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Courtney, R. J.; Paul, C. L.; Sanson-Fisher, R. W.; Macrae, F.; Attia, J.; McEvoy, M.
"Current state of medical-advice-seeking behaviour for symptoms of colorectal cancer: determinants of failure and delay in medical consultation", Colorectal Disease Vol. 14, Issue 5, p. e222-e229 (2012)

Available from: <http://dx.doi.org/10.1111/j.1463-1318.2012.02881.x>

This is the peer reviewed version of the following article: Courtney RJ, Paul CL, Sanson-Fisher RW, Macrae F, Attia JR, McEvoy MA, 'Current state of medical-advice-seeking behaviour for symptoms of colorectal cancer: determinants of failure and delay in medical consultation', Colorectal Disease, 14 e222-e229 (2012), which has been published in final form at 10.1111/j.1463-1318.2012.02881.x. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

Accessed from: <http://hdl.handle.net/1959.13/1065993>

The current state of medical advice seeking behaviour for primary symptoms of colorectal cancer: Determinants of failure and delay in medical consultation.

Ryan J Courtney*, PhD candidate health behaviour^{1,4}, Christine L Paul, Senior research academic health behaviour^{1,4}, Robert W Sanson-Fisher, Laureate Professor of Health Behaviour^{1,4}, Finlay Macrae, Professor of Medicine², John Attia, Professor of Medicine and Clinical Epidemiology^{3,4}, Mark McEvoy, Lecturer in Epidemiology^{3,4}

1. The Priority Research Centre for Health Behaviour,
School of Medicine and Public Health, Faculty of Health,
The University of Newcastle,
Australia

2. Department of Colorectal Medicine and Genetics
The Royal Melbourne Hospital
Australia

3. The Centre for Clinical Epidemiology and Biostatistics
Faculty of Health,
The University of Newcastle,
Australia

4. Hunter Medical Research Institute

* Corresponding author. Ryan J Courtney. University of Newcastle, Priority Research Centre for Health Behaviour, Room 269a, Level 2, David Maddison Building, Callaghan, 2308. Tel: 0249138143 Fax: 0249138779 e-mail (published): ryan.courtney@newcastle.edu.au

Conflict of Interest Statement: The authors declare that there are no conflicts of interest.

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Abstract

Aim

Little data exists on the factors associated with health care seeking behaviour for primary symptoms of colorectal cancer (CRC). This study described the determinants of failure and delay in seeking medical advice for rectal bleeding and change in bowel habit.

Method

1592 persons (56- 88 years) were randomly selected from the Hunter Community Study (HCS) and mailed a questionnaire.

Results

18% (60/332) of respondents experiencing rectal bleeding and 20% (39/195) reporting change in bowel habit had never consulted a doctor. Rate of delay (> one month) for each symptom was 18% and 37%. Reasons for delay included assumptions about symptom seriousness and benign nature. Triggers for seeking medical advice varied. Health care seeking behaviour for rectal bleeding had not significantly improved compared to a previous community-based dataset.

Conclusion

The seriousness of symptoms, importance of early detection, and prompt medical consultation must be articulated in health messages to at-risk persons.

Keywords

Colorectal neoplasms, early detection of cancer, primary health care, symptom

What is new in this paper?

- The present study is novel in its assessment of the current state of medical advice seeking behaviour within an at-risk community (56-88 years of age) and its exploration of not just the reasons of delay but also factors associated with earlier presentation times for both primary symptoms of CRC
- An understudied primary symptom (change in bowel habit) is investigated in the current study with new information provided on delay in seeking medical advice and the contributing factors to medical consultation.
- This study, using comparison to a previous dataset, indicated that despite increased public education regarding CRC, the rate of medical consultation and delay in seeking medical advice for rectal bleeding remains high with negligible improvements over time.
- Underestimation of symptom seriousness continues to be a commonly reported reason for delay/ failure in seeking medical advice. Perceived symptom seriousness is a triggering motive for medical consultation.

Introduction

Colorectal cancer (CRC) and primary symptom presentation.

