Modes of presentation and pathways to diagnosis of colorectal cancer in Queensland

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ABSTRACT

Objective: To describe the process of colorectal cancer diagnosis in Queensland, and to determine factors associated with time to diagnosis.

Design, setting and participants: Cross-sectional study of 1996 patients with colorectal cancer recruited through the Queensland Cancer Registry. Data were collected by computer-assisted telephone interview between May 2003 and August 2005.

Main outcome measures: Time to diagnosis: pre-presentation time (time from first noticing a symptom to first presenting to a doctor); and post-presentation time (time between the first presentation and diagnosis).

Results: Most patients (90%) had experienced symptoms before being diagnosed with colorectal cancer; only 2% of patients were diagnosed by faecal occult blood testing. Older participants and those who experienced abdominal pain had the shortest time from symptom onset to their first doctor consultation, while participants with a change in bowel habit, or rectal bleeding, and those without private health insurance tended to wait longer to see a doctor. Participants who experienced abdominal pain were diagnosed more quickly, whereas those who experienced a change in bowel habit, women, and those without private health insurance experienced a longer time to diagnosis.

Conclusions: The strong association between not having health insurance and longer post-presentation times is concerning. The other hypothesised predictors of time to diagnosis were not as strongly associated as we anticipated.

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Colorectal cancer is the most commonly reported cancer in Australia; in 2001, there were 12 619 new cases and 4686 deaths.[1] A diagnosis of colorectal cancer may be associated with considerable physical and psychological morbidity,[2-4] and the disease imposes a significant economic burden.[5] As the Australian population ages, the incidence of colorectal cancer is expected to increase accordingly.[1]

The prognosis for patients diagnosed with a localised tumour is good, with 5-year survival achieved by about 90%; however, only about 7% of patients with metastatic colorectal cancer achieve this goal.[6] For symptomatic patients, delay in diagnosis does not appear to be associated with more advanced disease.[7-10] Diagnosis of colorectal cancer in asymptomatic patients by faecal occult blood testing (FOBT) and flexible sigmoidoscopy has been shown to improve survival.[11-13]

In 1997, the Australian Health Technology Advisory Committee produced a report that called for an Australian trial of colorectal cancer screening by FOBT for individuals from the age of 50.[14] Subsequently, the Australian Government established the Bowel Cancer Screening Pilot Program in Mackay (Queensland), Melbourne and Adelaide, which found that screening for colorectal cancer using FOBT was feasible, acceptable and cost-effective.[15] The government has now introduced a national screening program, initially for those turning 55 or 65 years of age between May 2006 and June 2008, which will be evaluated in 2008.[15]

The aim of our study was to systematically describe the process of colorectal cancer diagnosis in Queensland before the introduction of a population screening program, and to establish if and how diagnosis could be improved. Specifically, we wished to determine the factors associated with time to diagnosis, focusing on patients' age, category of social advantage or disadvantage, and health insurance status.

