Perceptions of family history across common diseases: a qualitative study in primary care

Fiona M Walter<sup>a</sup> and Jon Emery<sup>b</sup>


Background. Having an affected relative is a strong predictor of an individual’s lifetime risk of developing many diseases. In primary care this is of importance in preventive healthcare.

Aim. To compare and contrast perceptions of family history across common diseases among primary care patients using the theoretical framework of Leventhal’s Common Sense Model (CSM).

Methods. Thirty semi-structured interviews were conducted with patients identified in general practice, who had a family history of either cancer, heart disease or diabetes. We performed qualitative constant comparative analysis of transcript data.

Results. People with a family history of cancer had a greater sense of personal vulnerability than people with a family history of heart disease: family history of diabetes was generally viewed as the least threatening. Using the CSM constructs we identified factors which determine individual perceptions of family history. Beliefs about consequences and timeline were influenced by witnessing painful, lingering or sudden familial death; people who felt their risk was determined by inheritance were more likely to feel vulnerable and have less control, while those who felt able to change lifestyle or behaviour felt more able to control their perceived risk.

Conclusion. Factors influencing perceptions of family history may vary between individuals and between diseases. To use the family history as a tool in preventive healthcare we will need to consider the individual’s personal understanding of disease risk and their ideas about cause and controllability of the familial illness. Perceived risk may then be used to motivate preventive health behaviours.

Keywords. Cancer, diabetes, heart disease, patients’ understanding, risk perception.

Introduction

For many common diseases, having an affected close relative is the strongest predictor of an individual’s lifetime risk of developing the disease. People with a first degree relative with breast or colorectal cancer have an increased relative risk which rises with increasing numbers of relatives and their diagnosis at a younger age. A family history of diabetes or heart disease also gives an increased risk of developing the disease which is further elevated by lifestyle factors such as smoking and obesity. Family history of common disease reflects not only inherited genetic susceptibilities but also shared environmental, cultural, ethnic and behavioural factors. However, people with an affected close relative do not necessarily consider themselves to have either a ‘family history’ or increased personal risk.

The literature on perceived health risk mainly focuses on women with a family history of breast cancer recruited from the genetics clinic setting, who perceive their personal risk to be higher than women without breast cancer in their families. Similar risk perceptions have also been shown to be held by people with a family history of prostate and colon cancer, diabetes and heart disease. Understanding of familial risk may influence appropriate use of screening tests and healthy behaviours: perceptions of elevated risk are associated with following recommended breast screening...
behaviours, and a strong family history of colorectal cancer is associated with better adherence to sigmoidoscopy.

This is of particular importance to the management of common diseases in primary care, where national organizations in several countries have already recognized the potential of using the family history both as a risk predictor and as a motivator for prevention of these common causes of morbidity and mortality. In the UK the Department of Health’s National Service Frameworks include consideration of the family history in clinical practice guidelines for cancer, heart disease and diabetes. The US Centers for Disease Control and Collaboration (CDC) Office of Genomics and Disease Prevention has collaborated with the National Institutes of Health on a family history public health initiative, and has developed a CDC Family History Tool which is currently under evaluation.

Health psychology theories may help with understanding the process of developing and coping with perceptions of family history risk. Structured models have been developed to integrate differing health beliefs and to understand their role in predicting health-related behaviours. Leventhal’s Common Sense Model of Self-Regulation (CSM) arose from the observation that biomedical symptoms (or ‘identity’) represented only one type of perceptual information needed to appraise a health-risk situation. Other psychosocial attributes of threat, or illness perceptions, were identified as: timeline, consequences, cause and control (see Fig. 1 and Box 1): each attribute adds to the person’s highly individualized understanding of the threat and also contributes to ongoing risk perception and worry. Other features of the CSM which make it particularly suited to understanding the development of perceptions of familial risk include the parallel processing of cognitive and emotional stimuli, and the iterative nature of evaluation and decision-making that influence behaviour. This model might therefore explain the influence of perceptions of cause and consequence upon the development of an individuals’ understanding of familial risk, and the influence of perceptions of controllability upon behaviour changes.

