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Beliefs and beyond: what can we learn from qualitative studies of lay people's understandings of cancer risk?

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ABSTRACT

Background: Clinicians and public health professionals are centrally concerned with mediating risk. However people often resist the risk-related information that is communicated to them by experts, or have their own models of risk that conflict with expert views. Quantitative studies have clearly demonstrated the importance of health beliefs and various cognitive and emotional processes in shaping risk perception. More recently, a growing body of qualitative research has emerged, exploring lay conceptualisations, experiences and constructions of cancer risk. To date, this literature has not been synthesised.

Objective: We report the findings of a synthesis of qualitative literature regarding the ways in which lay people construct and experience cancer risk.

Design: We identified 87 articles and used the method of "thematic synthesis" to identify and interpret key concepts from existing studies.

Results: Eight analytic categories were developed: 1) perceptions of risk factors; 2) process of risk perception; 3) seeking control and taking responsibility (motivational factors); 4) experiencing cancer directly; 5) constructing risk temporally; 6) embodying risk; 7) identifying with risk; and 8) constructing risk in a social context.

Conclusions: Qualitative enquiry can provide us with a rich and nuanced picture of the ways in which people understand, experience and construct risk and how being 'at risk' is managed, and can assist us in our communication with both individual patients and populations.

INTRODUCTION AND RATIONALE

Clinicians and public health practitioners are centrally concerned with effective communication of risk-related information. Unsurprisingly, people often resist the information that is communicated to them by experts, or have their own models of risk that conflict with expert views.¹ This makes it difficult for health professionals to

communicate risk, both to individuals and populations, and to help people make decisions about their risk-related behaviours. It is important, therefore, that both public health practitioners and clinicians have a good understanding of the ways in which people understand risk, including (but not limited to) the ways in which people might interpret epidemiological evidence in light of their beliefs, values and preferences.

This need for effective communication of risk is particularly relevant in the area of cancer prevention, where knowledge of even life-threatening risk factors does not always result in behaviour change. In recognition of this, a large body of research has attempted to elucidate the ways in which people conceptualise cancer risk. The greater part of this research has been quantitative, largely taking the form of surveys examining cancer-related knowledge and “health beliefs”,² and psychometrically-based studies of the effects of cognition, emotion and intuition on risk perception.³ But there is also a growing body of qualitative research into lay understandings, constructions and experiences of cancer risk. This research—like qualitative research more generally—has the advantage of being able to inductively derive the concepts used by participants to explain risk, and understand them in context, rather than deductively imposing a specific notion of risk.⁴

While qualitative research has the potential to assist with health communication, it is difficult for practicing clinicians and public health practitioners to access and make use of this information. It is increasingly recognised that syntheses of qualitative research (like meta-analyses of quantitative studies) have the potential to provide information that can inform clinical and public health practice.⁵⁻⁹ Thomas and Harden, for example, have argued for the use of qualitative synthesis to better understand a particular health-related behaviour or set of behaviours (such as healthy eating) from the perspectives of the people targeted by interventions, so as to better plan interventions that are likely to be effective in bringing about sustainable behaviour change, and to identify future research needs.¹⁰

With this goal in mind, we systematically reviewed the published qualitative research on lay conceptualisations of cancer risk, with the aims of: 1) determining what the qualitative research literature tells us about how lay people construct and experience the risk of developing cancer, and how this can enrich existing insights from the quantitative research literature; 2) making this information accessible and useful to clinicians and public health practitioners and 3) identifying any gaps requiring further research.

METHODS

Methods for synthesising qualitative research are currently under debate.⁶ Our method of qualitative synthesis was based on Thomas and Harden’s description of “thematic synthesis,”¹¹ a method designed for use in health promotion. What thematic synthesis has in common with other methods such as “meta-ethnography”⁹ and “metasynthesis”¹² is that they involve identifying key concepts from published studies, but then “going beyond” the studies to identify similarities and offer novel interpretations not found in any single study. Thematic synthesis uses the well-

established qualitative research technique of thematic analysis to inductively identify themes and abstract across published qualitative studies.