Internationally, CRC is diagnosed in over one million persons annually (9.4% of all cancer diagnoses) and ranks as the fourth leading cause of cancer related death [1]. Five-year relative survival rate for early stage CRC is 90%, compared to less than 10% for distant metastatic cancer. However, approximately 40% of CRCs are diagnosed at a localised stage [2]. Rectal bleeding and change in bowel habit are common symptoms experienced in the general population [3, 4]. It is estimated that 37-84% of all CRCs present with rectal bleeding [5-7], while change in bowel habit presents in approximately 48-77% of CRCs [5-7]. The majority of CRC cases present symptomatically to primary care, while 20-40% of cases present to emergency [8-11][12].

Current debate: Symptom duration and staging of disease.

It is axiomatic that, for an individual patient, the earlier the presentation and diagnosis, the greater likelihood that a tumour will be detected at an early curable stage [13]. There is however, a paradoxical relationship between symptom duration, earlier diagnosis and survival, which continues to be debated in the literature [14-17]. Some studies suggest symptom duration of 3 months or more are less likely to have early stage tumours [18-20], while other studies have indicated no relationship between symptom duration, pathological stage at diagnosis and survival [16, 21, 22]. This would suggest that the public health message should be to engage in screening for CRC, *before* symptoms develop. However, it would be unwise to diminish the importance of prompt medical advice for CRC symptoms, particularly given the high rate of symptomatic presentation (approximately 80% of CRC cases) and the present low rate of asymptomatic presentation [23, 24].

Studies examining emergency admissions have indicated a median symptom duration of 3 months prior to admission, without patients necessarily presenting at any earlier point to primary care [25, 26], and poor outcomes [12] [19, 27, 28]. This suggests a significant public health gain is achievable if the number of CRCs identified pre-emergency is increased.

A lack of knowledge about current symptom presentation.

Our knowledge of medical advice seeking behaviour for rectal bleeding is limited to a few population and community based evaluations [4, 29, 30]. Australian community-based studies [29, 30] have indicated that a third of persons experiencing a first episode of rectal bleeding delay longer than three months or fail to seek medical advice, potentially due to perceptions that the condition is not serious [3, 29-31] or a lack of pain or discomfort [3, 31]. For change in bowel habit (constipation or diarrhoea), little is known about medical advice seeking behaviour, with studies generally examining overall medical consultation rates [32-34] rather than time taken to seek medical advice. The present study is novel in its assessment of the current state of medical advice seeking behaviour within an at-risk community (56-88 years of age) and its exploration of not just the reasons of delay but also factors associated with earlier presentation times for *both* primary symptoms of CRC. The aims of the study were to identify for each primary symptom of CRC: (i) the proportion ever experiencing a symptom in their lifetime, and (ii) non-consultation rate - the proportion failing to ever seek medical advice and reason for non-consultation. For those who sought medical advice for their first symptom episode in the previous five years: (iii) the time taken to seek medical advice, the reason for delay and perceived triggers for seeking medical advice. Results for the time taken to seek medical advice

and consultation rate for rectal bleeding were compared to a previous study dataset in a similar geographic area to assess whether medical advice-seeking behaviour had changed over time.

Method

Design & Sample Descriptions

Hunter Community Study (HCS)

A cross-sectional sample of community dwelling men and women aged 56-88 years in the Hunter Region of New South Wales (NSW), Australia, were extracted from the Hunter Community Study (HCS) cohort [35]. The HCS sample is a longitudinal cohort of community dwelling men and women aged 55-85 years at cohort baseline from the Hunter Region, NSW, Australia [35]. Participants were randomly selected from the NSW State electoral roll between December 2004 and 2007. The HCS cohort provides a population profile reflecting that of the Hunter Region, state and national Australian profiles for gender and marital status but is slightly younger in age [35].

Comparative study

The comparative study [30] was a cross-sectional survey of NSW men and women aged over 40 years of age conducted between June-August, 2000. This study used a computer assisted telephone interview (CATI) method of data collection with free-recall provision. Participants were randomly selected from the NSW telephone directory. Compared with NSW census data, this sample was representative for age and marital status, with females slightly overrepresented [30].

Exclusion criteria

Persons previously identified on the HCS databank as diagnosed with CRC or self-reporting undergoing major abdominal surgery were excluded from analysis.

Procedure

A randomly selected subsample of HCS participants (n=1592) were mailed an information statement and a pen and paper questionnaire in November, 2009. A reminder telephone call was made to non-responders at 4-6 weeks following initial mail out.

Questionnaire

Symptom episode.