A synthesis of qualitative studies exploring people’s understanding of their family history of common diseases.

**Common Sense Model (CSM) of Self-Regulation of Health and Illness**

**DANGER CONTROL**

**FEAR CONTROL**

**FIGURE 1** The Common Sense Model of Self-Regulation of Health and Illness (CSM)\(^{15}\)

**BOX 1** Definitions of Labels used in the Common Sense Model of Self-Regulation of Health and Illness (CSM)\(^{15}\)

<table>
<thead>
<tr>
<th>Labels</th>
<th>Definitions</th>
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<tbody>
<tr>
<td>‘IDENTITY’</td>
<td>Defines and labels the threat which can arise from an internal source such as a symptom, but can also arise from an external source such as the information that a relative has the diagnosis of an illness such as cancer, diabetes or heart disease</td>
</tr>
<tr>
<td>‘TIMELINE’</td>
<td>Describes perceptions of the timescale of the threat such as length of the illness</td>
</tr>
<tr>
<td>‘CONSEQUENCES’</td>
<td>Defines the threat in terms of its potential to affect life expectancy and overall quality of life</td>
</tr>
<tr>
<td>‘CAUSE’</td>
<td>Describes the threat in terms of where it’s come from, such as a familial predisposition</td>
</tr>
<tr>
<td>‘CONTROLLABILITY’</td>
<td>Addresses issues of coping with, and control of, the perceived threat</td>
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diseases outlined the processes by which individuals develop and deal with their personal perception of disease risk. However, the majority of the studies included in this review were based on patients sampled from secondary care whose beliefs may have been altered by some form of genetic counselling, and the number of papers in the synthesis was insufficient to adequately compare and contrast perceptions across diseases. Factors common to all diseases which influence the development of understanding about their family history among primary care patients have already been reported. These factors may have different meanings and implications to people with a family history of different diseases. The aim of this study was to use the theoretical framework of the CSM to compare and contrast perceptions about family history among primary care patients with a family history of either cancer, heart disease or diabetes: the findings are reported in the context of the CSM framework.

Method

Participants and interviews
Semi-structured qualitative interviews were conducted between October 2002 and March 2003 with patients identified through primary care. The study was approved by the Cambridge Local Research Ethics Committee. Participants were recruited from two Cambridgeshire general practices (Practice 1: list size 2236, 30% population <18 years, 1% over 75 years; Practice 2: list size 10 564, 21% population <18 years, 8% over 75 years) using electronic searches of practice medical records to identify patients of 18 years and over, with a first degree relative with either cancer, heart disease or diabetes. The practice software was then used to randomly select potential study participants. Our sampling strategy aimed to gain as broad a view as possible by reflecting a range of age, gender, educational levels and degree of familial risk. Interviews lasting ~1 hour were conducted by FMW, mainly in the interviewees' homes, and continued until data saturation was achieved. The interview guide was informed by our systematic review, and piloted with the first five participants. Considerable flexibility during the interviews allowed participants to discuss issues that were most important to them.

Analysis
Audiotapes of the interviews were fully transcribed, and analysed manually, supported with NUD*ST software. We applied a constant comparative technique to allow the emergence of themes and development of underlying concepts, and later mapped the emergent concepts onto the theoretical model. Analysis began during data collection to inform subsequent interviews: it was conducted primarily by FMW, while JE independently read half the transcripts to confirm the integrity of the emerging themes and concepts. The quotations that follow were chosen to reflect a range of both consensual and dissenting views, and they are accompanied by the patient's study identification number, gender, age and relevant family history (FH).