Identification of papers for review

We undertook a search of CINAHL, Medline, Psychinfo, and Web of Knowledge using search terms including “cancer”, “risk” and “qualitative”, as well as a number of specific qualitative methodologies (such as “grounded theory”, “ethnography” and “narrative”). The search terms were deliberately broad so as to avoid missing important articles. The search was undertaken in three stages: 1) initial database search 2) hand search of the reference lists of papers identified in stage 1, and 3) database search for published studies citing papers identified in stages 1 and 2. As proposed by Margarete Sandelowski, our aim was to recall as many papers as possible (that is, we sought sensitivity more than specificity), and to this end we employed a dynamic and iterative searching strategy, following leads to maximise the inclusiveness of our search.¹²

A paper was included if:

- the study participants were lay people, with lay people defined as anyone who was not a healthcare professional;
- the aim of the published study was (at least in part) to explore how lay people thought about the risk of cancer (studies that were solely about treatment or the experience of having cancer were excluded);
- the data collection and analysis method were reported as qualitative by the authors; and
- it was published in English in a peer reviewed journal between March 1992 and February 2009

In total, 87 relevant papers were identified (refer to supplementary bibliography here).

Appraisal

All papers were independently reviewed by at least two authors. Excluding papers on the basis of methodological quality was made difficult by a frequent lack of detail in reporting methods and methodology, and we faced the well-recognised epistemological challenges in attempting to critically compare different qualitative methodologies.⁶ But insofar as we could evaluate quality, no studies were poor enough to warrant exclusion on methodological grounds. Moreover, our aim was to find maximum variability and make a useful interpretation of the literature, rather than to identify the “best” publications on the topic. We decided, therefore (like Thomas and Harden¹¹ and others⁷) to err on the side of inclusion rather than exclusion and to judge quality on the basis of conceptual contribution as much as methodological rigour.

Extracting data from studies and thematic synthesis

Following Thomas and Harden, analysis of the manuscripts was approached inductively with the broad research question: “what does this paper tell us about lay understandings, constructions and experiences of cancer risk?”. The synthesis

involved an initial phase of open, line-by-line coding, during which we tried to summarise the key concepts in each paper. We then looked for similarities and differences between the codes in order to start grouping them into a hierarchical tree structure consisting of a number of “descriptive themes”. These “descriptive” themes were then developed into more abstract “analytical” themes, by asking what they were all “about” in a more abstract sense, and these analytic themes were then grouped into eight overriding analytic categories (**Table 1**). This cyclical process was repeated until all of the line-by-line and descriptive themes were adequately captured in a more abstract analytic category. Each paper was read by two researchers and agreement was reached on the most important descriptive themes. Analytic categories were first developed by WL and their plausibility as syntheses of the descriptive themes was ensured through ongoing discussion among all of the authors.

Table 1: Examples of codes, descriptive themes and analytic themes

Examples of descriptive themes (based on groups of codes)	Analytic categories	Broad groups of analytic categories
<ul style="list-style-type: none"> - Cancer is caused by physical injury - Positive thinking is protective - Cancer and death can happen to anyone/ are inevitable - Absence of physical symptoms means absence of disease 	<ul style="list-style-type: none"> - Beliefs - Knowledge - Understandings - Views - Preferences - Attitudes 	Perceptions of risk factors
<ul style="list-style-type: none"> - Lowering perceived risk by focusing on physical differences (vs genetic similarities) - Justifying risky behaviour by focusing on the present and downplaying the future - Justifying risky behaviour by being fatalistic - Sense of risk being increased by degree of anxiety - Not being able to articulate perception of risk 	<ul style="list-style-type: none"> - Scales: rationality/irrationality; objectivity/subjectivity - Processes: attenuation, re-prioritisation, rationalisation, justification, filtering through personal philosophies and narratives, comparison, disavowal/denial - Reactions: emotions (fear, guilt, shame), intuitions 	Process of risk perception
<ul style="list-style-type: none"> - Maintaining illusion of control by downplaying risk - Maintaining sense of control by taking action/gathering information - Not wanting information unless action is possible - Resisting reassuring information - Protective action as responsible behaviour - Justifying inaction through fatalism 	<ul style="list-style-type: none"> - Agency/helplessness - Action/Inaction - Reassurance through information; - Responsibility/blame/regret 	Seeking control and taking responsibility (motivational factors)
<ul style="list-style-type: none"> - Risk salience increasing through personal experience of cancer 	<ul style="list-style-type: none"> - Risk as lived and increased by familiarity - Traumatic experiencing of risk 	Experiencing cancer directly