The pen and paper questionnaire asked whether participants had “ever noticed blood in bowel motions, in the toilet bowl or on the toilet paper?” or “a persistent change in your normal bowel habits that lasted longer than two weeks? This may include looser bowel motions/ needing to go to the toilet more than usual (diarrhoea) or an inability to pass bowel motions (constipation)”. These items were used to determine the proportion of respondents ever experiencing either symptom episode and are referred to hereafter as [*Symptom X*]. The item concerning rectal bleeding had been used in two previous Australian studies [29, 30] while the change in bowel habit item was devised for this study

Non-consultation rate.

For both symptoms, respondents indicating ‘yes’ to ever experiencing a symptom were asked “have you ever seen a doctor about: [*Symptom X*]?” These items were used to identify the proportion experiencing either symptom who had *never* consulted a doctor. Respondents ever experiencing each symptom and never having sought medical advice were asked: “What is the main reason you did not seek medical advice about [*Symptom X*]?” Please circle only one response.”

Time taken to seek medical advice: Reason for delay and triggers for seeking medical advice.

Respondents indicating they had ever sought medical advice were asked “did you first notice [*Symptom X*] in the last five years?” and “Did you see a doctor about it?” To reduce recall bias only those experiencing their first symptom episode in the last five years and consulting a doctor were included in the analyses of time taken to seek medical advice, reason for delay and triggers for seeking medical advice. Such respondents were asked to specify the time taken to seek medical advice: “How long after you first noticed [*Symptom X*] did you see a doctor about it? Please specify the amount of time.”; reason for delay: “What is the main reason you did not seek medical advice about [*symptom X*] sooner? Please circle only one response”; and trigger(s) for seeking medical advice: “What in particular prompted you to consult a doctor about [*Symptom X*]? Please circle all that apply.” Closed response options were provided relating to reasons for delay/failure to seek medical advice and triggers for seeking medical advice with an “Other (Please specify)” option included. The questions asked were identical to those asked in the comparative study [30] except for triggers to seeking medical advice which was not assessed in the former study.

Comparison between datasets

Cross-study comparisons are an insightful mechanism to track improvement in health outcomes overtime. Such a technique has been successfully adopted in previous studies assessing health behaviour change [36]. Comparisons between the existing survey and the comparative study data (a similar population group) were made to identify whether medical advice-seeking behaviour for rectal bleeding had improved. The comparative study dataset contained participants aged 40 years and over. The data were re-analysed for respondents aged 55 years or older to provide a

comparable dataset on the following outcomes: proportion ever experiencing rectal bleeding, non-consultation rate, and the time taken to seek medical advice.

Statistical analysis

Proportion of respondents ever experiencing each symptom episode (Yes/No) and ever consulting a doctor about each symptom episode (Yes/No) were assessed.

Frequency distribution was used to examine: the time taken to seek medical advice (95% confidence interval reported), reason for delay, reason for failure to consult a doctor, and triggers for seeking medical advice. A shorter cut point (> one month) was adopted in this study to constitute 'delay' compared to previous studies [29, 30] that have adopted a cut-point > 3 months. This tighter cut-point was used to assess reasons for delay across a wider trajectory with consideration that any 'delay' in this studied cohort is of critical importance given that the entire cohort is at increased-risk of developing CRC (> 55 years of age). It should be acknowledged that delay cut-points used within previous studies [29, 30] are arbitrary with no empirical evidence suggesting any critical 'delay' cut-point. Pearson chi-square tests were used to detect any significant differences across datasets for the non-consultation rate and time taken to seek medical advice for rectal bleeding. Data were analysed using STATA 11 (STATA, Texas, USA).

Ethics approval

The University of Newcastle in partnership with the Hunter New England Population Health Human Research Ethics Committee granted ethical approval (H-820-0504).

Results

Characteristics of the sample

Of the 1592 mailed surveys, 1117 respondents completed and returned a survey (consent rate = 70%). Respondents previously diagnosed with colorectal carcinoma

(n =24) as listed on the HCS databank or reporting they had undergone major abdominal surgery (n=8) were excluded from analysis, leaving a total sample of 1085 eligible participants for analysis. For those persons (n=475) not participating in the study: 19% (90/ 475) indicated an intention of returning survey with no subsequent return, 13% (63/ 475) refused to participate, 7% (33/475) were too ill, 2% (8/475) were deceased, and for 59% (281/ 475) a reason for nonparticipation was not given. Demographic characteristics of the sample are presented in table 1.

