Factors influencing consultation to discuss family history of cancer by asymptomatic patients in primary care

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Abstract Patient self-initiated consultations to discuss family history of cancer in primary care and the factors leading to these consultations have not been investigated. Seventy-one out of 150 asymptomatic patients with a family history of cancer at the Yorkshire Cancer Genetics Service participated in this study. A semi-structured questionnaire was administered. The results show that (1) family cancer events, doctors' advice and reaching the age of cancer-affected relatives were more salient in raising awareness of the added cancer risk due to family history than media and publicity, and knowledge of the genetics services; (2) knowledge of family medical history and its clinical value is not easy to ascertain; (3) the inter-relationships with other causal beliefs are of interest and could provide insights to understand the factors motivating patients to discuss family history or cancer risk; (4) the belief that 'cancer runs in the family' or is 'a family thing'

may not be sufficient to heighten perceived cancer risk and motivate patients to seek medical advice; and (5) understanding of the medical concept and clinical value of family history is poor even in this group of patients who initiated the GP consultations. In conclusion, because most primary care practitioners are likely to rely on patient initiated discussion to identify individuals at an increased risk of cancer because of their family history, these findings are therefore important to help doctors and health providers understand the reasons influencing asymptomatic patients to self-refer themselves in primary care and discuss cancer risk in order to provide appropriate care.

Keywords Family history of cancer · Perceived familial risk · Asymptomatic patients · Self-initiated consultation · Primary care

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Introduction

Background

Based on their study of 8,109 patients in a randomised trial of general health checks in primary care practices, Johnson et al. (1995) predicted that "a general practitioner (GP) could expect 40 to 50 patients to have a first degree relative diagnosed before the age of 70 years with colorectal, breast, ovarian or uterine cancers, and an average of 13.5 patients with a first degree relative having one of these diseases diagnosed before 50 years old". In some patients (approximately 5% of the whole), there is a dominantly inherited cancer predisposition which, if present, confers a high risk of cancer on the individual and their family members.

The White paper "Our Inheritance, Our Future" (Department of Health 2003) has assigned GPs, practice

nurses and other primary care practitioners the task to identify and manage individuals who may be at an increased risk of hereditary diseases. However, most GPs lack the resources, as well as the knowledge and skills in cancer genetics, needed to identify at risk patients effectively (de Bock et al. 1999; Watson et al. 1999, 2001); (Emery et al. 1998). Concerns over the legal implications of genetics, patient confidentiality and avoiding unnecessary anxiety have also been given as reasons for not initiating consultation, or even discussion with patients about their family history (Watson et al. 2001). For these reasons, most GPs rely upon a reactive approach, i.e. identifying patients at risk only when people with a family history of cancer present themselves in the surgery.

Literature review

Few studies of cancer genetics in primary care have examined patients' perspectives and none have included patient initiated consultations to discuss family history. Patients' understanding of genetics principles, their experience and expectations of consultations were investigated in three studies (Andermann et al. 2001; Stermer et al. 2004; Warner et al. 1999). One study assessed the psychosocial impact of patients experiencing a new family history taking tool (Brain et al. 2000). Three other studies evaluated information and decision aids for collection of family history and risk assessment (Qureshi et al. 2001; Rapport et al. 2006; Stacey et al. 2003). All except one were prospective studies: patients in the first six studies had a family history of either colorectal or breast cancer and had been referred to a genetics clinic or breast clinic. In the retrospective study, participants were unselected patients who had not received a health check in a general practice (Brain et al. 2000).

Some of the factors motivating patients to attend the genetics clinic have been reported. For American women with a strong family history of breast cancer, awareness of family history was reported as an important reason for attending familial breast cancer clinic (Lucassen et al. 2001). An increase in the demand for genetic services in the UK was attributed to public knowledge that the service is available in the National Health Service (Katapodi et al. 2004; Kinmonth et al. 1998). Some studies reported that individuals consulted their doctors because of their perceived risk about inherited cancer (Walter et al. 2004).