<ul style="list-style-type: none"> - Own cancer experiences “trumping” objective information 	<ul style="list-style-type: none"> - Changing receptiveness to risk - Tangible/vicarious/empathetic knowledge of risk 	
<ul style="list-style-type: none"> - Becoming an “at risk” person in stages/ through phases - Becoming an “at risk” person at the same age as a relative who developed cancer - Being chronically “at risk” - Giving varying levels of attention to risk 	<ul style="list-style-type: none"> - Phases of life - Waxing and waning risk - Family history - Danger zones - Chronicity 	Constructing risk temporally
<ul style="list-style-type: none"> - Test results seen as messages from the body - No symptoms meaning no risk 	<ul style="list-style-type: none"> - Corporeality; - Symptoms and signs (and the silent body/ body as messenger) - Threat from within/ the treacherous body 	Embodying risk
<ul style="list-style-type: none"> - Not being “healthy” or “sick” - Sense of a compressed life/ foreshortened future - Sense of urgency in achieving life goals - Becoming used to being an “at risk” person 	<ul style="list-style-type: none"> - Biographical disruption (including future memory and life goals) - Liminality - Risk and the lifeworld - Integration/ normalisation/ accommodation of risk 	Identifying with risk
<ul style="list-style-type: none"> - Health promotion as scare-mongering; - Pain of the stigma associated with at-risk status - Managing own risk to help others 	<ul style="list-style-type: none"> - Trust/mistrust of people and information - Importance of place/ family; community - Culture/society/narrative/politics - Importance of support - Pain of stigma - Risk behaviour shaped by concern for others 	Constructing risk in a social context

RESULTS

Who is studied in qualitative research?

For the most part, existing qualitative research has studied people considered to be at increased cancer risk, which has included people with: 1) symptoms or signs suggestive of increased risk (such as breast symptoms or abnormal pap smears); 2) family history or genetic susceptibility (most commonly to breast and ovarian cancer); 3) increased behavioural risk due to, for example, drinking alcohol, smoking or using sunbeds; 4) increased environmental risk due to exposure and 5) cancer survivors at risk of recurrence or second cancers. Interestingly, the exceptions, studies of ostensibly “healthy” people, focused on specific age groups or ethnic groups, who were seen to be at higher-than-usual risk, either due to higher rates of risky behaviour or lower rates of participation in screening programmes: targeted groups included young women, African-Americans, African and Latin-American immigrants to the United States and Asian immigrants to the United States, Canada and Australia (the majority of studies of migrant groups took place in the United States).

What methods are used in qualitative cancer risk research?

Data was gathered either through in-depth interviews, focus groups or analysis of extant texts. Data analysis methods, where stated, were described as thematic analysis, discourse analysis, ethnography, thought unit analysis, grounded theory, life course analysis and content analysis. While several studies were positioned within sociological theories of risk, analyses were largely inductive and focused on for the most part on cognitive or psychological phenomena.

Analytic categories derived from the qualitative synthesis

Fifty-five analytic categories were developed from the line-by-line codes which were, in turn, synthesised into eight overriding analytic categories (Table 1): 1) perceptions of risk factors 2) process of risk perception; 3) seeking control and taking responsibility (motivational factors); 4) experiencing cancer directly; 5) constructing risk temporally; 6) embodying risk; 7) identifying with risk; and 8) constructing risk in a social context. Categories 1,2 and 3 seemed to us to have the most overlap with existing psychological research into risk perception. Hence the names given to these categories would be familiar to quantitative psychologists. While these categories reflect broadly distinct domains, some degree of overlap was unavoidable and expected. Talk of fatalism, for example, was relevant to several of our categories (health beliefs, rationalisation processes and the perception of control and moral responsibility), and the various means of cognitively processing risk information emerged not only an analytic category in its own right, but also as an important component of several other categories. There was also unavoidable overlap between identity, embodiment and time. We recognise that it would be possible to categorise

these papers differently, with different emphases and with more or fewer divisions. We emphasise, therefore, that our goal in generating these eight categories was not to try to represent eight distinct and objective “realities”, but rather to generate an inductively-derived categorisation for use by clinicians and public health practitioners.

1. Perceptions of risk factors

Many of the qualitative studies of cancer risk explored people’s beliefs and attitudes regarding cancer risk factors and their management. Some of these studies focused on specific risk/protective factors, including diet, sexual activity, pesticide exposure, sunbed use, infection, heredity and genetic risk. Beliefs of different groups were often compared, including men and women, adults and adolescents, different ethnic groups, and lay people and health professionals. A number of culturally-specific beliefs about risk were identified. For example, in a study of the influence of traditional Chinese beliefs on cancer screening behaviour among Chinese-Australian women, Kwok and Sullivan¹³ found that these women are heavily influenced by cultural traditions related to the lifecycle, and disease prevention, and tended to take a fatalistic view of cancer risk. Beliefs and attitudes were found to stem not only from cultural belief systems but also from personal health narratives. In a detailed narrative analysis of one woman with breast cancer, for example, Lawson¹⁴ made the connection between a deprived and traumatic life history and various “misperceptions” about the cause of cancer, such as cancer being caused by trauma to the breast.

