



Relatives' Perspective

Assessment of family history of colorectal cancer in primary care: Perceptions of first degree relatives of people with colorectal cancer



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ABSTRACT

Objective: First degree relatives (FDRs) of someone with colorectal cancer (CRC) are at increased risk of the disease. In this study we examine the factors associated with discussing family history of CRC with a health professional.

Methods: People with CRC, recruited through the population-based Victorian Cancer Registry in Australia, were asked to refer FDRs to the study. Eight hundred and nineteen FDRs completed a telephone interview.

Results: Thirty-six percent of FDRs recalled ever being asked about their family history of bowel cancer by a health professional. Factors associated with having this discussion were being aged 50–60 years, having a university education, being in the potentially high risk category, being very worried about getting bowel cancer and knowing that family history increases risk through discussions with family, friends or their own education.

Conclusion: Despite evidence that doctor endorsement is a key factor in the uptake of CRC screening, our study shows that the majority of FDRs do not recall being asked by a health professional about their family history.

Practice implications: There is a need to identify the most appropriate method to improve rates of health professional discussion of family history with relatives of CRC patients in order to improve screening rates.

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1. Introduction

Colorectal cancer (CRC) is the fourth leading cause of cancer related death worldwide [1]. Australia has one of the highest incidence with 1 in 22 people developing the disease by the age of 75 [2]. Those diagnosed at an early stage have a 5 year survival rate of 90%, compared with 10% for those with advanced metastatic disease [3]. Despite this, less than 20% of CRCs in Australia are detected at the earliest stage of the disease [4].

The risk of developing CRC increases sharply over the age of 50 and among relatives of those with CRC [5]. Based on the number of affected relatives and the presence of high risk features, Australian guidelines classify first degree relatives (FDRs) as at average/

slightly above average risk, moderate risk, and potentially high risk. Different screening regimens are recommended for those in each risk category. Despite their higher risk, our data indicate that adherence to screening recommendations is only 39% among FDRs of people with CRC [6].

Adherence to screening guidelines requires that FDRs are aware of their level of risk, and the corresponding screening recommendations. There is no systematic mechanism for providing information about CRC risk for family members of those diagnosed with the disease. Therefore, it often falls to general practitioners (GPs) to assess risk and provide screening recommendations as part of preventive care. Our recent data indicate that being asked by a health professional about their family history of CRC was a significant predictor of being screened in accordance to guidelines among FDRs [6]. However, there is limited evidence that this does not routinely occur in clinical practice. In a survey of community dwelling Australians aged over 50, 38% reported ever being asked about their family history of CRC by a health professional [7]. A study in North America of patients with CRC who had a first or second degree relative affected reported 59% having a family history documented [8]. An audit of medical records in a North American family practice found 55% recorded a family history of

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cancer while only 8% recorded age of onset [9]. A similar study in a UK hospital involving patients diagnosed with CRC under age 60 found 54% of case notes referenced family history of cancer and 20% included the age of diagnosis of family members [10].

In this study we examine the factors that are associated with discussing family history of CRC with a health professional. Prior research has shown that a recent family cancer event is most commonly the motivator for a FDR to visit their GP [11,12], with level of education also predictive in influencing health maintenance visits [13].

The aim of the current project was to: (1) describe the proportion of FDRs who report discussing family history of CRC with a health professional; (2) how and when they became aware of family history as a risk factor; and (3) identify whether older age, female gender, country of birth, education, greater family risk status, worry about getting bowel cancer, or how became aware of increased risk is associated with greater likelihood of having discussed family risk with a health professional.

2. Methods

2.1. Eligibility

FDRs of people with CRC were eligible to participate in the trial if they were: (1) aged 18 or older; (2) English speaking; (3) able to provide informed consent; and (4) did not have a prior diagnosis of CRC, advanced adenoma, familial adenomatous polyposis (FAP), or Crohn's disease, ulcerative colitis, or other inflammatory bowel disease.