Results
One hundred and seventy-nine patients (Practice 1, 90; Practice 2, 89) were approached with 44 responding, giving an overall response rate of 25%. Telephone contact with each respondent confirmed they had at least one first degree relative with either cancer, heart disease or diabetes. Thirty interviews were completed by which time no new themes were emerging. Participants' characteristics are shown in Table 1. Three generational family histories were taken, and participants had one to five affected relatives. Over half the participants had more than one first degree relative with either cancer, heart disease or diabetes, and 5 (17%) had a family history of all three diseases. On current risk assessment criteria for cancer and heart disease, 13 only a minority would be considered significantly above

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Characteristics of participants (n = 30)</th>
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<tbody>
<tr>
<td>Characteristic</td>
<td>n (%)</td>
</tr>
<tr>
<td>Practice</td>
<td></td>
</tr>
<tr>
<td>Practice 1</td>
<td>12 (40%)</td>
</tr>
<tr>
<td>Practice 2</td>
<td>18 (60%)</td>
</tr>
<tr>
<td>FH of Disease</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>14 (47%)</td>
</tr>
<tr>
<td>Heart disease</td>
<td>15 (50%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7 (23%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>20–39</td>
<td>12 (40%)</td>
</tr>
<tr>
<td>40–59</td>
<td>14 (47%)</td>
</tr>
<tr>
<td>60+</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>14 (47%)</td>
</tr>
<tr>
<td>Female</td>
<td>16 (53%)</td>
</tr>
<tr>
<td>Ethnic origin</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>28 (93%)</td>
</tr>
<tr>
<td>Other (Japanese 1; Iranian 1)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Single, widowed, divorced</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Married, living with partner</td>
<td>26 (87%)</td>
</tr>
<tr>
<td>Children</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>7 (23%)</td>
</tr>
<tr>
<td>Yes</td>
<td>23 (77%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>1 = Primary education only</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>2 = Some secondary education</td>
<td>7 (23%)</td>
</tr>
<tr>
<td>3 = Completed O-levels/GSCE</td>
<td>7 (23%)</td>
</tr>
<tr>
<td>4 = Completed A-levels</td>
<td>5 (17%)</td>
</tr>
<tr>
<td>5 = Further education</td>
<td>9 (30%)</td>
</tr>
</tbody>
</table>
the population risk for their age. Eight participants (27%) had existing medical conditions including asthma, depression, hypothyroidism, Parkinson's disease and osteoarthritis, while three people had bypass surgery for heart disease, and two had diabetes.

**Consequences and timeline**

Cancer was universally felt to be a threatening and serious disease. Participants who had witnessed the suffering of their relative felt cancer often caused a long, lingering and invasive illness, leaving images of being ‘riddled with cancer’.

“My sister had cancer you know, it wasn’t in one place in the body, it was moving from one place to the other and...gradually taking her body over. [With cancer you] get the punishment of pain. I think you linger longer with cancer.” [ID13; M; 79; FH of heart disease]

Cancer was frequently viewed as an inevitable death sentence, and several people discussed the ‘awfulness’ of cancer, both in terms of the course of the illness and treatment, and the perceived inevitability of eventual death. This impact was felt from witnessing not only the illness of close relatives, but also illness of friends and more distant relatives. Witnessing a close relative’s final illness from cancer was described several times as a ‘rollercoaster of emotions’.

“I’ve had a lot of friends who’ve had breast cancer and it’s really awful, you’re never left alone, and you never know whether the zapping will have worked. It’s such a complicated business and you really need to be on the ball and you have to take all these very complicated medications, and get up in the night, and it just takes over your life and it’s horrible.” [ID06; F; 58; FH of cancer]

Heart disease also felt serious to many people who had experienced it among their relatives: the ‘awfulness’ of heart disease was often perceived, even many years after the familial event. However, people with a family history of heart disease held a broader range of views, and experiences of a relative with heart disease did not engender the same universal threat as experiences of a close relative with cancer. People who had experienced a relative or friend’s sudden death frequently described the heart attack as ‘massive’ to denote the sudden and fatal nature of the event. On the other hand, people whose experience included relatives or friends who had recovered from heart disease events, either by the use of medication or surgery, generally referred to the cardiac event as ‘not serious’. Participants held a mechanistic view of the arteries ‘clogging up’, which once dealt with, implied longer-term good health.