Only a few studies derived new risk typologies of beliefs about health risk inductively from participant’s accounts (something that can only be achieved through qualitative research). Chapman¹⁵, for example, studied the perceived link between diet and breast cancer and inductively developed three perspectives on what kind of diet might be protective against cancer: a “traditional” perspective (“meat and potatoes”); a “mainstream” perspective (a balanced, low-fat diet); and an “alternative” perspective (avoiding artificial additives and modifications).

Even where no direct comparison was made between the beliefs of lay people and health professionals, such a comparison was usually implicit in the interpretation of results. With only a few exceptions, whenever lay beliefs were found to differ from the biomedical model, these differences were considered to represent failures in knowledge, understanding and/or memory or, at best, to represent a state of understandable uncertainty in the face of conflicting information.

2. Process of risk perception

Many qualitative studies focused on the idea that the process by which risks are conceptualised is not purely “rational” or “objective” but rather is (re)configured through a number of cognitive processes. These included simplifying and suppressing information, making various kinds of comparisons and rationalising desired beliefs. In a study of reasons for sunbed use, for example, Murray and Turner¹⁶ found that

people engage a number of strategies to justify their ongoing use including suppressing undesirable information about the riskiness of their behaviour and rationalising their decision on the grounds that the short-term benefits outweighed long-term dangers. And in a study of women with a family history of breast cancer, Werner-Lin demonstrated the way in which women compared themselves to relatives, with the aim of finding phenotypic differences, so as to reduce their sense of being at risk.¹⁷

In addition to focusing on cognition, many qualitative studies emphasised the way in which discussions of cancer risk and personal experience of cancer (particularly at times of uncertainty) evoked strong emotions including guilt at not protecting oneself or others; shame associated with an expectation of stigma; as well as the obvious sense of anxiety and “ontological uncertainty”. It was not surprising, therefore, that many studies found that a person’s emotional state could affect the meaning that they give to cancer, their construction of risk and their associated behaviour. McAllister,¹⁸ for example, found that people at increased genetic risk of colon cancer can be more or less “engaged” (by which was meant that some people have greater “cognitive and emotional involvement” with their increased genetic risk), and that those who were more “engaged” were more likely to believe themselves to be carriers, irrespective of the risk estimate that they had been given by counsellors. Several studies attempted to link emotional responses to behaviour, and a strongly emotional response to risk was sometimes associated with the perceived need to engage in protective behaviour, and at other times with disavowal, denial or avoidance of risk.

Other studies showed that how the process of risk construction was shaped by intuitions, particularly when information was incomplete (which was often the case) or when emotional impacts of cancer were unresolved. Chalmers and Thompson¹⁹, for example, identified three methods by which women who had cared for relatives with cancer went about personalising their own risk: reasoned (reflecting an objective and knowledgeable view of risk), intuitive (especially when information was incomplete or emotional impacts of cancer were unresolved) and variable (especially during early experiences with cancer when the sense of risk could vacillate strongly). They described intuitive risk perception as an instinctive, imagined, semi-stable perception of risk based upon an emotional interpretation of information and experience.

3. Seeking control and taking responsibility (motivational factors)

In many of the analysed qualitative studies, a sense of control and the related ability to take action (whether information-seeking, screening or preventive behaviour) enabled people to avoid fatalism or existential uncertainty, reduce anticipatory regret, put their minds at rest (or at least know what was to be expected), find a degree of security and “get on with their lives”. A number of studies demonstrated that people went to great lengths to construct their cancer risk, or other people’s cancer experiences, such that a sense of control was sustained. Sanders et al,²⁰ for example, observed that, in an effort to maintain a sense of control, some

participants attempted to play down their genetic (and therefore unmodifiable) risks, even in the face of strong family histories of cancer. People had particular difficulty reconciling evidence that others had become ill despite engaging in protective behaviour, and needed to either come to terms with a fatalistic stance and accommodate uncertainty or (as discussed previously under “processing”) recalculate or rationalise their view of events in such a way that a belief in control could be sustained.

