

Table 2: Categories and themes by minority group

seeking								
Secrecy	•	•	•			•	•	
Avoidance					•	•	•	•
Stigma	•	•	•		•	•		•
Taboo		•				•		
<b>Knowledge and Beliefs</b>								
Low health literacy (LHL) about cancer	•	•	•	•	•	•	•	•
LHL about causes of cancer	•	•	•		•	•		•
LHL about cancer treatment and prognosis		•	•			•	•	•
LHL about cancer signs and symptoms	•		•				•	•

**Table 3: Examples of coded excerpts to categories and themes**

Category	Theme	Quote
EMOTIONAL REACTIONS TO CANCER	Fatalism	<p>“Life is like this, if it [cancer] has to happen in your life, you cannot escape it. If it’s yours, it’s yours. If it’s not yours, it’s not yours. That’s life” (Chinese migrant in Australia)</p> <p>“I am not afraid of death as I have gone through everything. Everybody has to go the same way. Nobody can escape.”</p> <p>“She said it was her fate to suffer as war can and from then onwards, she led a difficult life. As she could not change the ming and was fated to have cancer, she would accept it” (Chinese migrant in Australia)</p>
	God’s will	<p>“That is what I believe. If God sends something, we cannot stop it. And we must accept what he sends to us. I believe all things come from God. You cannot make things happen and you cannot not make them happen” (Arab migrant in Australia)</p> <p>“God healed me, and our faith helped us ..we got to be confident and got to carry on...We used to sit together, asked for forgiveness, we used to feel that we have to pray together”(South East Asian in UK)</p>
	Destiny	<p>“You make your own destiny. Because if [mammography] shows a lump in my breast, and I react ‘oh, I am meant to have cancer and will die, because this is my destiny’, No! I will look for my doctor and my medication first. My doctor must tell me what to do...you cannot let destiny influence you, allow destiny to do that to you. You must help destiny, you cannot allow yourself to be controlled by it.” (Latino woman in North America)</p>
	Superstition	<p>“my friend’s husband was having an affair and this mistress used Kong tau in an attend to make him sick but his friend’s brother got sick instead. Her friend has a servant who recognized the practice and suggested that they consult a Dukun, a type of Indonesian black magic practitioner” (Chinese migrant in Australia)</p>

		<p>migrant in Australia)</p> <p>“they must have done something wrong in their previous life. And in this life they get punishment or they have done something wrong in their early life ...my sister who had breast cancer believes it, that she has done something, even minor things and that gave her cancer” (Chinese migrant in Australia)</p> <p>As we Chinese people always say: “good people are rewarded and bad people are punished” (Chinese migrant in Australia)</p> <p>“they must have done something wrong in a previous life, and in this life they get punishment or they have done something wrong in their early life...my sister who had breast cancer believes it, that she has done something, even minor things and that gave her the cancer” (Chinese migrant in Australia)</p>
	Fear	<p>When asked about cancer in general, most women reported that when they heard the word cancer the first thing that came to mind was either “muerte (death),” “temor (fear),” and/or “emfermedad mortal (fatal disease)” (Hispanic woman in US)</p>
	Fear of finding cancer	<p>“When I am feeling sick or suspect cancer...I will not really go to the GP...I’m just scared I don’t know why. I will just keep it to myself till I feel I’m really not feeling good” (African migrant in US)</p> <p>“when you come to the GP for one thing, they will be telling you ...you are suffering from another thing...I mean when one hears it is cancer that you have ... . It is like you are already a dead meat ... .because of the way the cancer kills people ...so it scared a lot of people that they don't even want to hear that kind of thing or see their GP” (African migrant in US)</p>
	Fear of death	<p>“I will not have it [cancer] in Jesus’ name...I will not tell all of them because some of them are very sensitive. I will just tell maybe one of them...that one will keep to herself and encourage me to go for treatment...because if I do...they will say oh my God if the sickness takes mummy what are we going to do?” (African migrant in North America)</p>

