

REVIEW PAPER

A qualitative systematic review exploring lay understanding of cancer by adults without a cancer diagnosis

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Accepted for publication 23 November 2013

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BALMER C., GRIFFITHS F. & DUNN J. (2014) A qualitative systematic review exploring lay understanding of cancer by adults without a cancer diagnosis. *Journal of Advanced Nursing* 70(8), 1688–1701. doi: 10.1111/jan.12342

Abstract

Aim. To explore the lay understanding of cancer.

Background. Lay understanding of illness is shaped by social identity, personal biography and experience. It informs how ill health is defined, concerns are managed and interventions evaluated. An appreciation of lay understanding is therefore vital to enable relay of effective and appropriate health information to the public and care provision and support to patients.

Design. A qualitative systematic review using Thomas and Harden's (2008) approach to thematic synthesis.

Data sources. Key social science, nursing and medical databases, cancer organization websites for grey literature and a hand search of references retrieved from particularly relevant articles and journals.

Review methods. Thematic synthesis of eligible papers (studies on adults without a cancer diagnosis, generated from WHO-defined 'high-income' countries and published between 1990–2011). Only those focusing on the understanding of cancer, rather than screening or cancer genetics, were included.

Results. Six analytical themes were identified from 26 papers, generated from 25 studies. Explorations of the causes of cancer and interpretation of personal risk dominated the published work. These revealed a significant complexity in lay understanding. This review has also highlighted the need for additional work, particularly in gaining an understanding of the stigma and fear that surround cancer.

Conclusion. The themes identified by this review have the potential to inform the development of appropriate health promotion strategies and clinical services for those living with cancer and lead to a better understanding of problematic areas, such as late presentation, which continues to impede efforts to improve cancer survival.

Keywords: cancer, nurse–patient relationships, qualitative approach, sociology, systematic review

Why is this review needed?

- Lay concepts of health and illness are shaped through personal identity, biography and experience.
- They dictate how people define illness, maintain health and whether, when and why they seek professional medical help.
- An understanding of lay understanding and how it mediates concepts of health and illness is important to enable effective and appropriate care provision.

What are the three key findings of this review?

- Among people without a diagnosis of cancer, understanding of cancer is complex.
- Life experiences influence knowledge and understanding.
- Perceived causes of cancer and interpretation of individual risk interact with fear and stigma.

How should the findings be used to influence policy/practice/research/education?

- Our findings help explain persistent problematic areas, such as why people with suspicious symptoms delay accessing health care.
- Lay understanding of cancer should inform health promotion strategies.
- Healthcare professional education should continue to include awareness of lay understandings and how to elicit them from those seeking their expert advice.

Introduction

Studies of lay understanding of health and illness have led to an appreciation of how such concepts are rooted in the fabric of everyday life. People shape their understanding through cultural and social identity, personal biography and the *experience* of illness and its significance to daily living (Herzlich & Pierret 1987, Williams & Popay 1994, Nettleton 1995, Blaxter 2010, Henderson 2010). For example, Helman demonstrated a sophisticated local knowledge of the causes and treatment of colds and fevers. Although some interpretations seemed at odds with medical and nursing wisdom, they provided logical and valid explanations to situations and helped people to 'make sense' of illness (Helman 2000, p. 91).

Lay understanding also informs how health concerns are communicated, illnesses managed, interventions evaluated and ill health defined and validated (Leventhal *et al.* 1997, Dein 2004, Blaxter 2010). Most health work is performed by non-professionals, through self-care or by caring for others. Recognition of how lay understanding shapes and mediates concepts of health and illness is important to

enable effective and appropriate care provision and support (Noyes & Popay 2007, Lipworth *et al.* 2010).

The experience of cancer has changed in recent years. As survival rates improve, cancer is increasingly considered a long-term illness (Corner 2008, Macmillan Cancer Support 2011). However, for some cancers, late presentation of symptoms continues to thwart efforts to improve survival rates further (Almuammar *et al.* 2010). Understanding how people perceive cancer and respond to it in their everyday lives can contribute to the development of appropriate health promotion and access to health care.

The review**Aim**

The aim of this review was to explore the lay understanding of cancer through a thematic synthesis of contemporary studies employing qualitative methods. Our objectives were to establish what is already known about lay understanding of cancer, consider how this could inform policy and practice and to identify gaps in the research evidence. Our research question was: 'What is understood about cancer by those without a cancer diagnosis?'

Design

To meet our objectives, we undertook a systematic review to ensure that our review was transparent, identified as much of the relevant research as possible and included an assessment of the quality of the evidence (Bryman 2008, Aveyard 2010). Thematic synthesis of the literature was appropriate to our research question (Dixon-Woods *et al.* 2005, Thomas & Harden 2008). This approach seeks to develop descriptive and analytical themes through being inductive and adopting line-by-line coding and constant comparison (Barnett-Page & Thomas 2009).