Information seeking was one of the major strategies by which people attempted to achieve control, but attitudes towards knowledge and surveillance were mixed and people derived varying degrees of certainty from available information. While some struggled with uncertainty and saw information as a “lifeline”, for others uncertainty itself was a psychological resource and fatalism and inaction seemed a reasonable, and even comforting, stance. Attitudes towards information were particularly ambivalent if this information was not associated with clear means of control or if it generated more uncertainty, too much information or too many competing options. Ryan and Sugg Skinner,²¹ for example, found that first degree relatives of women with breast cancer were ambivalent about risk counseling in the absence of preventive measures. The extent to which information and action were linked was particularly clear in a study by Phelps et al²² which found that a significant subset of women undergoing genetic testing for breast cancer were paradoxically disappointed at being told that their risk was low or moderate, because this meant that immediate action was not warranted.

Several studies demonstrated an implicit link between taking control and a sense of moral responsibility. While many participants saw themselves as having a moral responsibility to take control and engage in personal advocacy (as, for example, in Chapple et al’s²³ study, which demonstrated the extent to which prostate cancer screening was construed as responsible behaviour), some resented the sense of personal responsibility and associated blame. These people used a lack of control (e.g. having “cancerous genes” or mistrusting health professionals), a sense of not needing to take control (e.g. not having a genetic risk, so not having to worry), or a lack of certainty about risks, to absolve themselves of the moral responsibility to engage in self-protective or screening behaviour.

4. Experiencing cancer directly

Several qualitative studies emphasised that risk perceptions were strongly influenced by one’s own personal experiences of having cancer or of caring for a family member with cancer. In these cases, risk was first *experienced*, and subsequent biomedical screening or the development of cancer tended to simply confirm what was already experientially known. Several studies demonstrated the ways in which an experience of cancer heightened risk in people’s awareness and showed that the sense of being at risk was greatest if the experience was more direct and traumatic.

In various studies, people described themselves as “*feeling*” at risk and developing a kind of “*tangible*” knowledge about risk. This kind of personal, vicarious or

experiential knowing seemed to override epidemiological evidence if, for example, one or one's relative had developed cancer despite their being at a low risk epidemiologically. D'Agincourt-Canning,²⁴ for example, studied people with a family history of breast and ovarian cancer, and observed the power of "empathetic" knowledge about cancer which often took precedence over objective clinical estimates of risk. Indeed, familiarity with cancer, either in oneself or in a family member, could breed contempt for biomedical predictions and subsequent testing. The power of personal experience was also evident in studies which suggested that cancer education could not have an impact unless people were first made receptive by personal experience.

5. Constructing risk temporally

Closely related to experiencing cancer directly, several studies emphasised that people's perceptions of cancer risk were related to the phases of life, and waxed and waned over time. Some studies focused on how people caring for relatives developed their own sense of risk, which tended to emerge only *after* the phase of "living through" cancer with the relative. Chalmers and Thomson,¹⁹ for example, identified three phases of becoming an "at risk person": living the cancer experience, developing risk perception and putting risk in its place. Other studies showed how a family history of cancer might become salient at a particular point in time. Werner Lin¹⁷ observed that, for women at increased risk of breast cancer, the age at which their relative was diagnosed became a temporal "danger zone" in their own lifecourse. Reaching the "danger zone" led to a fairly abrupt onset of a sense of vulnerability and increased efforts to cope and achieve control.

The temporality of the at-risk experience was described in a particularly rich way by Kenen et al,²⁵ who observed that in its chronicity and variation over time, the state of being at risk had much in common with chronic illness.

6. Embodying risk

A number of qualitative studies showed that people experienced risk as a "corporeal" or "embodied" phenomenon. For some people, personal risk was something that was at first "silent" (and perhaps only detectable through screening), then "activated" by the development of a symptom or sign. In their study of men previously diagnosed with prostate cancer, for example, Hedestig et al²⁶ noted that prostate-specific antigen (PSA) testing was seen by some men as a "message from the silent body". This is in contrast to other studies which demonstrated that people assume that if they are asymptomatic, they cannot possibly be at risk, as evident for example in Weitzman et al's²⁷ study of lay understandings of the risks of colorectal cancer.

An embodied sense of risk could have profound effects on the conceptualisation and experience of risk. People with bodily changes simultaneously confronted current disease and the possibility of future disease. They also faced a threat from within themselves which became incorporated into their sense of self. At worst, people

viewed their own bodies (e.g. those with precancerous cervical abnormalities²⁸) as treacherous because these bodies were the source of cancer risk.