“Not a serious heart attack you know, not one of those awful ones, but he had chest pain and he had a triple bypass when he was 58, he’s now 75.” [ID20; F; 75; FH of heart disease & cancer]

“My grandfather died of a massive heart attack, he must have been 85 or so, and my dad had a heart attack when I was a baby, and then had bypass surgery... It feels as if you’re stuck with the genes and you’ve got to do everything possible to fight against the genes by lifestyle. [It’s] not a certainty but enough of a risk that I should be aware of it, that if I were to close my eyes to it and do other things, that would put me further at risk, that I’d be putting myself in danger.” [ID19; F; 27; FH of heart disease]

Diabetes was generally regarded as an illness of age and not viewed as a death sentence; it therefore felt less serious to many people who had experienced it among their relatives. Most who discussed diabetes viewed it as a chronic disease of older age and at worst a minor inconvenience.

“Diabetes is a chronic illness and my Dad’s is very well controlled and you wouldn’t realise there was anything wrong with him. He did loose quite a lot of weight when he was first diagnosed, but he’s always been very thin anyway. I think it would be a lot more worrying if [my family] had all the complications that go with [diabetes] but they never did.” [ID11; F; 38; FH of cancer & diabetes]

The exception was one participant whose friend had two children with Type I diabetes. She viewed diabetes as a serious, life-threatening and debilitating illness, which explained her heightened perceptions of familial risk related to her own father’s Type II diabetes.

“Their diabetes is a very serious disease, not only in what it’s doing to the children but in terms of the impact on anyone around it. There’s all sorts of side effects with diabetes, and it’s not nice that your beautiful little girl may end up having fingers or toes amputated with gangrene and goodness knows what, and all the other problems that go with it.” [ID22; F; 45; FH of diabetes]

Despite this, she still felt: “There’d be a lot worse other things I could contract than diabetes I can tell you.”

**Cause**

Most people with a family history of cancer believed the disease was caused by more than one factor. They acknowledged the differing contributions of nature and nurture, although where no obvious environmental or behavioural cause could be found, they were likely to implicate their genetic susceptibility:

“Well there are certain traits you know, familial traits, and I think they’re probably causing illnesses, part of it, but I certainly don’t think it’s
the whole picture. I think that environment and nurture play a part as well.” [ID06; F; 58; FH of cancer]

“My grandfather wasn’t a great smoker and got lung cancer, my father’s had blood cancer, leukaemia, and I can’t see any obvious surrounding factors that would influence [either]. My experience has led me to think that it is a genetic, more than a surrounding thing.” [ID18; M; 37; FH of cancer]

People with a family history of cancer sometimes discussed environmental or lifestyle causes as ‘triggering’ an event on the background of inherited risk. People with a family history of heart disease or diabetes also held a multi-factorial model of disease risk, but they were more likely than those with a family history of cancer to view lifestyle factors as triggering an underlying risk:

“You tend to look more for the fact of what you’re doing to your own body than what...is coming down through the line. Although you know in the back of your mind that obviously there are certain parts of [your mother] in you, it’s more the smoking that you think...does cause heart problems.” [ID08; M; 39; FH of heart disease]

“My father has been diagnosed with diabetes and I believe that was triggered off by two factors actually, by diet because he was overweight at one stage and he did eat a lot of the wrong food, but also he had a very stressful time in his life that came about through a work situation, and I think that stress factor was the trigger to bring on the diabetes.” [ID22; F; 45, FH of diabetes]

The significance of lifestyle factors was apparent among people with a family history of heart disease who identified other family members, particularly siblings, as being more at risk than them:

“I think [my brother]’s a classic example of being an ‘at risk’ [for heart disease] person because to me he’s just a younger version of my Dad. He smokes, he goes out for a drink, and he’s in quite a high up job which is very, very stressful, and I would say his weight isn’t ideal, a bit over weight.” [ID29; F; 33; FH of cancer, heart disease & diabetes]