	Pessimism	“If I see someone who has cancer, I feel sorry for him. You cannot recover from cancer. For our community and especially in our culture, cancer is a death sentence” (Arabic migrant in US)
	Optimism	“if you go [to the doctor] early and get a [mammogram], if they find something it can be cured. You must get [a mammogram] and always see your doctor, always seek doctors – that’s always good.”
	Stoicism	“I have to be brave and strong. I cannot show the children I am sick. They need their mother to be well. They are still young” (South Asian migrant in UK)
	Secrecy	“when you family has taught you that everything personal is private, how would you go to the family...and say I have breast cancer” (Hispanic migrant in North America)
	Taboo	<p>“all of the general [community] ..., they can’t say ‘cancer’. They say ‘may this be far from us’ bheeden un neh. Yeah, they don’t even say the word” (Arabic migrant in Australia)</p> <p>“This negativity associated with the discussion of cancer amongst some in the community with traditional beliefs was described as one of the main potential barriers to access of health services” (Arabic migrant in Australia)</p> <p>“People feel that if they don’t talk or think about it, it won’t happen. The more you think about it, the higher the chance is that it [getting cancer] will happen.” (Chinse migrant in Australia)</p> <p>“My husband was so sick and to say he had cancer would have killed him faster.” (Arabic migrant in Australia)</p>
	Stigma	“Of course, I would not tell my friends if I had cancer. It [cancer] is not something good for sharing with friends. I don’t also don’t know whether they would tell someone else. I feel bad enough about my cancer. I don’t want to be upset by what people say behind my back. Your family members are different. I am not afraid of telling my family about it.” (Chinese migrant in Australia)

		<p>“we don’t even talk loudly about cancer: we whisper when cancer is mentioned or discussed ...might catch it ... knowing about it is bad luck therefore we don’t talk about it” (South East migrant in UK)</p>
<p>KNOWLEDGE AND BELIEFS</p>	<p>Low health literacy (LHL) about signs and symptoms of cancer</p>	<p>“I was perfectly alright, except that I had a lump that was not causing any problem” (South East Asian woman in UK).</p> <p>“The issue of cancer is something that many people don’t have knowledge of ... because in the first place they don’t know what are the common signs and symptoms of such things” (African migrant in US)</p> <p>“I was washing...and there was a lot of fluid coming out of my breast. My pillow was soaked ...I was shocked when my nephew told me it was cancer. We don’t have it in the family. I never hear about any relatives having it” (South East Asian woman in UK)</p>
	<p>LHL about causes of cancer</p>	<p>“I feel that if anyone goes to the hospital for an operation, he will come back with cancer as if it is an infection. There are also many germs in the hospital” (Arabic migrant in US).</p> <p>“every time someone tests for cancer with this shot, they are diagnosed with cancer” (Arabic migrant in US)</p> <p>“how do you begin to explain the sickness you know nothing of the cause”<sup>7</sup> (African migrant in US)</p> <p>“cancer can spread by saliva. When I eat out [in a restaurant], I wash all crockery before using it” (Chinese migrant in Australia)</p> <p>“... I think cancer is from God. It has no reasons” (Arabic migrant in the US)</p> <p>“God has nothing to do with [people getting diseases]. God would not punish a person in that way. He loves all his children and no father would want to harm his children.” (Latino migrant in US)</p> <p>“People feel that if they don't talk or think about it, it won't happen. The more you think about it, the higher the chance is that it [getting cancer] will happen.” (Chinese migrant in Australia)</p>
	<p>LHL treatment and</p>	<p>“Male” cancers were those that are able to be cured, whereas “female” cancers were described as being “trickier than the other;” “reproduces itself,” “spreads throughout the body.” (Arabic migrant in US)</p>