7. Identifying with risk

Qualitative research demonstrates clearly that cancer risk impacts upon identity. In many cases being “at risk” demanded use of the health system, affected relationships, and led to biographical disruption (that is, it disturbed the lifecourse one had imagined for oneself). Scott et al²⁹, for example, found that people who were at increased genetic risk of cancer tended to see themselves in a “liminal” position, unable to identify with either the healthy or the sick, and that such individuals consequently sought recourse to systems of medical surveillance that could continuously monitor their state of health. In keeping with the findings we previously reported regarding control and responsibility, this sense of liminality could be more acute for those who were found to be at low genetic risk and were thus excluded from surveillance and care. In addition to disrupting one’s life course, the state of being at risk could also create a sense of a compressed life, a foreshortened future and a sense of urgency surrounding the achievement of life goals, such as having children.¹⁷

While being at risk is clearly disruptive to identity, several studies also showed that people could accommodate, integrate, or normalise risk (and associated surveillance) into their sense of self, even becoming redefined by and “living” their risk of cancer. This was particularly the case when risk was experiential or embodied, and where it evolved over time. Hallowell et al³⁰, for example, described the way in which a heightened bodily awareness of risk and a high level of monitoring eventually gave way to a state in which people had learned to “accommodate” the risk of a recurrence within their lives. Identification with cancer was not, however, universal, and some studies demonstrated that people adopted a variety of stances to the information provided by mainstream medicine information, including a variable willingness to take on the role of an “at risk” person and engage in the related screening/preventive behaviours.

Qualitative research also demonstrates that the extent to which one incorporates risk into identity subsequently influences one’s perception of ongoing risk and one’s response to further risk-related information. Interestingly, for some participants, once cancer risk was incorporated into identity, further risk-related evidence seemed to cause relatively little further biographical disruption.³⁰

8. Constructing risk in a social context

Several studies emphasised the effects of social context on risk construction. Some studies focused on the clinical context within which risk was constructed, and found that people expressed variable levels of trust in their health professionals and the health system (a position which was frequently based on previous care-seeking experiences). Other studies also focused on personal relationships and showed that

these relationships could have a powerful role in shaping the experience of risk. While relationships could be helpful, they could also be a source of stigma and shame. Cramer Bertram and Magnussen,³¹ for example, identified the social stigma that could be associated with an at-risk status (in this case an abnormal pap smear due to infection with HPV). Intimate relationships could also make the experience of risk highly emotionally and morally charged (see also “control and responsibility”), particularly where children were involved. Indeed, Hallowell³² came to the conclusion that, for women at risk of ovarian cancer, managing risk was less an act of rational self management than the altruistic response of an emotional and relational self. Controlling risk was important in part because of the need to prevent others from suffering.

A few studies (although, interestingly not many) took a broader view of the social and examined the ways in which a person’s perception of risk might be affected by their embeddedness in particular communities with their collective memories (e.g. a shared sense of mistrust on the basis of previous victimisation); specific socio-economic stressors (perhaps with a correspondingly weaker focus on individual risk prevention); shared understandings of disease and risk (“community epidemiologies”) and expectations with respect to what constitutes acceptable environmental exposure, and acceptable behaviour. Salant and Gellert,³³ for example, observed that, for African Americans, risk perception was shaped by their community’s shared nostalgia for a better, less risky, time; its sense of communal victimization; and a number of competing communal concerns. Communities also had specific risk narratives (like illness narratives) which determined appropriate risk-related behaviour, including the degree to which one was expected to take responsibility and be active in preventing illness. Wong and King,³⁴ for example, observed that risk understandings were influenced by the dominant illness narrative of personal responsibility and restitution within Anglo-Western cultures. One participant in their study, for example, chose to dismiss public health statistics and recommendations about screening because they did not seem adequately proactive. Consequently, this participant was outraged when medical practitioners refused to perform a mammogram for her 28-year-old daughter. In keeping with the findings related to identity, these socio-politically-derived ideas about risk (and appropriate risk-related roles and behaviour) were sometimes adopted wholeheartedly by individuals and sometimes resisted.

DISCUSSION

What we can learn from qualitative studies of cancer risk

From this thematic synthesis we have found that qualitative research can perform two functions. First, it can confirm and elaborate what is already known from quantitative psychological research. The studies which we categorised under the heading of “perceptions of risk factors” have much in common with the myriad quantitative studies assessing people’s knowledge of cancer risk factors and their attitudes towards various preventive behaviours (i.e. their “health beliefs”).² Similarly, our category “process of risk perception” shows that qualitative research

can reinforce what is already known about the cognitive processing of cancer risk, and the effects of emotions on risk perception³. The psychological literature also repeatedly demonstrates that one's sense of control is critical in risk perception³, and this emerged in the qualitative studies we classified as "seeking control and taking responsibility (motivational factors)".