INSERT Table 1.

Proportion ever experiencing a primary symptom of CRC.

Of the 1075 respondents to the rectal bleeding question, 332 (31%) reported ever experiencing this symptom. For change in bowel habit 1049 respondents answered this question with 195 (19%) reporting ever experiencing this symptom. Overall, 609 (59%) respondents had never experienced either symptom, 235 (23%) rectal bleeding only, 101 (9.7%) change in bowel habit only and 94 (9.1%) had ever experienced both symptoms. Pearson's χ^2 test found that the proportion of respondents experiencing rectal bleeding in the HCS cohort (31%) was significantly higher (167/ 737 - 23%) than that found in the comparative study sub-sample ($\chi^2 = 16$; df = 1; $p < .001$).

Non-consultation rate.

For respondents ever experiencing rectal bleeding or change in bowel habit, 60 (18%) and 39 (20%) respectively had never consulted a doctor in their lifetime. Pearson's χ^2 test found that the rate of non-consultation for rectal bleeding in the comparative study (19/ 85 - 22%) was not significantly different from the HCS cohort ($\chi^2 = .8$; df = 1; $p < .369$).

Reason for never seeking medical advice following primary symptom episode.

Reasons for failure to ever seek medical advice for rectal bleeding and change in bowel habit are listed in table 2. The most common reason for non-medical consultation for rectal bleeding was a perception that the symptom was from a benign cause ("Thought it was haemorrhoids/ piles" - 66%). For change in bowel habit, reasons were mixed, including an underestimation of the seriousness of the symptom ("Thought it wasn't serious"- 37%) and an attitude towards waiting for the symptom to subside ("Decided to wait and see" – 23% and "Cleared up itself"- 23%).

INSERT Table 2.

Delay in seeking medical advice.

For those ever experiencing rectal bleeding and change in bowel habit respectively, 101 (30%) and 72 (37%) respondents reported consulting a doctor and experiencing their first symptom episode in the previous five years. For rectal bleeding (fig. 1) and change in bowel habit (fig. 2) 18 % and 37% of respondents respectively delayed greater than one month before seeking medical advice. Comparison between datasets indicated a greater proportion of respondents in the comparative study sought medical advice within one week (71% vs. 53%) and lesser proportion delayed between one to four weeks (17% vs. 29%) and greater than one month (12% vs 18%) in the comparative study. Such differences across datasets using Pearson's χ^2 test were not found to be statistically significant ($\chi^2 = 5$; $df = 2$; $p = .072$).

INSERT Fig 1

INSERT Fig 2

Reason for delay (> one week) in seeking medical advice.

For rectal bleeding (see table 3), the predominant reason for delay (76 %) was the perception of a benign cause ("Thought it was haemorrhoids/ piles"). For change in bowel habit (see table 3), more than half of respondents either indicated that they

wanted to wait before seeking treatment (“Decided to wait and see” - 32 %) or that they thought the symptom was not serious (“Thought it wasn’t serious” - 24 %).

INSERT Table 3.

Triggers for seeking medical advice.

Triggers for rectal bleeding included: “Thought the symptom was serious” (27%), “Symptom didn’t go away (15%)”, “Opportunity to talk during doctor visit for other reason (14%)”, “Family history of cancer” (9%), “Partner or family member suggested it” (8%). For change in bowel habit, the most common reported trigger was the persistence and duration of symptom episode “Symptom didn’t go away” (40%) followed by “Thought the symptom was serious” (13%) and “Opportunity to talk during doctor visit for other reason (9%).

Discussion

Both rectal bleeding and change in bowel habit are common symptoms experienced in the community, with 31% and 23% of respondents respectively ever reporting a symptom episode. Across both symptoms approximately one in five persons ever experiencing a primary symptom episode had never sought medical advice. For those consulting a doctor following their first symptom episode in the previous five years, a sizeable minority - 18% for rectal bleeding and 37% for change in bowel habit - delayed greater than one month. For both symptoms, the reason for delay in seeking medical advice was consistent with a tendency to underestimate the potential serious nature of symptom episode. Accordingly, the triggers for seeking medical advice for both symptoms related to perceived seriousness and persistence of the symptom. Comparison with data from an earlier comparative study [30]

suggest that no significant change had occurred in either the rate of medical consultation or time taken to seek medical advice for rectal bleeding in the community.