	prognosis	
INTERACTIONS WITH HEALTH CARE SERVICES	Embarrassment	<p>“we don’t say ‘breast’ to the doctor. We say ‘chest’ pain.”” (South East Asian migrant in UK)</p> <p>“when I went to see the doctor, I knew him and I did not want him to examine me, especially when he asked to look at my breasts – that does not feel right for him to examine me” (South East Asian migrant in UK)</p> <p>“For us, women from Latin America, sex is a taboo. Then, in the beginning it was hard enough for me to go to the doctor, and the clinic, and take off my brassiere and expose myself, and to let other people look at me” (Hispanic migrant in US)</p>
	Language Barriers	<p>“The patient should know what he/she has; this should be in a simple way because doctors use medical terminology that we do not understand; doctors should use simple language in explaining the condition to patients and what the treatment options are if there are any... we should always ask the experts; I will not know more than what the physician knows” <sup>11</sup> (Arabic migrant in US)</p>
	Discrimination	<p>“Hijab only covers my head and not my brains!” (Arabic migrants in the US)</p>
	Lack of autonomy	<p>“women indicated that they were not presented with any treatment options by their physicians, and they had to go with whatever treatment was recommended by their physicians because they were the experts.” (Arabic migrant in US)</p>

## Figure 2: CASP Criteria used to rate methodological quality and quality of reporting

### Methodological Quality<sup>1</sup>

1. Demonstrated congruity between the philosophical perspective and the research methodology.
2. Demonstrated congruity between the research methodology and the research question or objectives.
3. Demonstrated congruity between the research methodology and the methods used to collect data.
4. Demonstrated congruity between the research methodology and the representation and analysis of data.
5. Demonstrated congruity between the research methodology and the interpretation of results
6. Statement locating the researcher culturally or theoretically.
7. Influence of the researcher on the research, and vice-versa, addressed.
8. Participants, and their voices, adequately represented.
9. Research is ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body.
10. Conclusions drawn in the research report flow from the analysis, or interpretation, of the data.