Previous studies have explored the process and events that influenced the development of a personal perception of risk (Evans et al. 1993; Pilarski 2009; Rees et al. 2001). Some studies also explored lay understanding of familial risk of cancer and found that individuals' perceived risk and/or vulnerability was based on the burden of disease, i.e.

experience of disease or living with the disease and severity of illness of close relatives, rather than on family medical history or the hereditary nature of a faulty gene (McAlister 2003; Walter and Emery 2005). For some individuals, knowledge that 'it (the disease) runs in the family' was largely based on information such as the number of affected relatives, ages at diagnosis or death and patterns of ages or sex.

Problems/questions raised

For asymptomatic patients with a family history of cancer, there remain gaps of knowledge in the current literature about the reasons or events that led patients to consult the GPs to discuss family history of cancer. These factors have not been properly explored. What was the role of knowledge of a family medical history of cancer (number of affected relatives, ages at diagnosis or death and patterns of ages or sex) in influencing patients' decisions to initiate consultation and discuss cancer risk with their doctors? To what extent did individuals know about their family history of cancer? How important was perceived familial cancer risk in influencing decision to discuss cancer risk with the doctor? How was perceived cancer risk raised among these patients?

In a previous paper, we reported that asymptomatic patients in the study initiated all the GP consultations (Al-Habsi et al. 2008). In nearly 90% of cases, these patients also initiated the discussion of familial cancer risk. In this present paper, we will attempt to provide an insight into the reasons patients initiated consultation in primary care and whether knowledge of family medical history of cancer (number of affected relatives and age of onset) is enough to motivate them to consult and discuss risk with their doctors. We will explore patients' accounts of consultations in which family history of cancer was raised with the GP, paying particular attention to reasons for consultation; patients' understanding and awareness of family history and familial risk; and the perceived importance attached to family history.

Methods

Participants

In this study, we recruited only asymptomatic patients as the focus of the study was on the early identification of patients at increased risk of developing cancer and not on the early detection of patients with cancer.

The chosen method of finding asymptomatic patients who had discussed a family history of cancer with their GP was to identify them from referrals made by GPs to the

Yorkshire Regional Clinical Genetics Service (YRCGS). It follows that the study findings can only be applied to patients managed by their GP in this particular way, but given the practical difficulties of doing research on the topic, the experiences of this subgroup of patients were judged to constitute an important beginning.

Local research ethics committee approval was obtained before the study began. Staff at the YRCGS approached 150 eligible patients, on the waiting list to see the geneticist, for their participation in the study. Patients who agreed to participate were next sent an invitation by post and they were asked to provide a telephone contact in their reply. Eighty-three patients replied, but only 75 provided a telephone contact. Only the names, telephone contacts and postcodes of patients who consented to participate in this study were passed on to the researcher team. All the 75 patients were contacted to confirm that their referral originated from primary care. Three patients were excluded because they were referred from secondary care, and one patient decided to withdraw from the study at the interview stage.

Interviews

Individual face-to-face interviews were carried out with the use of a topic guide to explore the factors motivating asymptomatic patients to consult the GP, patients' accounts of the number of relatives affected by relevant and other type of cancers, patients' perceived importance and understanding of family history and familial risk, and knowledge of the existing genetics service (AHH). All except six interviews were carried out in the patient's home. Five interviews were carried out over the telephone, while one was conducted at a convenient location named by the patient. All the interviews were tape-recorded.

Analysis

Audiotapes of the interviews were fully transcribed. The descriptive coding process of Moser and Kalton (2004) was followed to develop meaningful categories for analysis. A coding frame was devised which coded for the presence, or absence, of responses predicted by the researchers (AHH, JH), as well as incorporating the respondents' own chosen terms of reference. This allowed frequencies of particular responses to be measured. The coding process was a lengthy one, involving coding and recoding several times over a period of months. The reliability and use of the coding frame was tested and any disagreement was discussed and resolved (AHH, JH, JL). Although the main purpose of the analysis was to characterise the types of views expressed, summary percentages were calculated to assist interpretation.