Controllability

Attributions of cause of a relative’s cancer became very important when people considered how to control their familial risk. Although some people chose lifestyles or behaviours which they felt could reduce their risk, those who felt that their risk was determined by inheritance were more likely to feel more vulnerable and have less control over their illness risk. They commonly used screening and self-examination to cope with their risk, and keenly pursued further relevant information:

“I think we just wanted to be as educated as we could about [our family history of breast cancer], as in having surveillance or screening or just finding out what all this was, yeah, I just wanted information to tell me what my options were. That’s just about as much you can do really, rather than maybe just being ignorant and not being informed.” [ID10; F; 38; FH of cancer]

Participants with a family history of heart disease felt they were able to reduce or control their familial risk by adopting certain lifestyles or behaviours, thus becoming more able to determine their own fate and feel empowered through healthy lifestyle choices:

“I believe you have the power if you like to decide what your future direction is going to be. I am not going to die at 54 of a heart attack like my Mum did because I told myself that I have to do something about it to make sure I don’t. It’s a bit as though, yes you can inherit certain things but then you take charge of it yourself.” [ID17; F; 38; FH of heart disease & diabetes]

Further control could sometimes be exerted with surgery or medication, which could make them ‘safe’ from their family history. People with a family history of diabetes generally held similar views to people with a family history of heart disease concerning the multi-factorial nature of familial risk, and their ability to reduce or control their familial risk by lifestyle choices:

“Some things we don’t have a choice about, but there are choices that we can make about keeping us in a healthy way. ... I think that it basically comes back to just living a balanced normal lifestyle, and I believe if you add to it continuously by being overweight or not exercising at all or drinking too much or smoking, you are putting yourself more at risk.” [ID22; F; 45; FH of diabetes]

The relative threats of cancer, heart disease and diabetes

The vast majority of participants felt that a family history of cancer was more serious than a family history of heart disease, which in turn was more serious than a family history of diabetes. Very few mentioned the influence of health professionals or the media in forming these perceptions: rather, the understanding was based on personal experiences of the illnesses of relatives and friends.

“I suppose cancer to me feels scarier than heart disease. Cancer of the breast feels quite scary because, although my sister is alive, most people
that I’ve known that had breast cancer actually died, so it feels more life threatening. […] I suppose in a way heart disease seemed much more dramatic in a way, when people had heart attacks and died.” [ID04; F; 56; FH of cancer & heart disease]

“If you’re diagnosed with cancer you’d be wondering how long you had. When my Dad got diabetes he didn’t think of it as a death sentence, it was a change in lifestyle for him.” [ID11; F; 38; FH of cancer & diabetes]

The ability to gain control or cope with the perceived risk seemed at the root of this ‘severity ranking’ between diseases, together with the common perception of cancer as a death sentence.

“With cancer if you can’t control it, that’s it you know, whereas heart disease, you can live with it. I mean, some people do get over cancer don’t they, but it’s a bit dodgy, it’s a bit 50:50, isn’t it?” [ID15; M; 75; FH of cancer & diabetes]

“I think cancer and heart attacks are different because you either survive your heart attack and you may well not be quite the same man you were before, but with cancer there doesn’t seem to be any or very little chance of you actually surviving. I don’t think you have much choice in either. With a heart attack you can say, well, if you had a healthier lifestyle, if you’d eaten less fat or if you’d exercised more then you could have an input into actually delaying it… When it comes to cancer you don’t appear to have people saying you shouldn’t do that. I think they have a different degree of threat.” [ID09; M; 52; FH of cancer]

Some people viewed deaths from heart disease as ‘a good way to go’, particularly when the death was at an older age and therefore not viewed as ‘premature’. This sentiment was seldom expressed by anyone discussing their relative’s death from cancer which could only be viewed as an acceptable cause of death when it had occurred in old age. Diabetes was also never discussed as ‘a good way to go’, but this was because it was never considered as the primary cause of death, rather as a contributor.