Search methods

Our search was conducted by CB during Summer 2012. As lay understanding is rooted in the social and cultural experience of illness (Helman 2000), we focused on social science-related databases (e.g. Web of Knowledge, ASSIA, Sociological Abstracts, PsychInfo), but also searched Medline. Using Boolean terms and connectors, the permutations of keywords and terms in Box 1 were searched.

The review was augmented by a hand search of references from retrieved articles and journals identified as

particularly relevant. Websites of large cancer charities and organizations were also searched for pertinent grey literature, such as policy documents or ongoing studies.

Box 1: Permutations of keywords and terms searched

lay/social/cultural/public understanding	cancer/oncology/tumour /tumor/neoplasm
lay/social/cultural/public knowledge	cancer diagnosis/ diagnoses
lay/social/cultural/public perspective(s)	cancer treatment(s)
lay/social/cultural/public belief(s)	cancer prognosis/ prognoses
lay/social/cultural/public attitude(s)	cancer outcome(s)

Search outcome

Our search produced many papers that had explored understanding with patient populations. However, it is argued that people with a diagnosis of cancer are more influenced by the biomedical understanding of cancer than those without a diagnosis (Lipworth *et al.* 2010, Del Castillo *et al.* 2011). We were interested in the understanding people without a diagnosis hold as this may influence presentation where cancer is suspected. It has been shown to influence the response of individuals towards family members, friends or colleagues who are diagnosed with cancer and the support they offer (Buick 1997, Weinman *et al.* 2003). We, therefore, selected only studies on populations without a diagnosis of cancer. Our initial search also identified many reports based on quantitative surveys. However, these rely on a limited range of responses, whereas methodologically an understanding of lay knowledge should be as egalitarian as possible and phenomenologically open (Williams & Popay 1994). We only included studies that had employed qualitative methods. As lay understanding is a dynamic phenomenon, influenced and changed by social and political time and place (Williams & Popay 1994, Nettleton 1995), searches were limited to contemporary studies (publication 1990–2011, inclusive).

We excluded papers exploring the understanding of genetic testing or screening, such as mammography. These areas are important in contemporary oncology, but beliefs about them may be different from understanding of the disease itself. However, studies that incorporated genetic understanding while also containing data on general cancer understanding were included (e.g. Sanders *et al.* 2003) as were studies that reviewed lay understanding of other illnesses if cancer was included (Walter & Emery 2005, Lindenmeyer *et al.* 2011).

We only included research generated from countries defined as ‘high income’ by the World Health Organisation (WHO 2010) (Box 2). We recognize that geographical exclusion may seem crude, but lay understanding of health and illness is culturally framed (Helman 2000) and we wished to eliminate papers that provided an understanding about cancer in cultures very different from our own. Studies on immigrants to ‘high income’ areas or indigenous populations with a unique culture and history, such as Aboriginal Australians, were also excluded as these tended to highlight ethno-specific factors only.

Box 2: World Health Organisation-defined ‘high income’ (WHO 2010)

Andorra, Antigua and Barbuda, Australia, Austria, Bahamas, Bahrain, Barbados, Belgium, Brunei, Darussalam, Canada, Croatia, Cyprus, Czech Republic, Denmark, Equatorial Guinea, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Kuwait, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Oman, Portugal, Qatar, Republic of Korea, San Marino, Saudi Arabia, Singapore, Slovakia, Slovenia, Spain, Sweden, Switzerland, Trinidad and Tobago, United Arab Emirates, United Kingdom, United States of America.

There is a small body of literature describing children’s understanding (e.g. Oakley *et al.* 1995, Williams & Bendelow 2000, Forrest *et al.* 2006, Mosavel & El-Shaarawi 2007). However, as children appear to differ in their understanding of cancer causality and risk depending on age (Sigelman *et al.* 1993) we excluded this literature. Where a study included both adults and younger people (e.g. Silk *et al.* 2006), we included the results relating to adults. Twenty-five eligible studies (reported in 26 papers) were identified, as shown in Table 1.

Quality appraisal

Two researchers (CB and FG) independently appraised the papers and came to a consensus about which to include and exclude through discussion. To ensure rigour, credibility and relevance, we used the Critical Appraisal Skills Programme Appraisal Tool for Qualitative Research (PHRU 2007), which is a commonly used means of appraising health research (Campbell *et al.* 2003, Walter *et al.* 2004). The outcome of our appraisal is presented in Table S1. We did not reject any study due to poor quality.

Table 1 Summary of studies included in review.