Results

The response rate was 49.3% and 71 patients completed the study. The majority of them were women (92%; Table 1). Most of the patients reported that they had been referred for an assessment of family history of breast, ovarian or bowel cancers (91%), and the rest were referred for throat and liver cancers. The majority of participants (65%) were 30–50 years old, 18% were under 30 and 17% were over 50 years old. Based on patients' postcodes, we found that more than a third of the 71 patients resided in middle class residential area, 23% lived in well-to-do area and 33% were from low socio-economic residential area. The high proportion of participants from middle class and well-to-do residential areas was as expected because individuals from these areas are known to be more motivated and articulate in their use of health services.

In terms of cancer in the family, 51 patients (72%) reported that they had at least two relatives with a cancer

Table 1 Patients' demographic characteristics

Characteristics	No. of patients (%)
Gender	
Male	6 (8)
Female	65 (92)
Age	
<30	13 (18)
30–50	46 (65)
>50	12 (17)
Ethnicity	
White	70 (99)
Asian	1 (1)
Cancer type	
Breast	34 (48)
Ovarian	16 (23)
Bowel	14 (20)
Others	7 (9)
Socio-economic background based on postcode	
Middle class residence	
Wealthy and live in affluent area	31 (44)
Live in poor area/high unemployment/council	16 (23)
Flats/single parents	24 (33)
No. of cancer affected relatives	
At least 2 relatives with relevant cancer	51 (72)
1 Relative with relevant cancer and other relatives affected by other types of cancers	10 (14)
1 Relatives with a relevant cancer	9 (13)
2 Relatives with other types of cancer	1 (0.1)

relevant to the one for which they themselves had been referred. Ten patients (14%) had one relative with a relevant cancer but others in the family affected by other types of cancers. Nine had only one family member affected by a relevant cancer while one patient had two relatives but they were affected by other types of cancers. The patient with two unrelated cancers specifically requested for a referral to genetics.

Factors/events influencing GP consultations about family history of cancer

The following were reported by patients as factors influencing their visits to the GPs and these factors are not mutually exclusive.

More than half of the patients (47 patients) reported that a family cancer event (diagnosis of cancer, death(s) and cancer recurrence) raised their concern about their cancer risk and motivated them to consult the GPs. Family events in the past acquired new salience with the passage of time and raised the awareness of familial cancer risk:

“My auntie was diagnosed with bowel cancer last year, then my father, we really took it seriously” (R14).

“I thought that after the second brother died, there must be some link in the family” (R29).

Twenty-nine patients said that the specialists or hospital consultants looking after their relative(s) advised that they should consult the GP. Thus, direct input from professionals raised awareness about the significance of family history:

“When the oncologist nurse caring for my relative advised me to see my GP and be screened, I became worried...” (R41).

“Because my mum had got breast cancer for the second time... her consultant recommended that I went to see my doctor ...” (R11).

“...because of what happened to my mum, the doctor (in the hospital) said that she should see about her daughters going to see the GP if we are at risk” (R33).

Sometimes advice and an awareness of cancer risk due to the age when relatives were diagnosed with or died of cancer went hand in hand:

“My cousin, who is my age, has developed cancer. My daughter is studying genetics and she suggested that perhaps we should visit the doctor and mention it” (R39).

“Because I’d lost my mum, she was 56 when she died and she has had it at 45 and my grandmother had died at 52... I am approaching 40” (R18).

Media and publicity produced direct effects in which some patients were alerted to the significance of their own cancer risk due to a family history.

“...I read and watched documentaries, things in the magazine” (R8).

“...something I watched on the television about genetics and things” (R35).

“It was on Radio Four news in the morning...” (R9)

Poor knowledge of the services offered by the YRCGS was reported by this group of patients; indicating only a limited effect on patients’ decision to initiate consultation with GPs. Only 23 patients knew about the type of services provided by the genetic centre. Twenty-one patients said they did not know what to expect when they saw the geneticist. Twelve patients said they expected to be offered regular screening for cancer, nine patients said they were going for blood test and DNA testing, while the remaining six patients said they were expecting to receive advice on the management and prevention of cancer.