2.2. Recruitment

Data for this study were collected between February 2010 and November 2012. CRC patients were identified by the cancer registry and invited to participate in the trial if they were over 18, within ten months of diagnosis, English speaking and able to provide informed consent and considered able to participate by their clinician [14]. Consenting patients completed a baseline computer-assisted telephone interview (CATI) which asked about: (1) family history of CRC, high risk related cancers, high risk genes and FAP; and (2) total number of living FDRs over the age of 18, and whether the research team could contact them to invite the FDRs to participate. Information collected from the CRC patients was used to classify the family risk status of their FDRs according to a modified version of the National Health and Medical Research Council's risk categories [15]:

Category 1. At or slightly above average risk: Index cases (ICs) with no first or second degree relatives diagnosed with bowel cancer and who were diagnosed themselves over age 55.

Category 2. Moderately increased risk: ICs diagnosed before the age of 55 without other high risk factors and those with 1 or 2 first or second degree relatives not on the same side of the family diagnosed with bowel cancer without any high risk features.

Category 3. Potentially high risk: ICs diagnosed under the age of 55 with multiple bowel cancer or 2 or more first or second degree relatives on the same side of the family diagnosed with bowel cancer, or a first or second degree relative with any high risk features. High risk features include multiple bowel cancers in one person; bowel cancer diagnosed before the age of 50; a relative with cancer of the endometrium, ovary, stomach, small bowel, renal pelvis, ureter, biliary tract or brain; a FDR with FAP; or a relative with a high risk gene identified through genetic testing.

FDRs that consented participated in a brief screening interview to assess trial eligibility. Those with a prior diagnosis of CRC, advanced adenoma or FAP, or Crohn's disease, ulcerative colitis, or other inflammatory bowel disease were considered ineligible.

2.3. Measures

Eligible FDRs completed a baseline CATI comprising a series of modules a subset of which are reported here.

Socio-demographic questions: Items included age, gender, country of birth, postcode, marital status, level of education, employment status and whether they have private health cover. The relationship between the FDR and the IC was known from the IC interview.

Awareness of family risk: FDRs were asked when they first became aware that having a family history of bowel cancer increases a person's risk of developing bowel cancer ("less than a month ago"; "1 month to less than 12 months ago"; "12 months to less than 2 years ago"; "2 years to less than 5 years ago, 5 years or longer"; "Don't know that family history increases risk"), and were asked what first alerted them to this fact ("The letter I received from the Cancer Council"; "A member of my family was diagnosed with bowel cancer"; "Information from the TV, radio or newspaper"; "My doctor discussed the risk of bowel cancer with me"; "Other"; "Don't know/Not sure").

Discussions with health professional: FDRs were asked whether a health professional had ever asked about their family history of bowel cancer, the type of health professional who asked ("GP", "cancer specialist", "genetic counsellor" or "other"), how long ago they were asked ("less than a month ago"; "1 month to less than 12 months ago"; "12 months to less than 2 years ago"; "2 years to less than 5 years ago, 5 years or longer"; "Don't know/ Not sure") and how many times they have consulted that health professional about family history or bowel cancer or screening for bowel cancer.

2.4. Data analysis

All analyses were conducted in Stata 11.2. Responses to the survey questions were tallied and divided by the total number of participants to calculate proportions, taking the response "Not sure" as a negative response. The characteristics of FDRs associated with having discussed their family history of CRC with a health professional were assessed using logistic regression modelling in a generalized estimation equation framework to account for multiple FDRs per family. The variables age, gender, Australian born, education, family risk category, level of worry and how they became aware that a family history increased risk were entered into the model. Those who knew that a family history increased risk due to discussions with a doctor were excluded from the regression analysis.

2.5. Ethical approval

This study was approved by the University of Newcastle (2008-0047) and Cancer Council Victoria (0810) ethics committee, and all participants provided written consent.

3. Results

Of the 2928 eligible ICs sent a letter by the registry, 1084 (37%) gave consent for their details to be given to the research team and 753 (69%) completed the baseline interview. Of these, 649 (86%) had FDRs and agreed to them being invited to participate in the study. This led to 2376 FDRs being sent an invitation letter and 904 (38%) consenting to complete the interview to assess trial

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