Authors, date published & setting	Stated aim of study	Sample & how recruited	Method of data collection
Armstrong and Murphy (2008), East Midlands, UK	Explore interplay between lay and professional understanding of cervical cancer risk	35 women aged 20–64 recruited via community groups & snowballing in difficult-to-reach groups	Semi-structured interviews
Baron-Epel and Klin (2009), Tel-Aviv, Israel	Identify beliefs and attitudes of cancer from a Jewish urban population	41 men and 41 women aged over 50	9 focus groups
Chalmers and Thomson (1996), Canada	Explore & describe meaning of risk in women with primary relatives with breast cancer using a symbolic interaction framework	55 women aged 20–70 recruited via index cases, responding to adverts & snowballing	Semi-structured interviews
Emslie <i>et al.</i> (2001), West of Scotland, UK	Explore lay beliefs of heart disease (<i>included in this review because perceptions of death from CHD compared with perceptions of death from cancer</i>)	61 men and women aged 40–49 purposively sampled and recruited from a large epidemiological survey	Topic-guided interviews
Hallowell (2006), London, UK	Explore understanding of risk in women with a family history of ovarian cancer	49 women aged 31–50 recruited via the national Familial Ovarian Cancer Register & 2 cancer genetics clinics	Semi-structured interviews
Han <i>et al.</i> (2009), Washington DC & Chicago, USA	Explore laypersons' understanding of cancer risk & identify conceptual problems that may limit understanding	48 men & women aged 50–74, purposively sampled & recruited by telephone	8 focus groups
Heikinen <i>et al.</i> (2010), Finland	Examine accounts given by smokers in response to argument that smoking is a risk to health	40 male & female current or former smokers, aged 24–58, recruited via workplace adverts in 14 companies & organizations & snowballing	Semi-structured interviews
Johnson and Dickson-Swift (2008), Victoria, Australia	Explore young women's perceptions of breast cancer	6 female students aged 20–25 recruited via university-placed flyers & personal contacts	Semi-structured interviews
Katapodi <i>et al.</i> (2005), USA	Identify heuristics that influence perceived breast cancer risks	11 women who had experienced abnormal breast symptoms recruited via community survey of breast health behaviour	Semi-structured interviews
Kenen <i>et al.</i> (2003), UK	Explore how people from suspected hereditary breast & ovarian cancer families are influenced by family stories & heuristics when interpreting & applying genetic information	21 women referred to genetics service, but with unknown status, recruited from clinics	Semi-structured interviews & observation of clinical encounters
Lindenmeyer <i>et al.</i> (2008), UK	Explore how personal experience of ill health translates into vulnerability (<i>included in this review because some understanding of breast cancer evolved from explorations of experience</i>)	69 women, minimum age 45 (not stated how many with experience of cancer) recruited via health care & community organizations	Semi-structured interviews
Lindenmeyer <i>et al.</i> (2011), UK	Explore the definitions & understanding of family history held by lay people (<i>included in this review because some discussions about cancer understanding evolved from exploration</i>)	10 White, British men & women aged 51–69 recruited via urban library reading groups & adult education venues	Semi-structured interviews

Table 1 (Continued).

Authors, date published & setting	Stated aim of study	Sample & how recruited	Method of data collection
Lowry and Craven (1999), North East England, UK	Examine perceptions & understanding of oral cancer among drinkers & smokers	27 male drinkers & smokers aged 45–60 recruited via door-to-door market research interviewers	3 focus groups
McAllister <i>et al.</i> (1998), Ireland	Describe attitudes and experiences of brothers of women with hereditary breast cancer	22 men (brothers) aged 25–60 recruited via index cases.	Semi-structured interviews
McFall <i>et al.</i> (2006), Oklahoma City & Houston, USA	Compare beliefs across 3 racial/ethnic categories about prostate cancer aetiology, risk, screening & decision-making	33 African American, 35 Hispanic & 22 non-Hispanic White men & women, mean age 54, recruited via adverts in clinics & clinical identification.	12 focus groups
McKenna <i>et al.</i> (2006), Northern Ireland, UK	Explore understanding, attitudes & behaviours relating to cancer prevention measures.	Full study consisted of questionnaire-based study & focus groups. Only analyses of focus group data included in this review. Exact number of participants not stated; men & women aged 35–54 recruited via letter from Northern Ireland Health & Social Services Board	6 focus groups (qualitative analysis)
Robb <i>et al.</i> (2007), South West England, UK	Investigate perceived risk of developing colorectal cancer	Full study consisted of mailed questionnaire & interviews to investigate perceived risk. Only analysis of interviews reviewed here. 16 men & women aged 60–63 recruited via 2 urban GP practices & about to take part in a screening study for colorectal cancer	Topic-guided interviews (qualitative analysis)
Salant and Gehlert (2008), Chicago, USA	Explore community understanding of breast cancer & breast cancer risk	Exact number not stated, predominantly African American men & women recruited via community & local media adverts	18 focus groups
Sanders <i>et al.</i> (2003), Bristol, UK	Explore perceptions of heredity, genetics & risk.	24 purposively sampled first-degree male & female relatives of people with breast, colon or prostate cancer recruited via index cases (8 in each group)	Semi-structured interviews
Sanders <i>et al.</i> (2007), UK	Examine how people rationalize risk in relation to health problems (<i>included in this review because of some exploration of perceived cancer risk</i>)	16 men & women recruited from 4 GP practices	Semi-structured interviews
Scanlon <i>et al.</i> (2006), London, Manchester & Glasgow, UK	Identify and explore explanatory models of cancer among Irish & British people.	Purposive sample of 58 1 st , 2 nd or 3 rd generation Irish & 57 White British men and women aged 35–75 recruited via community, workplace, local media & cancer organization adverts plus snowballing	20 topic-guided interviews & 10 focus groups

Table 1 (Continued).