METHODS

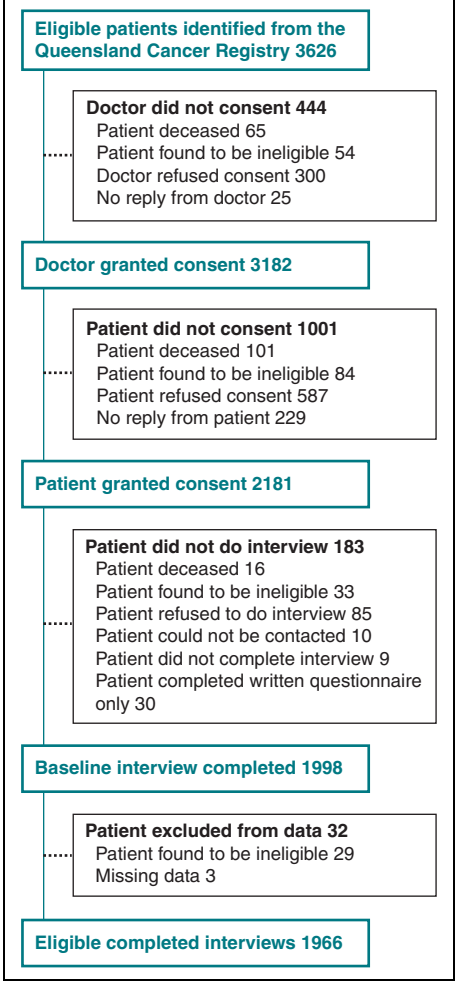
Study population

All residents of Queensland with a histologically confirmed diagnosis of a first, primary colorectal cancer, notified to the Queensland Cancer Registry between 1 January 2003 and 31 December 2004, were eligible for the study. Eligibility criteria also included speaking English (costs precluded hiring translators); having adequate hearing, speech and cognitive functions for a telephone interview; and being aged between 20 and 80 years. The University of Queensland's Behavioural and Social Sciences Ethical Review Committee approved the study procedures.

A flow diagram describing recruitment to, and participation in, the study is presented in Box 1. The treating doctors of 3626 eligible patients were approached in writing for permission to contact their patients regarding the study. Letters were re-sent to non-responding doctors 2 weeks after the initial mailing, and doctors were then telephoned weekly until an answer was received.

The 3182 patients for whom consent from the doctor was obtained were mailed a letter

1 Flow diagram of study recruitment and participation



signed by their treating doctor, explaining the study; a study information sheet; and a consent form. Those who did not respond were sent a second letter 2 weeks later, and non-responders received two follow-up telephone calls.

Data collection

All those who agreed to take part in the study were telephoned soon after their written consent was received. Eighty per cent of participants were interviewed within 6 months of their diagnosis (mean, 4.5 months; SD, 1.5 months). Data were collected by trained interviewers using a computer-assisted telephone interviewing system between May 2003 and August 2005. Information on the process of diagnosis (symptoms, date of first recognition of an abnormality, date of first appointment with a doctor, outcome of that appointment, tests administered, and so on, up to the point of diagnosis) was collected, along with demographic information, and the patient's address to determine the Socio-Economic Indexes for Areas (SEIFA) category (the Australian Bureau of Statistics' method of determining average level of social and economic wellbeing). We also collected clinical and demographic information from the Queensland Cancer Registry, specifically sex, date of birth, date of diagnosis, tumour site, and approximate stage of the cancer.

Statistical analysis

We calculated two measures of time to diagnosis:[16] *pre-presentation time* — the time from first noticing a symptom or thinking something was wrong to first presenting to a doctor; and *post-presentation time* — the time between first presenting to a doctor and a diagnosis being made.

Some participants were unable to nominate exact dates, and instead provided dates to the nearest week or month. As some of the estimates were based on days, some on weeks and others on months, we categorised each measure of time into four categories: less than 1 week; between 1 week and 1 month; between 1 and 2 months; and more than 2 months.

As we needed to collapse the time variables into categories, we used multinomial logistic regression models to determine which medical and sociodemographic factors were associated with pre- and post-presentation times. Separate models were used for each of the two categorical (four level) outcome variables. Factors included in each multivariate model were those that had significant ($P<0.20$) bivariate associations with the respective time-to-diagnosis measures, and those specified by our a priori hypotheses (age, SEIFA category, health insurance status).

We excluded participants from these measures of time to diagnosis if they reported a duration of more than 12 months for either time period. Forty-seven participants (2%) were excluded from the pre-presentation time phase for this reason, and 44 (2%) from the post-presentation time phase. We also excluded an additional 20 participants (1%) from the post-presentation time phase, as their diagnosis date preceded the date of their first doctor's appointment.