Amongst these factors, family cancer events, doctors’ advice and reaching the age of cancer-affected relatives were frequently reported to influence patients’ awareness of the added cancer risk due to family history and motivated consultations with the GPs.

It is tempting to conclude from these evidence that patients became aware of their cancer risk and acknowledged their familial cancer status, i.e. that they had a family history of cancer. However, the evidence provided in the following sections reveal a more complex picture.

The importance of perceived ‘family history of cancer’

Patients were asked about the importance of their family history in relation to their own cancer risk. Less than half of the 70 patients who provided an answer (46%) perceived family history to be very or quite important. Another 17 patients thought there was some increase in their risk. Three patients said family history was not important. Seventeen patients (24%), on the other hand, said they were unsure and did not know what a ‘family history of cancer’ meant.

The belief that there was a cancer genetic problem in the family prompted some patients to seek advice from their GPs.

“It’s always been at the back of my mind but when my mother died from the same thing as my father and grandfather, I thought it is genetic” (R15).

“I thought it must be hereditary... I lost two aunts and a cousin at the age of 30 years old, and now another cousin and my sister, how it is not hereditary?” (R34).

For many patients, it seemed that knowledge of the number of cancer-affected relatives did not affect their own perceived vulnerability to cancer. For them, it was the knowledge that cancer is a ‘family thing’, ‘runs in the family’ that appeared to heighten their perceived vulnerability to the disease.

“I thought there was a family link because my elder sister died when she was 44, then my twin sister got it...” (R17).

“It’s always been a thing in our family because it’s been so prevalent. I kind of grew up thinking I would get cancer because so many people in my family did” (R11).

About a third of the patients did not relate family medical history to a risk to the disease and therefore did not place any significance on this aspect of family medical history. This evidence suggested poor knowledge of inherited cancers and poor understanding of family history of cancer.

“I am not sure. I read that the most important factor is age” (R16).

“I don’t think the family thing is important” (R55).

“I do not think it is important ... other factors are more important like older age, having children” (R31).

The findings revealed that, firstly, the knowledge of family medical history and its role in motivating consultation to discuss cancer risk in this group of patients is difficult to ascertain. Secondly, the inter-relationships of knowledge of family history with other causal beliefs are of interest and these require further investigation to understand the factors motivating patients to initiate and discuss cancer risk with the doctors. Thirdly, the belief that ‘cancer runs in the family’ or is ‘a family thing’ did not appear to be sufficient to raise perceived cancer risk and motivate patients to seek medical advice.

Influence of the number of cancer-affected relatives on perceived importance of family history

The extent to which knowledge of the number of cancer affected relatives influenced perceived importance of family history was further examined through a cross-tabulation (Table 2).

Out of the group of 51 patients who had two or more relatives with a relevant cancer, only about half (27 patients) accepted that family history of cancer was an important influence on their own cancer risk. A further quarter (13 patients) thought there would be some increase in risk. Nine patients did not appreciate the importance of family history of cancer to their own cancer risk despite having two or more relatives with relevant cancers. One patient said family history was not important.

These results further emphasised that knowledge of the number of cancer incidents in the family did not necessarily mean that patients understand the importance of family history. Nor did it translated into an awareness of the role that family history might have in determining cancer risk.

Age of onset of cancer in affected relatives

Many patients could remember the exact age that their relatives were diagnosed or died of cancer. This was one of the factors that motivated patients to visit their GPs as discussed above. The quotes below suggest that some patients did not have proper understanding of the age aspect of family medical history. It appeared that they might be mistaken in thinking that they could only contact the disease at the same age or nearer the age when their relatives were diagnosed or died of cancer.

“I think it’s because of my age. My mum died of breast cancer when she was only 45. I am 45 this year” (R35).

“I went to see the GP because of my age. My mother had ovarian cancer when she was younger than me” (R12).