Comparison with other studies

The higher reported rate of rectal bleeding experienced in the current study compared to previous studies is likely due to the older age demographic under investigation compared to previous studies. Study findings indicate that approximately one in five persons will experience at least one primary symptom episode without ever seeking medical advice. The direct comparison of the rate of non-consultation with a previous dataset in the current study and figures from other Australian community-based studies [29, 30] suggest little improvement in two decades. Data from the United States [4] and England [37] suggest similar rates of poor consultation. Respectively 18% of respondents experiencing rectal bleeding and 37% change in bowel habit for their first time in the previous five years delayed longer than one month before seeking medical advice. If the time elapsed to consult a doctor is averaged across both symptoms and extrapolated to the community setting, over one in four persons will delay greater than one month. Unfortunately, similar to the rate of medical consultation, the figures relating to timely access to medical advice for rectal bleeding in Australia has improved little if at all [29, 30, 37]. Studies outside of Australian communities are scant. A very small (n=30) study from England indicated a median delay of two months in seeking medical practitioner advice [3].

The current study, to our knowledge is the first to evaluate time taken to seek medical advice for change in bowel habit (constipation/ diarrhoea). Reason given for delay and not seeking medical advice following rectal bleeding episode appear to be

similar to the underestimation of symptom seriousness elucidated previously in the literature [3, 29-31]. In the current study, underestimation of symptom seriousness with a benign perception – “Thought it was haemorrhoids/ Piles” was often cited. The decision to consult was due to a perception of the symptom’s serious nature. For change in bowel habit, the reason for delay/ failure to seek medical advice for a large proportion was consistent with a tendency to underestimate the serious nature of the symptom. For a significant proportion of respondents the decision to consult was due to the persistence of the symptom.

Limitations and strengths of study

The present study is the first to assess both the reason for delay and triggers for seeking medical advice for primary symptoms of CRC in an at-risk community sample (56-88 years of age). This study importantly provides an across-time comparison of medical advice seeking behaviour for rectal bleeding. A large sample size was obtained with a response rate (70%) comparable to previous community-based studies [4, 29, 30]. It should be acknowledged that sample representativeness and methodological differences between the present and comparative study place some limitations on the interpretation of findings. While the delay data suggests a trend towards no change or negligible improvement in prompt reporting of rectal bleeding, two truly representative samples and identical methodology may have provided a more accurate depiction. It must be noted that the method of investigation of non-consultation differed slightly across the current and comparative study [30] for rectal bleeding. Non-consultation was only assessed in those experiencing their first symptom episode in the previous five years in the comparative study compared to assessment of all respondents that had ever experienced rectal bleeding

(irrespective of symptom onset) in the current study. Further, data obtained was self-reported and may be subject to recall error. This limitation however is inherent to studies throughout the wider literature that have assessed retrospective recall of symptoms. In the interpretation of study findings it is important to consider whether persons in the current study who may have had only one symptom would behave in a similar way to symptomatic CRC patients, who sometimes present with symptom complexes [38]. Given the importance of symptom persistence and severity as triggers for action, the experience of a symptom complex may reduce rates of delay or rates of non-consultation. The influence of symptom complexes on patient delay in both groups requires future consideration.

Conclusions and implications

While the likely impact of specific delay times on disease outcomes cannot be estimated, the data suggest that a sizeable proportion of those at-risk (55 years +) do not promptly seek medical advice for CRC symptoms. Currently a general lack of awareness of CRC symptoms and understanding of the importance of CRCs early detection is present in communities [30, 39, 40]. One of the challenges for those charged with public education surrounding cancer is the need to provide consistent and concrete recommendations regarding what may constitute 'prompt' advice seeking [41]. It is also crucial that future public education messages highlight the potential seriousness of CRC symptoms and the need for prompt medical consultation

among the at-risk population. An additional approach to encourage earlier detection of symptoms is intervention within the primary care setting, given that 88% of persons present to a GP annually [42]. Currently the acceptability and feasibility of systematic assessment of ovarian symptoms during GP practice visits is being

assessed in the general practice setting [43]. A similar approach for CRC symptoms might improve symptom reporting and may be cost-effective if an efficient mechanism is used. Systematic use of Computer Risk Assessment Tools (CRATs) that screen for symptomatic patients and provide real-time feedback to GPs is one such mechanism.

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