“I think it is just the suddenness that leaves the shock there, and the age…. For instance, for my father, if [his stroke] had of been in another 20 years it would have been a fantastic way for somebody to go, not for the people left behind but for the person, they don’t have any suffering or nothing.” [ID21; M; 59; FH of cancer, heart disease & diabetes]

“I just think well if they are into their eighties before they get diagnosed with cancer, they’ve had a good innings really.” [ID26; F; 44; FH of cancer & heart disease]

Discussion

In this study we used the CSM to provide a framework to examine the cognitive and emotional issues which lead to the development of perceptions of family history across common diseases. The findings suggest that primary care patients’ perceptions of familial risk are considerably influenced by their understanding of the various consequences, timeline, causes and controllability of the disease. A negative impact generally leads to a greater sense of threat or personal vulnerability, and the impact varies between diseases. This complex process by which past experiences, expectations and beliefs are integrated with new information gives insight into which factors determine decisions (coping) and actions (control). Our findings suggest factors which may underpin differing perceptions between diseases. Witnessing the consequences of a family member with diabetes generally led to perceptions of diabetes as a minor inconvenience and a chronic disease of older age, in contrast to witnessing the consequences of a close relatives’ suffering or premature death from cancer: this may explain some women’s raised and persistent sense of vulnerability to breast cancer.23 We have already described other important factors that determine a personal sense of risk: these include the nature of personal relationships within a family such as emotional closeness and personal likeness with the affected relative.17 Together, these results suggest that understanding how individuals processing of risk information could inform individual’s motivations for screening and other preventive behaviours.16

Many theoretical models of health-protective behaviours such as the CSM have perceived risk as a central construct, and make the assumption that the higher the perceived risk, the more likely an individual will be to modify their behaviour. Although the literature has demonstrated a positive association between cancer screening behaviours for people with a family history of breast and colorectal cancer,24 there is less evidence regarding the impact of family history on lifestyle changes such as diet, exercise or smoking cessation. The occurrence of a heart attack or stroke in an immediate family member did not lead to self-initiated, sustained change in modifiable risk factors among young adults in a recent study.25 In Vernon’s24 review of risk perception and risk communication for cancer screening behaviours, she argued the need for methodological studies of how best to measure perceived risk, and this study has shown the value of a qualitative approach over a one-dimensional quantitative measure to explore family history risk perception.

A family history of cancer was viewed as the greatest threat by the study participants. Their perceptions were particularly informed by witnessing the suffering of close relatives, and notions of cause, fatalism and genetic determinism. The findings suggest that people
felt less able to prevent the development of cancer by dietary or lifestyle modifications, and chose screening behaviours to attempt to control their risk instead. A large literature on explanatory models and perceptions of cancer in a range of cultural groups supports these findings. Cancer is generally viewed with fear: in the popular imagination cancer equals death. Metaphors such as ‘evil force’ are used to define cancer, and relate to its severity and evasion of medical treatment. Emotional responses to cancer have been shown to affect decisions about treatment and the doctor patient relationship.

Hunt et al. have shown that using family history of heart disease to target screening and intensive intervention is efficient because most cardiovascular events, particularly those occurring at an early age, are concentrated in a relatively small subset of families. As Kardia et al. recently argued, ‘An individual’s familial risk of [heart] disease may, in fact, be a better indicator of the many complex interactions among predisposing genetic and environmental factors than can be captured by an individual’s own risk factors.’ In this study, people with a family history of heart disease exhibited a wide range of perceptions of their family history: some viewed it as very threatening while others considered heart disease to be a ‘good way to go’. Again, family history risk perceptions were informed by factors concerning the severity of the relative’s illness and the consequences, from fatality to full recovery. Perceptions were further modified by people’s understanding of the cause and controllability of heart disease: as lifestyle factors were significant triggers of genetic predisposition, people felt more able to control their own fate by making behaviour changes.