Table 2 Perceived importance of family history of cancer and number of relatives affected by cancer

Perceived importance of history of familial cancer	2 or > Relatives with relevant cancers	1 Relative with relevant cancer and any other cancer	1 Relative with relevant cancer and no other cancer	2 Relatives with irrelevant cancers	Total
Important/quite/very	27	3	2	1	33
Higher chance/slight increased risk	13	3	1	0	17
Not sure/do not know	9	3	5	0	17
Not important	1	1	1	0	3
Missing data	1	0	0	0	1
Total	51	10	9	1	71

The quotes above suggest poor understanding of the medical concept (number of affected relatives and age at diagnosis) and the clinical value of family medical history in the prevention and management of familial cancer in this group of patients.

Discussion

The findings of this study have several important implications. First, family cancer events, the advice of doctors and reaching the age of cancer-affected relatives were more salient than media and publicity, and knowledge of the genetics services in raising awareness of the added cancer risk due to family history. Second, knowledge of family medical history and its clinical value in this group of patients is not easy to ascertain. Third, the inter-relationships with other causal beliefs are of interest and could provide insights to understand the factors motivating patients to discuss family history or cancer risk. Fourth, the belief that ‘cancer runs in the family’ or is ‘a family thing’ may not be sufficient to heighten perceived cancer risk and motivate patients to seek medical advice. Fifth, there is poor understanding of the medical concept and the clinical value of family history even in this group of patients who initiated the GP consultations.

Previous studies had demonstrated that a substantial proportion of people with a significant family history of cancer were unaware of their heightened risk (Kash et al. 1992; Murabito et al. 2001). Our study revealed similar findings: family medical history (as indicated by number of affected relatives and age of onset) was not perceived as significant to their own cancer risk in many cases even though patients knew that the disease sometimes can run in families. Illness events, cancer diagnosis and deaths in families were more significant. Recent events were most frequently reported as the factors giving rise to the awareness of familial cancer risk leading to a visit to the GP. Individuals with strong family histories may acknowledge an increase in risk, but may not place significance on their family history information and are more influenced by their particular familial experience of the condition. Their perceived vulnerability may be based on the burden of cancer in the family rather than on the hereditary nature of a faulty gene or a family history. Other studies also reported this factor as an important triggering factor in considering personal risk and vulnerability (Evans et al. 1993; McAlister 2003; Rees et al. 2001; Walter and Emery 2005). Individuals’ perceived vulnerability to a familial condition was defined and heightened by their experience of going through the illness with their affected relatives, and/or demise of their close ones. Family illness events (recent diagnosis or

recurrence of cancer or death) thus may prompt patients to consult about their own cancer risk for a variety of reasons that have little to do with the way individuals understand the clinical value of family medical history.

Knowledge of the number of cancer-affected relatives was not significant in motivating patients to consult their GPs for many patients. For the 51 patients who had two or more relatives with a relevant cancer, about a quarter did not perceive family history to be of importance. These findings suggest that knowledge of a family history of cancer, as indicated by the number of affected relatives, might not be sufficient to heighten a feeling of vulnerability to disease, leading to a visit to the GP for everyone. Moreover, the term ‘family history’ was never mentioned as a trigger to consult the GP about familial cancer risk (Al-Habsi et al. 2008). This finding also suggests that not all patients associated this type of family history with cancer risk, and their poor understanding of the value of family history for the management of familial cancer risks.

Nearly a quarter of the 71 patients said they were unsure and did not know what was ‘family history of cancer’. Of these, ten patients had two or more relatives affected by cancer for which they were referred. Poor understanding of family history is also reflected when patients talked about ‘age’ as a trigger to initiate consultation with the doctor. Patients quoted their age, not age of onset of disease in relatives, as the reason to visit the doctor and this highlighted a lack of understanding of the age concept in the context of familial cancers and its use in risk assessment. These patients appeared to think that they had an increased risk of developing cancer at the same or nearer the age of onset of disease in relatives. Age of onset of disease in relative(s) is an important predictor of cancer risk in the family but it does not always indicate cancer risk. Claus et al. (1990) found no evidence of correlation among relatives in age at cancer onset. In another study, interfamilial heterogeneity in age at onset in hereditary cancer was observed (Lynch et al. 1988). Thus, having one or more relatives diagnosed at the same or nearer the age does not necessarily imply that the other relatives will also contact the disease at the same age (Lynch and Watson 1990).