But qualitative research does not merely reinforce and elaborate what has already been demonstrated quantitatively. This synthesis has shown that well-conducted qualitative studies can provide us with a rich and nuanced picture of what it means to individuals to be at risk, and how this state is managed in the context of complex individual lives. More specifically, qualitative research seems to uniquely demonstrate the ways in which people's cancer-related beliefs, behaviours and experiences are shaped by the individual and relational dimensions of their lives: their personal experiences with cancer; their life narrative; their bodily experiences; their personal identity and their intimate and communal relationships. These highly personal dimensions of the construction and experience of cancer risk are unlikely to emerge from standardised quantitative studies which are necessarily reductive and are not well suited to in-depth exploration of individual experience.

At the same time, this qualitative synthesis shows us that, while the construction and experience of cancer risk is in some ways unique to each individual, these infinitely complex processes can nonetheless be grouped according to a relatively small number of over-arching categories. This has important implications for clinical and public health communication, since it suggests that even the most psychologically disparate individuals may recognise another's experience, and that health communication might be markedly improved through systematic consideration of a relatively small number of issues. The rich data provided by qualitative research would be valuable in sensitising clinicians to the range of factors that might influence patients' understanding of risk information, and that may need to be considered when they counsel patients about cancer risk. Applying these nuanced findings to public health communication may be more difficult, but it may be possible to develop creative campaigns targeted at groups who are likely to construct and experience risk in particular ways (e.g. posters at an early childhood centre might emphasise the importance of screening for the good of the family, whereas posters at a gym might alert people to the potential silence of the body and the importance of screening even when feeling healthy).

Future research directions

While this analysis was confined to studies of cancer risk, there is no reason to think that these broad categories would be relevant only to cancer, and it would be useful to carry out other qualitative syntheses in order to determine the general salience of our analytic categories for other disease risks. It would also be useful to use the results of this synthesis to extend quantitative psychological research beyond its existing categories.

This synthesis has highlighted the tendency in existing studies to focus on "at risk" groups, and further qualitative research is needed into the perceptions and

experiences of the general population who are ostensibly the target of much clinical and public health communication. Finally, while there is nothing wrong with using qualitative research to further develop quantitative findings, this synthesis has drawn attention to the importance of carefully considering the purposes of qualitative health research and distinguishing research questions that can only be explored qualitatively from those that simply confirm the results of quantitative studies. There may also be potential for quantitative risk research to take up some of the domains suggested by this study as variables in future studies.

Summary

This synthesis of qualitative studies suggests domains that might complicate individual and population understandings of epidemiological information about cancer risk. These understandings are not only affected by people's feelings, their intuitions, and the degree to which they feel in control or wish to be responsible for their risk (i.e. by traditional psychological factors). They are also changed by people's personal experience of cancer, their life-stage relative to their previous (direct or vicarious) cancer experiences, their sense of their own bodies, the way in which they are able to incorporate cancer risk into their identities, and their intimate and communal relationships. In conclusion, we suggest that these eight domains should be attended to in the design, implementation and evaluation of health promotion campaigns, and could assist clinicians to tailor their communication with individuals and families. Attention to these domains should ensure greater responsiveness to each person's or group's unique conceptualisation, experience and construction of risk at any given point in time, thus serving the goals of cancer control while minimising the potential harms associated with risk communication.

REFERENCES

- (1) Lupton D. Risk. London: Routledge, 1999.
- (2) Becker M. Health belief model and preventive health behaviors. *Health Education Quarterly* 1974; 2: 324-508.
- (3) Slovic P. The Perception of Risk. London: Earthscan, 2000
- (4) Ben-Ari, Or-Chen, K. Integrating competing conceptions of risk: A call for future direction of research. *Journal of Risk Research* 2009; 12: 865-877.
- (5) Kuper A, Lingard L, Levinson W. Critically appraising qualitative research. *British Medical Journal* 2008; 337: a1035.
- (6) Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. *British Medical Journal* 2008; 337: a288.
- (7) Atkins S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Medical Research Methodology* 2008; 8: 21.
- (8) Thomas JR, Harden A, Oakley A, et al. Integrating qualitative research with trials in systematic reviews: an example from public health. *British Medical Journal* 2004; 328: 1010-1012.
- (9) Campbell R, Pound P, Pope C, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Social Science & Medicine* 2003; 56: 671-684.