2 Comparison of demographic and medical characteristics of study participants and non-participants

	No. (%) participants ($n=1966$)*	No. (%) non-participants ($n=1456$)†
Sex		
Male	1176 (59.8%)	840 (57.7%)
Age group (years)		
20–49	167 (8.5%)	111 (7.6%)
50–59	382 (19.4%)	239 (16.4%)
60–69	665 (33.8%)	407 (28.0%)
70–80	752 (38.3%)	699 (48.0%)
Site of colorectal cancer		
Colon	1203 (69.9%)	965 (66.5%)
Rectum	519 (30.1%)	486 (33.5%)
Stage of colorectal cancer		
Dukes A	437 (29.4%)	244 (22.9%)
Dukes B	521 (35.1%)	365 (34.3%)
Dukes C	487 (32.8%)	403 (37.9%)
Dukes D	40 (2.7%)	52 (4.9%)

* Missing data within some categories: site (244); stage (481).
† Missing data within some categories: site (5); stage (392).◆

3 Bowel symptoms or reasons for first presentation to a doctor ($n=1966$)*

Spontaneously reported symptoms	No. (%)
Rectal bleeding	653 (33.2%)
Change in bowel habit	501 (25.5%)
Pain in lower abdomen	393 (20.0%)
Lack of energy/tiredness	164 (8.3%)
Nausea/vomiting	110 (5.6%)
Pain elsewhere	55 (2.8%)
Unexplained weight loss	39 (2.0%)
Increased flatulence	25 (1.3%)
Loss of appetite	26 (1.3%)
Other symptoms	
Bloating	45 (2.3%)
Dizziness	24 (1.2%)
Shortness of breath	22 (1.1%)
Symptoms not thought to be related to cancer	328 (16.7%)
Asymptomatic presentation	**No. (%)**
Faecal occult blood test results	37 (1.9%)
Routine bowel follow-up (eg, for polyps)	72 (3.7%)
Bowel cancer screening examination	80 (4.1%)

* Multiple responses were allowed. ◆

RESULTS

A total of 1966 of the 3426 eligible participants (57.4% overall response rate) completed the interview. To examine the representativeness of our sample, we compared participants with those who were eligible but not recruited to the study, across the demographic and disease-specific variables available to us. Non-participants comprised those whose doctors did not grant consent for them to be contacted about the study and those who declined to participate (Box 2). There was no difference in sex distribution between participants and non-participants. However, our sample under-represents older (70–80 years) colorectal cancer survivors, those with rectal cancer, and those with more advanced disease (χ^2 test, $P<0.05$ for each).

Study participants were asked to describe the symptoms that made them think something was wrong, or the other reasons that prompted them to see a doctor. These data are presented in Box 3 (multiple responses were allowed). Of the 1467 participants who reported experiencing colorectal cancer symptoms, 927 (63%) reported one symptom, 425 (29%) reported two, 96 (7%) reported three, 12 (1%) said they had four symptoms, and seven reported five or more symptoms thought to be related to colorectal cancer. Only 37 participants (2%) reported that they had first seen a doctor in order to collect FOBT results. Of these, 15 were from the Mackay region, where the Australian Government's Bowel Cancer Screening Pilot Program was conducted during much of our study recruitment phase.

General practitioners were the first doctors to be seen in the process of diagnosis