Authors, date published & setting	Stated aim of study	Sample & how recruited	Method of data collection
Sheikh and Ogden (1998), UK	Explore understanding of cancer & reasons for seeking help for symptoms	Full study consisted of questionnaire to assess cancer symptom understanding & follow-up interviews to explore understanding of cancer & reasons for seeking help. Only analysis of interviews included. 6 men & 14 women, aged 18–66, recruited via urban GP practice	Interviews based on 6 open-ended questions
Silk <i>et al.</i> (2006), USA	Evaluate adolescent & adult females' understanding & perceptions of breast cancer & environmental factors using the Health Belief Model	36 women (aged 21–55) & 55 girls (aged 9–15) recruited via university, school & youth organizations. 'Mother' & 'girl' groups analysed separately allowing just adult understanding to be reviewed here.	10 focus groups (4 'mother only' groups)
Thomas (2010), Denver, USA	Explore awareness & knowledge of male breast cancer among men using framework of critical social theory & hegemonic masculinity	28 men aged 30–60 without breast cancer, but with ≥ 1 maternal relative(s) with breast cancer, recruited via flyers placed in local businesses, newspapers, churches & University of Colorado	Semi-structured interviews
Walter and Emery (2005), Cambridgeshire, UK*	Explore how people understand & come to terms with their family history of cancer, heart disease or diabetes	30 adult men & women with an identified family history (14 with cancer) recruited from 2 GP practices	Semi-structured interviews
Walter and Emery (2006), Cambridgeshire, UK*	Compare % contrast perceptions of family history across common diseases using the Common Sense Model of Self-Regulation of Health and Illness	30 men & women with an identified family history (14 with cancer) recruited from 2 GP practices	Semi-structured interviews

*Separate analyses from the same study reported in two papers.

Data abstraction

Thematic synthesis advocates computer-assisted qualitative data analysis software (CAQDAS) to ensure thorough scrutiny of the data (Thomas & Harden 2008, Barnett-Page & Thomas 2009). The text in each eligible paper relating to our research question was extracted and uploaded into the CAQDAS package NVivo8.

Thematic synthesis

The extracted text was studied line by line, annotated and organized into hierarchical 'nodes' following the three stages of thematic synthesis (Thomas & Harden 2008). Stages one and two involved an iterative process of coding

text and developing emerging descriptive themes. As we were not approaching the data from a particular theoretical stance, we adopted an integration/aggregation, rather than interpretive, approach to this (Sandelowski & Barrosa 2007). The third stage involved going beyond the content of the original studies to generate additional understanding and analytical themes. This involved identifying where themes interconnected and how they could be synthesized. The themes identified and the nodes from which they were developed are illustrated in Table S2.

Results

The numbers of articles identified, screened, included and excluded are outlined in Figure 1. Six themes were identified,

three relating to understanding of cancer generally in contemporary society ('causes of cancer', 'identifying cancer', 'the social image of cancer') and three relating to cancer and the individual. These included 'interpreting personal risk of cancer', 'dealing with an awareness of cancer' (how cancer and risk are addressed and managed on a day-to-day basis) and 'obtaining information about cancer' (where reliable cancer information is seen to come from).

Causes of cancer

Lay understanding about cancer causation (cancer generally or referring to a specific 'type' of cancer) was explored in

all the papers reviewed. The chance of developing cancer was often reported as being arbitrary, but the most commonly cited specific causes were hereditary factors, age and lifestyle and environment (e.g. smoking, exercise, diet, sexual activity, pollution).

The emphasis we found on hereditary factors may have been because of the focus of some studies'. For example, Kenen *et al.* (2003) interviewed genetic service attendees and others recruited family members of people with cancer (Chalmers & Thomson 1996, McAllister *et al.* 1998, Sanders *et al.* 2003). However, participants in studies recruiting from more general settings also referred, explicitly or implicitly, to hereditary factors. Many participants'