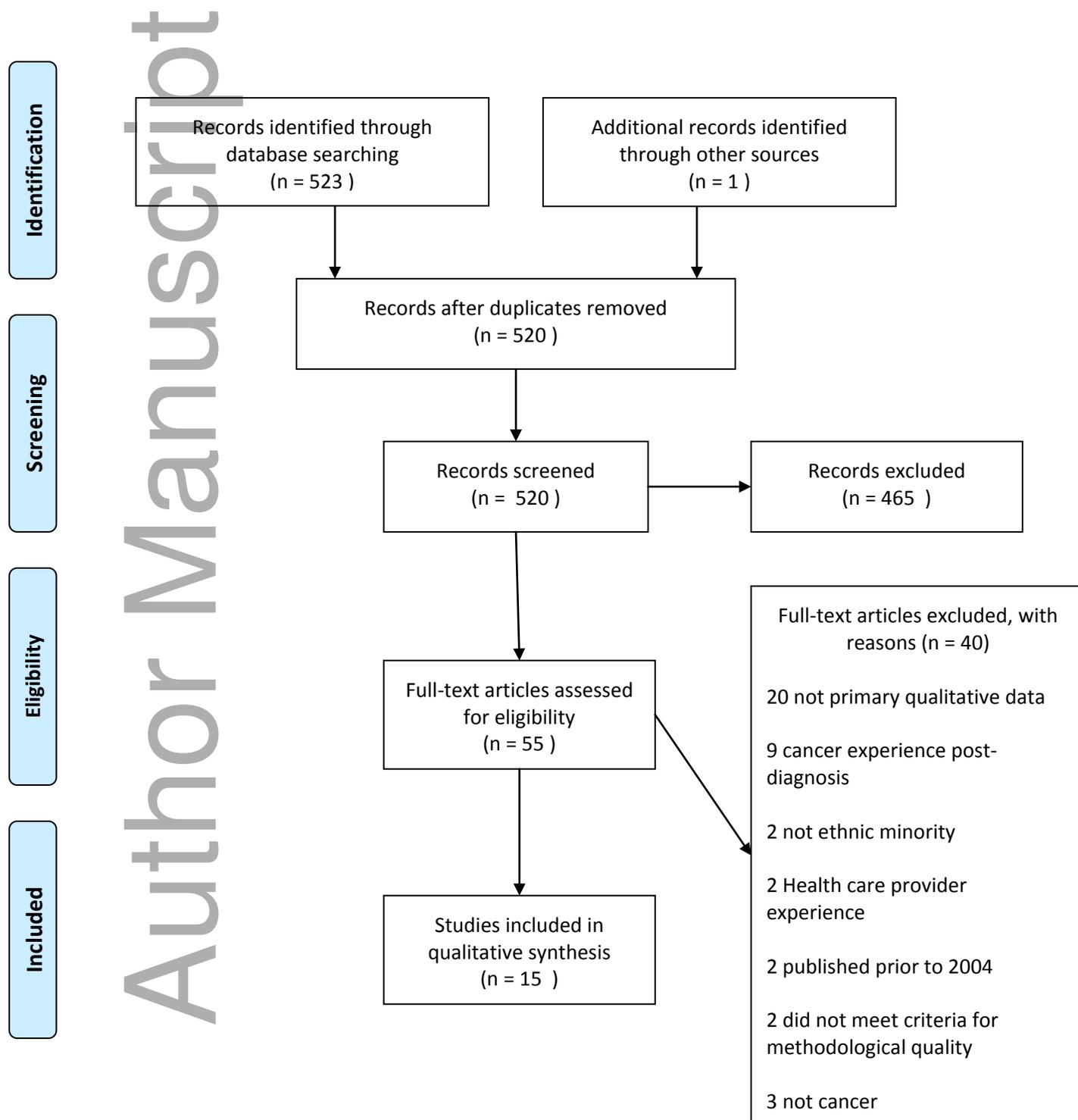
### Quality of Reporting<sup>2</sup>

1. Clear statement of the aims of the research
2. Sampling:
  - a. Where the sample was selected from?
  - b. Why this setting was chosen?
  - c. Who was selected?
  - d. Sample selection appropriate & justified?
  - e. How the sample was selected?
  - f. How many people accepted or refused to take part in the research?
  - g. Why some participants chose not to take part?
  - h. Adequate information given on the characteristics of the people in the sample?
3. Setting and data collection:
  - a. Setting of the data collection
  - b. Why that setting was chosen
  - c. How the purpose of the research was explained and presented to the participants
  - d. How data were collected
  - e. How data was recorded
  - f. Whether the methods were modified during the process and if so, why?
  - g. Who collected the data
4. Analysis:
  - a. How the analysis was done
  - b. How the categories/themes were derived from the data
  - c. Adequate description of the themes/categories
  - d. Attempts to feed results back to respondents
  - e. If different sources of data about the same issue been compared where appropriate (triangulation)
  - f. If analysis was repeated by more than one researcher to ensure reliability
5. Findings:
  - a. Whether the researchers critically examined their own role, potential bias and influence
  - b. Consideration of relationship between researchers and participants
  - c. Sufficient data presented to support the descriptive findings

- Author Manuscript
- d. Quotes numbered/identified
  - e. Researchers explain how the data presented in the paper were selected from the original sample
  - f. Researchers indicate links between data presented and their own interpretations of what the data contain
  - g. Is it possible to summarise the findings?
  - h. Were the findings explicit and easy to understand?
6. Discussion/conclusion
- a. Negative, unusual or contradictory cases presented
  - b. Adequate discussion of the evidence both for and against the researchers' interpretations?
  - c. Conceptual and or theoretical congruence between this and other work
  - d. Discussion of limitations and implications

## PRISMA 2009 Flow Diagram

### Cancer Beliefs in Ethnic minority groups: a review and metasynthesis



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097



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