

## RESEARCH ARTICLE

# Sociodemographic Predictors of Recall and Recognition of Colorectal Cancer Symptoms and Anticipated Delay in Help-Seeking in a Multiethnic Asian Population

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### Abstract

**Background:** Colorectal cancer is the second most common cancer in Malaysia. The prognosis of the disease is excellent if detected at an early stage, but the majority of Malaysian patients present at late stages. We aimed to assess the awareness of cancer warning signs and anticipated delay in help-seeking as possible contributors to this phenomenon. **Materials and Methods:** A population-based cross-sectional survey using the Colorectal Cancer Awareness Measure was initiated in Perak, Malaysia. A total of 2,379 respondents aged 18 years and above were recruited using a multi-stage sampling in five locations. Analysis of covariance was used to examine independent sociodemographic predictors of scores for symptom awareness. **Results:** Younger age, being female, a higher education, and higher income were significantly associated with better scores for both recall and recognition of warning symptoms. Among the ethnic groups, Malays had better recognition of symptoms whereas Chinese recalled the most symptoms. Passing bloody stool was associated with the least anticipated delay and unexplained anal pain had the highest anticipated delay. **Conclusions:** The level of awareness across all ethnicities in Malaysia is generally low, especially among minorities. Targeted public education, which is culturally and linguistically appropriate, should be developed to encourage early help-seeking and improve clinical outcomes.

**Keywords:** Asia - colorectal cancer - awareness measure - ethnicity - rural population - Malaysia

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### Introduction

Colorectal cancer (CRC) is one of the most common cancers in the world. However, in contrast to the West, the incidence of CRC in Asian populations has been increasing rapidly (Ng et al., 2013). This trend is also seen in Malaysia, where it is the second most common cancer in both males and females (Ministry of Health Malaysia, 2007), with an age-specific incidence of 10.2 per 100,000 population. Among the three major ethnic groups, the incidence was found to be highest among the Chinese (Lim et al., 2008).

In developed Asian countries, national CRC screening programmes have been initiated (Hyodo et al., 2010) as they have been shown to reduce mortality (Heresbach et al., 2006; Kerr et al., 2007; Steele et al., 2009). Such a programme does not exist in Malaysia. Hence, delayed diagnosis continues to be a major setback to favourable outcome, since stage of tumour at time of presentation is the key prognostic factor for survival (Roncoroni et al., 1999). Currently, cancers are only localized in less than 40% of cases at the time of diagnosis (Greenlee et al., 2001; Ministry of Health Malaysia, 2007).

Although there have been major advancements in the management of CRC, delays in diagnosis and treatment are still common (Langenbach et al., 2003). Poor awareness of CRC is still evident in many population studies globally (Gimeno-Garcia et al., 2011; Hashim et al., 2011). Lack of awareness of symptoms and late presentation to medical practitioners result in the longest delays (Langenbach et al., 2003). The main factor influencing delay is the patient's knowledge, which is a pre-requisite for interpreting symptoms correctly (Mor et al., 1990). Hence, this study aimed to assess the ethnic differences in the knowledge of CRC warning signs among rural Malaysians and examine for independent sociodemographic predictors of scores for symptom awareness and anticipated delay in seeking medical advice.

### Materials and Methods

#### *Participants and methods*

A population-based cross-sectional household survey was initiated in Perak, Malaysia. This was a pilot study conducted at five locations (Gerik, Kampar, Kuala Kangsar, Parit Buntar and Taiping). Each sampling

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location comprised four villages and each village a number of households proportionate to their respective sizes by random sampling. For each household, the interviewer determines the household composition and identifies all adults aged 18 years and above. The eligible individuals were invited to participate in face-to-face interviews using pre-tested questionnaire administered by trained interviewers after written consent was obtained. The study protocol was approved by the Ethics Committee, University of Malaya Medical Centre (Reference Number: 890.6).

A range of socio-demographic characteristics were obtained from the respondents. Socio-economic status (SES) was defined according to the Malaysia Standard Classification of Occupations (MASCO, 2008; Ministry of Human Resources, 2010). Occupational class is traditionally considered one of the most important indicators to characterize SES. SES was classified as high (includes managers; professionals; technicians and associate professionals), medium (clerical support workers; service and sales workers; skilled agricultural, forestry and fishery workers; craft and related trade workers) and low (plant and machine-operators and assemblers; elementary occupations).

#### Cancer awareness measure

The Bowel/Colorectal Cancer Awareness Measure (Bowel/Colorectal CAM) questionnaire was used to assess the level of colorectal cancer awareness, and the duration of which the respondents would contact their doctor to discuss each of the nine cancer symptoms listed in the questionnaire. The validated survey instrument (Stubbings et al., 2009; Power et al., 2011) in English was also translated to Malay, our national language and Chinese. Forward and backward translation was performed by independent individuals. Face validity was done before conducting survey. Interviewers were trained on how to use the questionnaire prior to conducting the study.

Knowledge of cancer warning signs was assessed using open-ended questions by asking respondents to recall as many symptoms as possible and closed-ended questions by asking respondents on their ability to recognise the nine symptoms. The nine signs listed in the C-CAM were lump in abdomen, abdominal pain, bleeding from back passage, change in bowel habit, inability to completely empty bowel, blood in stools, pain in back passage, tiredness or anaemia and unexplained weight loss.