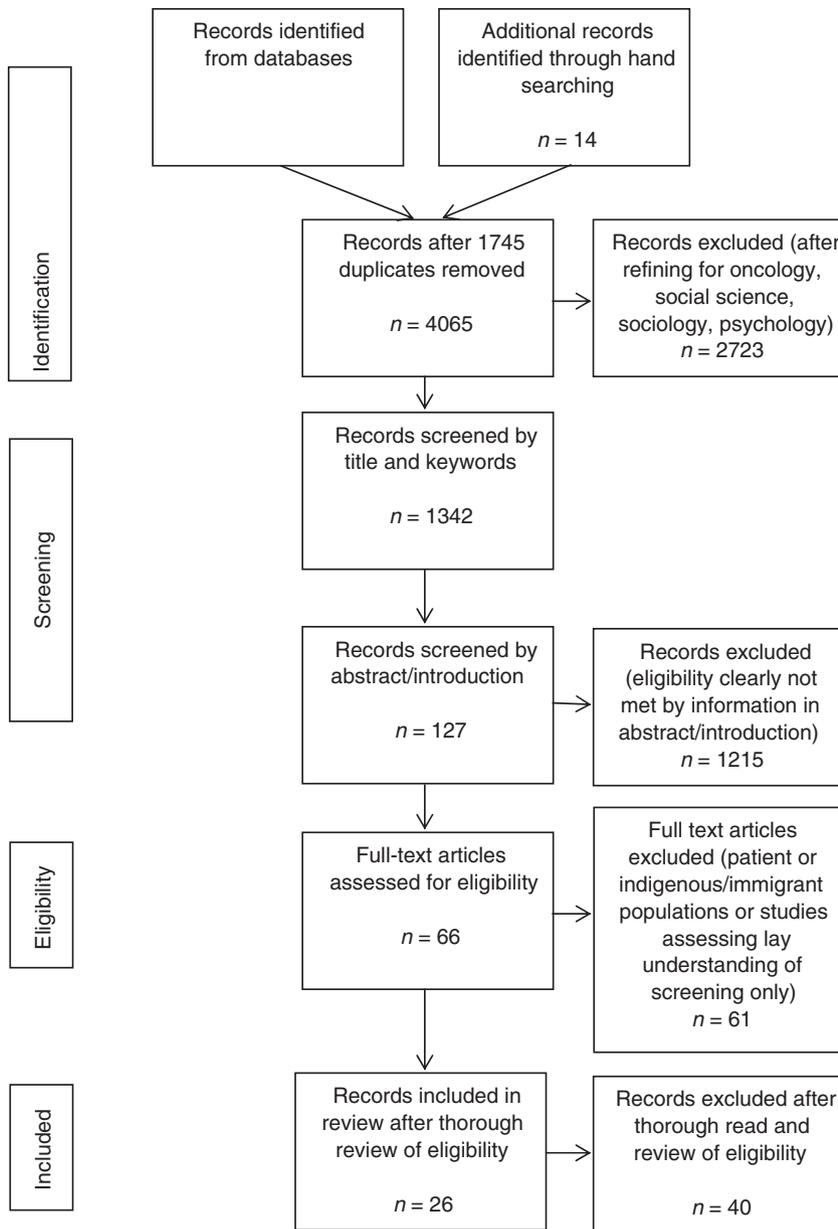


Figure 1 Information flow diagram (after PRISMA 2009).

explanations were cautious and descriptions uncertain: 'something in the family blood flow that gives everyone this little bit of cancer' (participant in study by Kenen *et al.* 2003). Cancer was described as missing generations, favouring genders or being 'stronger' if passed from certain individuals: 'the genes of my father go through the females in our family' (participant in paper by Robb *et al.* 2007). Despite awareness that cancer often has a genetic cause, the concept that cancer risk may be hereditary was hard to acknowledge for both people with a family member with cancer and those without. Sanders *et al.* (2003), McAllister *et al.* (1998) and Kenen *et al.* (2003) all describe participants who referred to other causes to explain their relative's cancer, such as lifestyle, non-adherence to screening or trauma, rather than conceding genetic factors. The lack of a family history was seen as a reassuring protection (Lindenmeyer *et al.* 2011).

Many studies' participants identified increasing age as a cause of cancer, although often secondary to hereditary factors. For instance, one of Lindenmeyer *et al.*'s (2008) participants said 'suddenly, in their eighties and nineties, relatives have got it. We didn't have cancer in the family now I'm thinking, oh it's started, so therefore – you know, is there a risk?' Youth was seen as a protective factor; consequently, risk was sometimes not addressed until an older age. A participant in her twenties in Katapodi *et al.*'s (2005) study described how she would lose weight in her forties to lower her perceived higher risk of breast cancer and Silk *et al.*'s (2006) younger participants did not consider breast self-examination as relevant to them. Certain age-related milestones were perceived to be times when the body was vulnerable. Armstrong and Murphy's (2008) participants identified the menopause as a particularly risky time when 'things can happen in your balance and everything is upset'.

Understanding of lifestyle causes was often complex and ambiguous. Participants across the studies had an image of those likely to develop cancer. These were sedentary, poorly educated, 'worriers' who often ate 'unhealthy' diets. Study participants felt they could exert control over their cancer risk by avoiding certain lifestyles. However, many knew of people with cancer who did not fit this stereotype, which confused their image of who 'gets' cancer. The cancer risks related to smoking and alcohol were infrequently mentioned. People who did smoke and/or drink recognized the risks, but related them to a greater consumption than theirs. The risks and benefits of lifestyle choices were debated by participants in many studies. For example, is it beneficial to avoid a 'pub culture', which usually involved alcohol consumption (when and where many of these studies were conducted) or embrace it as it provides a sense of belonging and an escape from

stresses (Lowry & Craven 1999, Scanlon *et al.* 2006); can smoking control food intake and prevent obesity or are there too many smoking-related cancer risks (Heikinnen *et al.* 2010); should HRT be taken as it prevents osteoporosis or not as it increases breast cancer risk (Lindenmeyer *et al.* 2008)? The modern environment was sometimes seen as a cause of cancer. Participants in two studies, which recruited participants from both minority and majority ethnic groups, understood cancer diagnoses to be greater in minority groups because they lived and worked in more polluted locations (Scanlon *et al.* 2006, Salant & Gehlert 2008).