- (10) Thomas J, Sutcliffe K, Harden A, et al. Children and Healthy Eating: A systematic review of barriers and facilitators. London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London. 2003.
- (11) Thomas JR, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology* 2008; 8: 45
- (12) Sandelowski M, Barroso J. *Handbook for Synthesising Qualitative Research*. New York: Springer, 2007.
- (13) Kwok C, Sullivan G. Influence of traditional Chinese beliefs on cancer screening behaviour among Chinese-Australian women. *Journal of Advanced Nursing* 2006; 54: 691-699.
- (14) Lawson E. A narrative analysis: A black woman's perceptions of breast cancer risks and early breast cancer detection. *Cancer Nursing* 1998; 21: 421-429.
- (15) Chapman G, Beagan B. Women's perspectives on nutrition, health and breast cancer. *Journal of Nutrition Education and Behaviour* 2003; 35: 135-141.
- (16) Murray C, Turner E. Health, risk and sunbed use: A qualitative study. *Health, Risk & Society* 2004; 6: 67-80.
- (17) Werner-Lin A. Danger zones: Risk perceptions of young women from families with hereditary breast and ovarian cancer. *Family Process* 2007; 46: 335-349.
- (18) McAllister M. Personal theories of inheritance, coping strategies, risk perception and engagement in hereditary non-polyposis colon cancer families offered genetic testing. *Clinical Genetics* 2003; 64: 179-189.
- (19) Chalmers K, Thompson K. Coming to terms with the risk of breast cancer: perceptions of women with primary relatives with breast cancer. *Qualitative Health Research* 1996; 6: 256-282.
- (20) Sanders T, Campbell R, Donovan J, Sharp D. Narrative accounts of hereditary risk: Knowledge about family history, lay theories of disease, and "internal" and "external" causation. *Qualitative Health Research* 2007; 17: 510-520.
- (21) Ryan E, Sugg Skinner C. Risk beliefs and interest in counseling: focus-group interviews among first-degree relatives of breast cancer patients. *Journal of Cancer Education* 1999; 14: 99-103.
- (22) Phelps C, Wood F, Bennett P, Brain K, Gray J. Knowledge and expectations of women undergoing cancer genetic risk assessment: a qualitative analysis of free-text questionnaire comments. *Journal of Genetic Counseling* 2007; 16: 505-514
- (23) Chapple A, Ziebland S, Hewitson P, McPherson A. Why men in the United Kingdom still want the Prostate Specific Antigen test. *Qualitative Health Research* 2008; 18: 56-64.
- (24) d'Agincourt-Canning L. The effect of experiential knowledge on construction of risk perception in hereditary breast/ovarian cancer. *Journal of Genetic Counseling* 2005; 14: 55-69.
- (25) Kenen R, Ardern-Jones A, Eeles R. Living with chronic risk: healthy women with a family history of breast/ovarian cancer. *Health, Risk & Society* 2003; 5: 315-331.
- (26) Hedestig O, Sandman P, Widmark A, Rasmussen B. Meanings of prostate-specific antigen testing as narrated by men with localized prostate cancer

- after primary treatment. *Scandinavian Journal of Urology and Nephrology* 2008; 42: 101-109.
- (27) Weitzman E, Zapka J, Estabrook B, Valentine Goins K. Risk and reluctance: understanding impediments to colorectal cancer screening. *Preventive Medicine* 2001; 32: 502-513.
- (28) Kavanagh A, Broom D. Embodied risk: my body, myself? *Social Science & Medicine*. 1998; 46: 437-444.
- (29) Scott S, Prior L, Wood F, Gray J. Repositioning the patient: the implications of being 'at risk'. *Social Science & Medicine* 2005; 60: 1869-1879.
- (30) Hallowell N, Foster C, Eeles R, Ardern-Jones A, Watson M. Accommodating risk: Responses to BRCA1/2 genetic testing of women who have had cancer. *Social Science & Medicine* 2004; 59: 553-565.
- (31) Cramer Bertram C, Magnussen L. Informational needs and the experiences of women with abnormal Papanicolaou smears. *Journal of the American Academy of Nurse Practitioners* 2008; 20: 455-462.
- (32) Hallowell N. Varieties of suffering: Living with the risk of ovarian cancer. *Health, Risk & Society* 2006; 8: 9-26.
- (33) Salant T, Gehlert S. Collective memory, candidacy, and victimisation: community epidemiologies of breast cancer risk. *Sociology of Health & Illness* (2008); 30: 599-615.
- (34) Wong N, King T. The cultural construction of risk understandings through illness narratives. *Journal of Consumer Research* (2008); 34: 579.

SUPPORTING INFORMATION

The following supporting information is available:

- 1) The bibliography of included qualitative studies and the major analytic categories developed from each study