Hospital doctors’ advice emerged as more salient than knowledge of family medical history in prompting individuals to consult a GP about their own cancer risk. Many patients in this study consulted their GPs because they were advised to do so by the hospital consultants looking after their cancer-affected relatives. Hospital doctors’ advice also had an influence on GP’s decision to refer these patients to genetics (Al-Habsi et al. 2008). The effects of doctors’ advice on patients’ participation in healthcare decision-making had been reviewed (Guadagnoli and Ward 1998). Thus, patients consulted their GPs not necessarily because

they believe their family history of cancer could increase that risk. Nor was it based on patient's knowledge of the existence of genetic services as two third of the patients did not know of the services provided by the genetic centre.

For some patients, the media produced direct effects in motivating a consultation with the GP. A PhD study reported similar findings: news reports of public figures or celebrities diagnosed with cancer increased awareness of cancer risks in women with a family history and therefore set off the discussion of risk with the GPs (Reid 2007).

For the foreseeable future, it seems likely that most GPs will rely on patient initiated discussion to identify people at increased risk of cancer because of their family history; as the evidence showed that GPs prefer to take a reactive role in initiating the discussion of family history for a variety of reasons (Al-Habsi et al. 2008; Suchard et al. 1999). It is therefore important to improve our understanding of the reasons patients behave as they do, and to do that, further research including non-referred patients and patients referred to cancer diagnostic services is needed. It may be, for example that family cancer events prompt patients to consult about their own cancer risk for a variety of reasons that have little to do with genetics or family medical history: such events may increase the saliency of cancer as a disease, increase awareness that cancer can happen to fit people, young people, people with healthy lifestyles, and so on, and increase people's fear that they might develop or indeed already have cancer. Research is also needed to explore the important role played by hospital doctors in raising awareness and motivating asymptomatic patients to consult their GPs.

Strengths and limitations

Our study is the first to explore asymptomatic patients' self-initiated consultation in primary care to gain insights into the factors giving raise to awareness of family history and familial risk and motivation to initiate consultation with GPs. Our findings emphasised the saliency of the role played by hospital doctors and cancer events in motivating the GP consultation and raising awareness of the added risk due to family history of cancer.

We made an assumption in the present study that individuals with a family history of cancer had knowledge and understanding of the term 'family history' and shared similar understanding of family history with healthcare professionals as they also counted the number of affected relatives and were knowledgeable of their relatives' ages at diagnosis. We asked this group of patients whether they had a family history of cancer but we did not explore their answers further, or their understanding and knowledge of the type of information required to make a family history of cancer.

The participants in this study were patients who were referred by their GPs to genetics because they have a family history of cancer. We did not recruit and capture views of patients who consulted their GPs whose vulnerability was raised by media publicity, knowledge and experience of cancer in friends and neighbours. Therefore, the findings of this study cannot be generalised to all individuals who may be susceptible to an increased risk of familial cancer.

The low response rate in this study also means that our findings cannot be generalised amongst asymptomatic patients who initiated consultation with their doctors in primary care to discuss familial cancer risk.

Clinical applications

Our findings highlight that knowledge of family medical history (the number of affected relatives and age of onset of disease) is not sufficient to raise awareness of the added risk due to family history or to motivate consultation with GPs to discuss cancer risk. This finding is in tangent with health education policy which assumed that people knew their family medical history and would consult their doctor because of a family history. Our findings also highlight the important roles played by hospital doctors' advice and cancer events in the family in raising awareness of familial risk and motivating consultation with GPs in this group of patients. More research is needed therefore to understand and determine the roles played by hospital doctors in influencing individuals who may be susceptible to an increased cancer risk to seek medical advice from the GPs. Efforts are also needed to promote people's understanding of the clinical value of family medical history in the management and prevention of cancer.

Primary care doctors are in the best position to collect family history given their role as family physicians. Efforts and resources should therefore be provided to promote and encourage a pro-active attitude towards family history collection amongst GPs.

Conflict of interest The authors declared no conflict of interest.

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