Physical and emotional trauma and infections were also cited as causes of cancer and were related to the belief that cancer was innate and just needed something to trigger it. These causes were often used to explain cancer occurring in non-stereotypical people.

Identifying cancer

Understanding of the signs and symptoms of cancer was often vague, for example, 'lumps anywhere they shouldn't be' and 'blood from anywhere it shouldn't be' (participant from Sheikh & Ogden's 1998 study). In all papers, there was little discussion on symptoms specific to cancer types. Sometimes participants admitted being unsure about specific symptoms and their meaning. Participants in three studies debated whether painful 'lumps' were something to worry about or not (Katapodi *et al.* 2005, Silk *et al.* 2006, Thomas 2010). Only two studies compared gender and cancer awareness. Both reported women being more confident about their understanding of symptoms than men (e.g. McKenna *et al.* 2006, Scanlon *et al.* 2006).

Self-examination and screening were considered reliable ways of detecting cancer and 'buying yourself a bit more life' (participant in Sheikh & Ogden's 1998 study), although many admitted to not doing this. Screening was occasionally perceived as something to begin once symptoms became apparent (Sheikh & Ogden 1998). The few studies that addressed different types of cancers diagnosis differentiated between 'good' cancers with identifiable symptoms, which could be detected quickly and 'bad' cancers with vague or commonly experienced symptoms, which were therefore diagnosed late and inevitably led to death (Katapodi *et al.* 2005, Scanlon *et al.* 2006).

The social image of cancer

Cancer was described in eleven studies as something to be feared (McAllister *et al.* 1998, Sheikh & Ogden 1998, Lowry & Craven 1999, Walter & Emery 2005, 2006,

McKenna *et al.* 2006, Scanlon *et al.* 2006, Silk *et al.* 2006, Salant & Gehlert 2008, Baron-Epel & Klin 2009, Lindenmeyer *et al.* 2011). A participant in Sheikh and Ogden's (1998) study explained, 'I think when you hear the word cancer it seems to hit you between the eyes...you hear about other diseases, that can be just as bad, but there is something about cancer'. Although it was generally appreciated that treatments had improved and cancer was no longer an 'automatic death sentence' (participant in Salant & Gehlert's 2008 study), the 'cancer equals death' (participant in Scanlon *et al.*'s 2006 study) equation was still pervasive. Salant and Gehlert (2008), Sheikh and Ogden (1998), Silk *et al.* (2006), Scanlon *et al.* (2006) and Walter and Emery (2005) all reported participants for whom the fear of cancer was so great that they did not engage in self-examination or information seeking.

Cancer was more feared than other life-threatening diseases, such as heart disease or diabetes (Emslie *et al.* 2001, Walter & Emery 2006) and death from it was seen as more inevitable and somehow worse. Perceptions of 'quick' deaths following heart attacks or trauma were contrasted with images of protracted and painful cancer deaths. Participants recalled friends and relatives 'fighting for every breath, wanting an extra day all the while' and ending up in a 'pitiful state' (participants in Hallowell's 2006 study). Even those who had not witnessed cancer imagined sufferers 'dying inch by inch' (participant in Sheikh & Ogden's 1998 study).

The image of cancer as shameful or a personal weakness was also strong for many study populations (McAllister *et al.* 1998, Lowry & Craven 1999, Kenen *et al.* 2003, Scanlon *et al.* 2006, Salant & Gehlert 2008) exemplified by a woman in Walter and Emery's (2006) study who described 'the punishment of pain' associated with cancer.

Interpreting personal risk of cancer

In the many studies that explored this, most participants were optimistically biased about their risk of developing cancer: 'I'm much more like my Dad's side...they live real long' (participant in study by McAllister *et al.* 1998). Participants distanced themselves from risks they were aware of or offset them with 'healthy behaviour', for example, smoking was counterbalanced by exercise (Heikinnen *et al.* 2010) and hereditary risk was lessened by healthy eating (Kenen *et al.* 2003). A participant in Lindenmeyer *et al.*'s (2011) study admitted being complacent about her breast cancer risk and not attending for mammography because she felt her risk of heart disease was greater.