A family history of diabetes was seldom viewed as a serious threat. Diabetes was felt to be a disease of older age, which was seldom severe, or life threatening, and more commonly an inconvenience. Behavioural causes such as diet and lack of exercise were sometimes mentioned, and people felt able to gain control of their familial risk by modifying these behaviours. The individual who had witnessed more severe manifestations and consequences of diabetes had a heightened sense of perceived vulnerability. Harrison et al. recently reviewed the risk of diabetes associated with a positive family history of diabetes, and concluded that although weight loss, dietary interventions and exercise are fairly effective in reducing the risk of diabetes, perceived risk is less than actual risk among those with a positive family history of diabetes. There are few data about the effect of risk perception on behaviour modification in people at risk of diabetes: if such individuals do not feel at personal risk it may be more difficult to initiate such behaviour changes.

There is currently considerable interest in using the family history to identify at-risk groups to inform targeted disease prevention, and the validity and utility of a public health orientated family history tool is being assessed. However, both prediction and intervention require a ‘common language’ of risk perception and risk communication between patient and health professional. Other data from these interviews demonstrate an obvious dichotomy between the patients’ and health professionals’ perspectives. While the biomedical estimation of familial risk comprises counting affected relatives, and their ages at illness or death, the patients’ understanding of familial risk also encompass the emotional impact of witnessing the illness in the family, particularly if the illness was sudden, premature or fatal. The nature of personal relationships within a family that determine a sense of emotional closeness and personal likeness with the affected relative also contribute to the development of these risk perceptions. There are variations in the relative importance of some factors between common diseases: the survival and return to a near normal lifestyle of the relative with heart disease or the perceived inconsequential nature of diabetes could make the family history less threatening. These findings suggest that different beliefs about the contributions of nature and nurture, and the triggering effect of risk factors to disease can affect patients’ views on the degree of control they can exert.

**Strengths and limitations of this study**

This is the first study to examine inter-disease variations in perceptions of their family history among a primary care sample, although a recent quantitative study of an unaffected general population confirmed that having a family history of breast or colon cancer, heart disease or diabetes impacts upon personal perceived risk. The work arose from an investigation into lay understanding of familial risk which treated cancer, diabetes and heart disease as single conditions: in this study, most participants discussed cancer, diabetes and heart disease as single conditions (e.g. ‘family history of cancer’ to describe grandfather with lung cancer and father with ‘blood cancer’ ID18, p. 9). It would have required a much larger sample to identify subtle variations between people with relatives affected by different cancers, people who have several relatives affected by different cancers, the number of affected relatives and family size. Although reflective of gender, age, marital and educational patterns in our community, the sample was not ethnically diverse. Further study among other populations to search for ethnic and cultural variations in familial risk perceptions of common diseases is required. The sample contained five participants (17%) who had personal experiences of one or more of the illnesses under discussion, and this may have influenced their responses.
Implications for future research or clinical practice

The theoretical framework of the CSM has permitted this comparison and contrasting of perceptions of family history across several diseases. Psychological theory has already informed intervention programmes to increase physical activity among the sedentary offspring of people with diabetes. Future research should explore the utility of the CSM in predicting and promoting behaviour change within the primary care setting. These findings have been used to inform the development of the F-Risk questionnaire to establish the strongest determinants of familial risk perceptions in primary care (paper in preparation). As the study also demonstrated a ‘severity ranking’ between diseases which could interfere with public health and individual measures to effect preventive behavioural changes, measures also need to be developed to assess perceived severity of familial risk.

Over 40% of individuals in the general population have reported a family history for at least one of the diseases cancer, diabetes or heart disease, so the findings of this study have strong clinical implications for primary care practice. The impact of a family history on the individual’s perception of that disease may vary between individuals and between diseases. These perceptions could be used to motivate preventive health behaviours such as the promotion of screening (mammography, colonoscopy) or behaviour change (smoking cessation, diet and exercise modification). Such interventions will need to be placed in the individuals’ context and their personal understanding of their familial risk.

Acknowledgements

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References