4 Adjusted odds ratios* of predictors of pre-presentation time: results of multinomial logistic regression model

Covariate	Pre-presentation time (reference, > 2 months)			Overall effect†
	< 1 week	1 week – 1 month	1–2 months	
Rectal bleeding				$\chi^2 = 6.44$; $P = 0.092$
Yes	1.44 (0.97–2.13)	1.05 (0.73–1.49)	0.81 (0.52–1.27)	
Abdominal pain				$\chi^2 = 7.89$; $P = 0.048$
Yes	1.70 (1.12–2.57)	1.10 (0.74–1.64)	1.16 (0.71–1.89)	
Change in bowel habit				$\chi^2 = 30.37$; $P < 0.001$
Yes	0.35 (0.24–0.52)	0.74 (0.53–1.03)	0.79 (0.53–1.20)	
Site				$\chi^2 = 26.14$; $P < 0.001$
Colon	1.00	1.00	1.00	
Rectum	0.43 (0.29–0.64)	0.76 (0.54–1.07)	1.16 (0.76–1.77)	
Age group				$\chi^2 = 14.82$; $P = 0.002$
20–49	1.00	1.00	1.00	
50–59	0.96 (0.53–1.76)	1.77 (1.00–3.13)	1.95 (0.97–3.94)	
60–69	1.40 (0.80–2.43)	2.00 (1.17–3.42)	1.67 (0.84–3.29)	
70–80	1.98 (1.14–3.45)	2.61 (1.52–4.47)	1.92 (0.97–3.80)	
SEIFA groups				$\chi^2 = 2.57$; $P = 0.462$
Decile 1 (disadvantaged)	1.00	1.00	1.00	
Deciles 2–9	0.75 (0.34–1.63)	0.94 (0.45–1.95)	1.13 (0.45–2.84)	
Decile 10 (advantaged)	0.62 (0.23–1.68)	0.71 (0.28–1.81)	0.34 (0.08–1.37)	
Health insurance				$\chi^2 = 6.48$; $P = 0.090$
No	0.64 (0.45–0.90)	0.75 (0.55–1.02)	0.80 (0.54–1.18)	

* Values represent odds ratios (adjusted for the other variables in the table) of having a specific pre-presentation time compared with a time of > 2 months. † Overall association of the covariate on the pre-presentation time. SEIFA = Socio-Economic Indexes for Areas. ◆

by 93% of respondents. During the first consultation, 50% of participants reported their doctor performed a test; 39% were given a referral to see a specialist; 7% were given something to treat their symptoms; 2% were told that their symptoms would be monitored; and 2% were told there was nothing wrong. Half of the study participants had two consultations before being diagnosed with colorectal cancer; 29% had three; 13% had four; 7% had five; and six participants (0.5%) saw a doctor six or more times before their cancer was diagnosed. Colonoscopy was the most frequent mode of diagnosis; 88% of participants reported that this test detected their cancer. The other tests nominated as the mode of diagnosis included: computed tomography scan (4% of participants), flexible sigmoidoscopy (2%), and barium enema x-ray (2%).

The distribution of patients in the pre-presentation time categories was: 25% of participants saw their doctor less than 1 week from the onset of symptom(s); 35% between 1 week and 1 month; 15% between 1 and 2 months; and 25% more than 2 months after onset. The distribution of patients in the post-presentation time categories was: 12% less than 1 week; 42% between 1 week and 1 month; 18% between 1 and 2 months; and 28% more than 2 months.

The following factors were entered into the multinomial logistic regression model for pre-presentation time: rectal bleeding, abdominal pain, change in bowel habit, site of colorectal cancer, age group, SEIFA category, and health insurance status (Box 4). Abdominal pain, change in bowel habit, site, and age group were significantly associated with the time between first noticing a symptom and seeing a doctor. Patients with abdominal pain, and those who were older, tended to have shorter pre-presentation times. For example, people who presented to a doctor within 1 week were 1.7 times more likely to experience abdominal pain than those who waited for 2 months or more. The odds of having longer pre-presentation times were greater among patients with a change in bowel habit, and those with rectal cancer. People without health insurance were more likely to have longer pre-presentation times, but this difference was not statistically significant.

For the post-presentation time model, similar variables (sex instead of site) were included (Box 5). Abdominal pain, change in bowel habit, sex, and health insurance status were significantly associated with the time between seeing a doctor and a diagnosis of colorectal cancer being made. Patients with abdominal pain were significantly more likely to have shorter post-presentation times, while women, as well as patients who experienced a change in bowel habit, were significantly more likely to have longer post-presentation times. Patients without private health insurance were significantly more likely to have a longer time to diagnosis than those who were insured.

DISCUSSION

The results of our study suggest that the majority of people diagnosed with colorectal cancer in Queensland in 2003 and 2004 were symptomatic. Fewer than 10% of the sample were diagnosed through screening or routine surveillance; only 2% of patients with colorectal cancer in Queensland were reportedly diagnosed by FOBT screening. Given this low starting level, we expect to see a large increase in colorectal cancer diagnoses as population screening is introduced.