Awareness of a 'difficult' cancer death heightened risk perception, but the factor that seemed to influence it most across the studies was an individual's resemblance to a family member with cancer, both physically or in personality and mannerisms (McAllister *et al.* 1998, Kenen *et al.* 2003, Sanders *et al.* 2003, 2007, Walter & Emery 2005, Lindenmeyer *et al.* 2008). A participant in Kenen *et al.*'s (2003) study reported taking her son to see his great aunt when she was very sick with cancer and saying to him: 'there's you in that bed, even your faces look alike' in an attempt to stop him smoking. Conversely, distinction in looks or characteristics reduced perceived risk.

Dealing with an awareness of cancer

Cancer was rarely addressed in day-to-day life by healthy, unaffected people: 'You are thinking about providing food for your children – whether or not you are going to have shelter, with the economy being the way it is now, cancer sits on the back burner. It only comes up when it becomes personal' (participant in study by Salant & Gehlert 2008). Many studies described active avoidance of talking about or acknowledging it (McAllister *et al.* 1998, Sheikh & Ogden 1998, Lowry & Craven 1999, Kenen *et al.* 2003, Sanders *et al.* 2003, McKenna *et al.* 2006, Scanlon *et al.* 2006, Salant & Gehlert 2008). A participant who had a sister with breast cancer explained: 'I just wouldn't want to think about it...Because I think if you did, my goodness me, you'd be down that road. I can't afford to think like that' (Sanders *et al.* 2003). For some of Salant and Gehlert's (2008) participants, dwelling on cancer was seen to cause it by increasing anxiety. However, this was frustrating for others who felt they needed more family information to determine personal risk (e.g. women in Kenen *et al.*'s 2003 study).

The exclusively male participants in two studies saw dealing with cancer as a gendered activity and reported that women were more likely to consider risk and talk about cancer than men (McAllister *et al.* 1998, McKenna *et al.* 2006). Some of the largely African American participants in Salant and Gehlert's (2008) study felt that addressing cancer risk was an indulgence that could not be afforded by the less advantaged.

Obtaining information about cancer

Some studies reported information sources that their participants had accessed (Sanders *et al.* 2003, Katapodi *et al.* 2005, Hallowell 2006, Robb *et al.* 2007, Salant & Gehlert 2008). Predominant sources were family members and social networks, including friends, peers and public figures

diagnosed with cancer. Witnessing the treatment, and sometimes death, of someone close was perceived as the most reliable source of information. Scanlon *et al.* (2006) suggest that this may lead to a laissez-faire attitude about risk in those with less personal exposure, such as younger people. Other cited information sources were television, the internet, books and newspapers. Although there was debate about its trustworthiness (e.g. McKenna *et al.* 2006), media sources were seen as most reliable by younger people (Johnson & Dickson-Swift 2008).

The experience of personal contacts was quoted as counter evidence to medical information (Heikinnen *et al.* 2010). Information sourced from health professionals was the most criticized, being seen as inconsistent (Lowry & Craven 1999), unreliable (McKenna *et al.* 2006), causing misunderstanding (Kenen *et al.* 2003, Armstrong & Murphy 2008) or unavailable (Thomas 2010). Two African American participants in Salant and Gehlert's (2008) study talked of a historical 'cultural aversion to doctors' and 'distrust for the medical system', which stemmed from most doctors they knew being White and therefore 'insensitive to the needs of black folks' and affirmed by, for example, the Tuskegee experiments (Jones 1989).

Discussion

As this review has shown, lay understanding of health and illness is necessarily reinterpreted in terms of experience and everyday life and reconstructed via narrative to explain its relationship with an individual's life as a whole (Davison *et al.* 1991, Williams & Popay 1994, Stacey 1997). As Blaxter (2010) describes, most medical histories related by patients are long, interconnected and carefully worked through accounts of events and circumstances combining the influences of heredity, life events, working and living environments, personalities and choices. In contrast, literature with a biomedical emphasis tends to privilege scientific knowledge. The public are perceived as passive consumers of health information whose failure to comply with cancer health promotion messages or non-responsiveness to possible signs and symptoms of cancer is explained by knowledge deficit (Springett *et al.* 2007, Henderson 2010). In common with other sociological work on health beliefs, the analytical themes we identified reveal a significant complexity in lay understanding of cancer, particularly concerning understanding of its causes and the interpretation of personal risk (Blaxter 1983).

Many people played the risk of cancer down, believing that age or personal lifestyle choices would prevent it in themselves and others (fitting a stereotype) would get it. This is similarly explored in the work on lay understanding

of coronary heart disease by Davison *et al.* (1991, 1992). They describe how people identify 'candidates' more at risk of developing heart disease. This notion of 'candidacy' provides a mechanism where risk can be assessed (usually reassuringly) and strategies to decrease risk and explain distressing events can be formulated. People also incorporate a certain amount of fallibility into the concept of candidacy so that it only indicates an increased risk while death remains random (Davison *et al.* 1991). Likewise in the themes identified here, participants recognized that 'non-stereotypical' people could receive a cancer diagnosis and some causes were capricious.

