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

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

## **Abstract**

People from ethnic minorities often experience poorer cancer outcomes, possibly due to later presentation to healthcare and later diagnosis. We aimed to identify common cancer beliefs in minority populations in developed countries, which can affect symptom appraisal and help seeking for symptomatic cancer. Our systematic review found 15 relevant qualitative studies, located in the United Kingdom (six), United States (five), Australia (two) and Canada (two) of African, African-American, Asian, Arabic, Hispanic and Latino minority groups. We conducted a meta-synthesis that found specific emotional reactions to cancer, knowledge and beliefs and interactions with healthcare services as contributing factors in help seeking for a cancer diagnosis. These findings may be useful to inform the development of interventions to facilitate cancer diagnosis in minority populations.

## **Keywords**

ethnic, populations, minority, review, meta, cancer, synthesis, qualitative, beliefs, studies

## **Disciplines**

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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).

Culture is considered a social determinant of health that acts at a community and population level. Broadly speaking, the definition of culture encompasses ideas, customs, social behaviour, attitudes and characteristics of a particular social group. Whilst culture appears to influence understandings about cancer, cultural explanations must also be considered in light of other economic and social determinants (Dein 2004). 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). A collaborative research initiative, the International Cancer Benchmarking Partnership (ICBP), has been established to explore how social and/or cultural factors influence cancer patients' symptom appraisal and help-seeking, and to determine if these factors influence diagnostic delay. ICBP recently reported international differences in cancer awareness, and barriers to help-seeking but there were insufficient participants from culturally diverse backgrounds to examine the effect of culture (Forbes et al. 2013).

Ethnic diversity is a characteristic of many high-resource countries as migration from developing to developed countries is growing rapidly. One-fifth of the world's migrant population resides in the United States with representation from over 60 countries. This cultural diversity is also reflected in populations in Australia, the United Kingdom, Canada

and New Zealand (Parsons & Walmsley 2011). Studying cancer beliefs, and factors specific to ethnic minorities, is therefore essential to inform health services provision within countries and globally.

Previous meta-syntheses exploring cancer from an ethnic or cultural perspective have been conducted, yet they focus either on experiences post-diagnosis, (Harun et al. 2013; Macleod et al. 2009; Evans et al. 2008; Yoo et al. 2014) participation in screening, (Lu et al. 2012; Javanparast et al. 2010; Masi et al. 2007) Indigenous peoples' beliefs and knowledge about cancer screening, (Kolahdooz et al. 2014) or understanding of cancer risk (Lipworth et al. 2010). There has also been a meta-synthesis of studies of diagnostic intervals in specific ethnic populations in the United Kingdom (Martins et al. 2013) and a quantitative synthesis focussing on diagnostic delays and health service access related to bowel cancer screening (Javanparast et al. 2010). This review is the first to identify cancer beliefs commonly held in ethnic minority populations.

## **Methods**

### **Data Selection**

We searched Medline, CINAHL, Cochrane, PsycINFO and Web of Knowledge for full-text articles published in peer-reviewed journals from 2004 to April 2015. The inclusion criteria were; qualitative studies published in English reporting primary findings about cancer beliefs in ethnic minority populations with participants over 18 years, who may or may not have experienced a cancer diagnosis. We included only qualitative studies because the methodology allows an in-depth exploration of this topic. Studies focussing on cancer screening participation, health care provision and survivorship were excluded because we wanted to focus on beliefs that may influence decision-making and help-seeking for a cancer diagnosis. The publication years were limited to the previous ten years to ensure the data were contemporary, considering the changing nature of cultural contexts. The search strategy was approved by all co-authors. The following search terms and keywords were used in various combinations for the respective database searches by two researchers (SL; PPCC): cancer or neoplasms; culture; ethnolog\*; diagnosis; beliefs; health knowledge; health care access; attitudes; humans (Figure 1). Articles with keyword 'screening' were excluded because attitudes to screening have been published in previous reviews. Reference lists of included articles were searched by the reviewers for further relevant articles and where

possible the authors were contacted to request further information or identify additional papers for review.

### **Study Selection**

Two reviewers (SL; PPCC) conducted the literature searches and identified papers suitable for abstract review. Papers were selected by these reviewers for full-text review. Additional studies were identified by screening reference lists of included papers and by consultation with authors.

### **Data extraction**

Data were extracted by two reviewers into a pro-forma modelled on the Critical Appraisals Skills Program (CASP) (CASP UK 2013) criteria (Figure 2). The 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 this pro-forma. Demographic data and findings were then uploaded into *Dedoose*<sup>®</sup> (Sociocultural Research Consultants (“SCRC”) 2014) software for analysis.

### **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 526 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 United Kingdom (six), United States of America (five), Australia (two) and Canada (two). The mean number of study participants was 31.7 (range 20-56), with a total of 476 participants included 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). The quality of reporting and methodology was measured using CASP criteria (Figure 2), with scores ranging from 24-30/35 points.

The following six categories were identified: knowledge, fatalism, attitudes, secrecy, fear, health service barriers. These categories were present across all of the ethnic minority groups. There were differences in the specific themes within each of these categories, between cultural groups (Table 2). Examples of quotations for each theme and category are provided in Table 3.

### **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 low levels of knowledge about cancer. Established causes of cancer, such as lifestyle and genetic factors, were mentioned infrequently. Low levels of knowledge 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.

Low health literacy 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.

Lack of knowledge 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 low level of health literacy in regard to treatment and prognosis.

### **Fatalism**

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'.

### **Attitudes**

Attitudes about cancer included optimism, pessimism, pragmatism, stoicism, self-sacrifice and denial. Fear and knowledge about cancer influenced the attitudes that people within the ethnic groups expressed toward cancer. Most of the migrant groups had a pessimistic attitude about cancer prognosis; except for Latino Americans who were optimistic about treatment and prognosis for breast cancer when detected early. Pessimism influenced decisions about help-seeking: some ignored their symptoms out of fear, which led to denial and secrecy (e.g. Southern Asians in the UK). Others' fatalistic beliefs engendered a pragmatic attitude, such as Chinese Australians, who saw illness as a natural part of life and symptoms or discomforts a normal process of aging which did not require consultation with a medical practitioner. The American Latino women's optimism about cancer treatment (when detected early) motivated them to seek help early. In contrast, stoicism was a barrier to help-seeking for breast cancer in the English South East and Southern Asian groups as well as the African-American men in regards to prostate cancer. The Arabic, South East and Southern Asian, Hispanic and English Africans tended to put their family needs above their personal health, and would delay help-seeking out of concern for their family's emotional or practical needs.

### **Secrecy**



Secrecy and 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.

### **Fear**

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 expressed a nihilistic belief that cancer diagnosis equates to death. The Australian Chinese and South East Asians were more likely to hold fatalistic, faith-based beliefs about death and dying which engendered a pragmatic attitude towards illness and death, and were therefore less fearful of death from cancer. 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 people. For example, because of beliefs around contagion, stigma and taboo, the South Asian groups expressed fears of being diagnosed with cancer because they would then be avoided by friends and family. These issues led to women hiding symptoms from their family and avoiding help-seeking.

### **Health Service Barriers**

Themes relating to barriers to accessing health services included 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.

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.

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 is not yet available.



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