It is concerning that not having private health insurance was strongly associated with a longer post-presentation time. There was also an overall trend towards longer pre-presentation times for those without insurance, with a significant difference between the shortest and the longest time categories. Our other hypothesised predictors of time to diagnosis were not as strong as we anticipated. Older age was associated with shorter pre-presentation time, but not post-presentation time.

Other characteristics were also identified as being associated with time to diagnosis: abdominal pain was associated with a shorter time to diagnosis, perhaps because pain is often a distressing symptom that is not easily ignored. Change in bowel habit, however, may easily be attributed to other causes, perhaps explaining its association with a longer time to diagnosis. Participants diagnosed with a rectal tumour did not wait as long to consult a doctor as participants with colon cancer.

It is not clear why there was a longer post-presentation time for women, and, if this difference is real, it is a concern that the

5 Adjusted odds ratios* of predictors of post-presentation time: results of multinomial logistic regression model

Covariate	Post-presentation time (reference, > 2 months)			Overall effect†
	< 1 week	1 week – 1 month	1–2 months	
Rectal bleeding				$\chi^2 = 2.25$; $P = 0.523$
Yes	0.80 (0.57–1.14)	1.04 (0.81–1.33)	0.95 (0.71–1.28)	
Abdominal pain				$\chi^2 = 8.49$; $P = 0.037$
Yes	1.44 (0.99–2.08)	0.86 (0.65–1.15)	0.90 (0.63–1.27)	
Change in bowel habit				$\chi^2 = 14.60$; $P = 0.002$
Yes	0.68 (0.47–0.97)	0.62 (0.48–0.80)	0.76 (0.56–1.03)	
Sex				$\chi^2 = 17.78$; $P < 0.001$
Female	0.72 (0.52–0.99)	0.63 (0.50–0.79)	0.88 (0.66–1.15)	
Age group				$\chi^2 = 1.10$; $P = 0.778$
20–49	1.00	1.00	1.00	
50–59	0.60 (0.32–1.10)	1.32 (0.83–2.11)	1.05 (0.60–1.83)	
60–69	1.07 (0.61–1.85)	1.72 (1.10–2.68)	1.46 (0.86–2.48)	
70–80	0.73 (0.42–1.25)	1.31 (0.84–2.03)	1.11 (0.66–1.86)	
SEIFA groups				$\chi^2 = 4.71$; $P = 0.194$
Decile 1 (disadvantaged)	1.00	1.00	1.00	
Deciles 2–9	1.21 (0.57–2.60)	0.99 (0.59–1.66)	1.00 (0.53–1.88)	
Decile 10 (advantaged)	1.16 (0.45–2.97)	0.69 (0.35–1.36)	0.48 (0.20–1.14)	
Health insurance				$\chi^2 = 38.15$; $P < 0.001$
No	0.55 (0.40–0.76)	0.50 (0.39–0.63)	0.69 (0.53–0.92)	

* Values represent odds ratios (adjusted for the other variables in the table) of having a specific post-presentation time compared with a time of > 2 months. † Overall association of the covariate on the post-presentation time. SEIFA = Socio-Economic Indexes for Areas. ◆

diagnostic process appears to favour one sex over the other. It may be that women are also investigated for gynaecological disorders when they present to their doctor with symptoms, thus slowing the process of diagnosis.

The data we have presented come from a large, population-based cohort of colorectal cancer patients in Queensland. The overall response rate of 57.4% may limit the generalisations we can make from our findings, in terms of under-representing those with more advanced cancers, those aged over 70 years, and those diagnosed with rectal cancer. There are also the limitations of self-reported data that are inherent in this type of study. Nevertheless, we have presented a comprehensive picture of the process of diagnosis of colorectal cancer in Queensland, before the introduction of FOBT screening. Our results provide a benchmark against which to evaluate the impact of the National Bowel Cancer Screening Program.

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COMPETING INTERESTS

None identified.

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