Our review identified hereditary factors as the most commonly cited cause of cancer. This has been noted elsewhere. For example, in her classic study of women's concepts of disease causation, Blaxter (1983) identified that hereditary factors were given much more credence by her participants than medical science assumed. However, participants found it difficult to accept a genetic tendency and searched for additional reasons to explain a cancer diagnosis. Hallowell (1999) explains this by suggesting that the 'geneticisation' of cancer has led to the re-categorization of healthy people as 'at risk'. This implies a responsibility towards both themselves and future generations and an obligation to manage their risk, which may cause unwanted anxiety.

Another explanation may relate to the stigma around cancer (Sontag 1991, Stacey 1997). Similarly to Blaxter's participants, some participants from the papers we reviewed admitted rarely acknowledging cancer, as if 'to talk about it was to invoke it' (Blaxter 1983, p. 67). This may lead to late presentation of symptoms or prevent people from seeking support (Sontag 1991, Chapple *et al.* 2004). Those considered 'at risk' may also experience stigma. For example, Lindenmeyer *et al.* (2011) describe cancer being spoken about in their study of health talk in families, but excluded from narratives of inheritance and suggest that this is due to the enduring stigma attached to cancer. The perceived likelihood of death following a cancer diagnosis endures despite the advances in treatment and survival in the last 30 years (Macmillan Cancer Support 2011). The images held of a cancer death are horrific and frightening. Such fatalistic beliefs may influence the observance of 'expert' health advice and health promotion strategies (Nettleton 1995).

However, the participants represented in this review understood the most reliable source of cancer information to come from individuals with experience of it (either known personally or heard about through other people or the media). The experiences and circumstances of such people challenged biomedical information, sometimes causing non-adherence to health promotion strategies or mistrust of

expert advice. People know individuals who experience cancer, some will have lived 'unhealthy' lives, but some will not and this will influence their understanding of cancer.

Health promotion remains stubbornly positivist and modernist and obscures the complexity of how people negotiate their lives, socially, economically and politically (Williams 2003, Springett *et al.* 2007). Furthermore, strategies are necessarily population-based and rely on small gains achieved through considerable alterations in individual lifestyle (Davison *et al.* 1991, Springett *et al.* 2007, Blaxter 2010). For example, the increase in life expectancy gained from a 10% reduction in serum cholesterol in a population is only between 2.5–5 months, but, for an individual, this requires lifelong dietary modifications or drug treatment, with attendant side effects (Fitzpatrick 2001). Rose (1985) calls this the 'prevention paradox' in that preventative measures that benefit populations often bring no benefit to the participating individual.

Strengths and weaknesses of review

We believe all relevant and eligible articles were identified as the same references appeared repeatedly in our database searches. Of the studies exploring a specific diagnosis, many were about breast cancer and some cancer types were absent from the literature. Although, class, gender and ethnicity issues were discussed in some studies, it is difficult to draw any conclusions on these issues due to insufficient information about study samples, the number of single-gender studies (female:male 8:4) and the different disease sites represented.

Few authors were specific about the motivation behind their research, but differences were apparent. Some studies sought to explore how lay understanding was framed, created and incorporated (Hallowell 2006, Armstrong & Murphy 2008). Many were explicit in their aim of motivating compliance with screening and adherence to healthy behaviour (Johnson & Dickson-Swift 2008, Baron-Epel & Klin 2009). These authors took an educative standpoint and appeared to assume that lay interpretations were 'misunderstandings' that needed correcting. Kenen *et al.* (2003, p. 849) describe widespread 'misconceptions' in their population and Johnson and Dickson-Swift (2008, p. 253) talk about their participants having 'very low levels of knowledge about breast cancer' and the need to 'increase knowledge and adherence'.

Conclusion

Cancer will affect a large proportion of individuals living in 'high income' countries. However, there are a relatively

small number of qualitative studies that have examined understanding of cancer among people without a diagnosis of cancer. Further research is needed to clarify the role and impact of stigma and fear related to cancer among those without a diagnosis. This might lead to a better understanding of delay in help seeking. Studies of lay understanding have also been criticized for being over descriptive and not exploring actual behaviour (Blaxter 2010) and we recognized this in our review. However, we identified several themes from the existing literature concerning lay understanding of the causes, identification and risk of cancer and how people deal with (or ignore) these. These are important as they provide detailed understanding, frame perception and form a basis of what is known about cancer in society and lay communities. This review draws together evidence of how people notice, talk about and develop their own experiential explanations about cancer and other illnesses, possibly incorporating, but not simply reinterpreting, 'expert' knowledge. Health professionals who recognize this will be well placed to provide effective and appropriate health information and advice about cancer.

Funding

This review was part of a fellowship funded by the West Midlands Strategic Health Authority research training fellowship for nurses, midwives and allied health professionals.

Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

All authors meet at least one of the following criteria (recommended by the ICMJE: http://www.icmje.org/ethical_1author.html) and have agreed on the final version:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

Supporting Information Online

Additional Supporting Information may be found in the online version of this article:

Table S1. Outcome of CASP appraisal.

Table S2. Key themes identified and nodes from which they evolved.

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