The open-ended question was asked before the closed questions to explore the ability to recall colorectal cancer symptoms. For both types of question, the number of warning signs endorsed was summed to produce total scores. Respondents were also asked the duration it takes to consult a doctor if they experienced any of the symptoms. The answers for this section were dichotomised to less than 2 weeks or 2 weeks or longer. The later was considered as anticipated delay in help seeking (Waller et al., 2009).

#### Statistical analyses

All data were stored, structured and analyzed by using the SPSS-system for Windows, SPSS Inc., Chicago (SPSS

v20). Descriptive statistics were computed for all socio-demographic variables and items from the C-CAM. The chi-square tests and analysis of variance (ANOVA) were used to examine relationships between ethnicity with C-CAM items and anticipated delay in help seeking. All reported P-values were two-tailed and the cut-off point of statistical significance was 0.05. Analyses of covariance (ANCOVA) were used to examine for independent sociodemographic predictors of recall and recognition of cancer symptoms. A Spearman's Rank Order correlation was run to determine the correlation of scores on the recognition and recall measures.

## Results

### Demographic characteristics

A total of 2379 respondents aged 18 years and above was recruited in the study. The sociodemographic profile of respondents is shown in Table 1. The majority of our respondents were aged 45 years and above (65.3%), females (56.7%), married (76.5%), Malay ethnicity (78.3%), completed up to secondary school education (80%), of medium SES (60.9%) and income less than RM1000 (67.4%).

### Awareness of warning signs

Responses to the open and closed questions about warning signs are shown separately for each ethnic group in Table 2. In the recall format, abdominal pain was the most commonly cited symptom, mentioned by 10.9 to

**Table 1. Sociodemographic Profile of Respondents using the Bowel/Colorectal CAM (n=2379)**

Sociodemography		N	(%)
Age group (n=2377)	18-24	218	9.2
	25-34	248	10.4
	35-44	360	15.1
	45-54	499	21
	55-64	525	22.1
	≥65	527	22.2
Sex (n=2379)	Male	1030	43.3
	Female	1349	56.7
Ethnicity (n=2379)	Malay	1863	78.3
	Chinese	332	14
	Others	184	7.7
Highest qualification obtained (n=2411)	None	326	13.5
	Primary	1024	42.5
	Secondary	904	37.5
	Certificate/Skill	87	3.6
	College/University	70	2.9
	Socioeconomic Status (SES) (n=1129)	High	126
Medium		688	60.9
Low		315	27.9
Marital status (n=2370)	Single	330	13.9
	Married	1815	76.5
	Divorced	21	0.9
	Widowed	204	8.6
Income (n=1077)	<RM500	371	34.4
	RM500-RM1000	355	33
	RM1000-RM2000	228	21.2
	>RM2000	123	11.4

15.4% of respondents across the groups. All the other eight symptoms were mentioned in less than 10% in any group. The chi-squared tests were only used to examine differences between groups for three symptoms, namely abdominal pain, tiredness or anaemia and blood in stools because all other cells had expected count of less than five. There were no significant differences in recall of

abdominal pain and tiredness or anaemia, but passage of bloody stools differed significantly between groups (p value <0.05). The mean number of symptoms cited in this format was 0.5 (95%CI: 0.4, 0.5). The Chinese named most (0.5; 95%CI: 0.4, 0.6) and the ethnic minorities (including Indians) named fewest (0.2; 95%CI: 0.1, 0.3), with significant between-group differences (F(2,

**Table 2. Awareness of Cancer Warning Signs by Ethnic Group**

		All groups (n=2379)	Malay (n=1863)	Chinese (n=332)	Others (n=184)	Between group difference (p)
Recall of warning signs, n(%)	Lump or swelling in abdomen	48 (2.0)	37 (2.0)	10 (3.0)	1 (0.5)	a
	Abdominal pain	346 (14.5)	286 (15.4)	40 (12.1)	20 (10.9)	0.075
	Unexplained weight loss	55 (2.3)	34 (1.8)	17 (5.1)	4 (2.2)	a
	Bleeding from back passage	158 (6.6)	126 (6.8)	29 (8.7)	3 (1.6)	a
	Back passage pain	33 (1.3)	31 (1.7)	2 (0.6)	0 (0)	a
	Incomplete bowel emptying	97 (4.0)	85 (4.6)	11 (3.3)	1 (0.5)	a
	Change in bowel habit	93 (3.9)	77 (4.1)	14 (4.2)	2 (1.1)	a
	Tiredness/anaemia	94 (3.9)	76 (4.1)	11 (3.3)	7 (3.8)	0.754
	Blood in stools	142 (5.9)	106 (5.7)	30 (9.0)	6 (3.2)	<0.05
	Total (mean number recalled)	0.53	0.54	0.58	0.38	<0.05
Recognition of warning signs, n (%)	Lump or swelling in abdomen	845 (35.5)	691 (37.1)	115 (34.6)	39 (21.2)	0.112
	Abdominal pain	858 (36.1)	721 (38.7)	87 (26.2)	50 (27.2)	<0.05
	Unexplained weight loss	787 (33.1)	632 (33.9)	108 (32.5)	47 (25.5)	0.189
	Bleeding from back passage	879 (37.0)	741 (39.8)	100 (30.1)	38(20.7)	0.337
	Back passage pain	585 (24.6)	511 (27.4)	40 (12.1)	34 (18.5)	<0.001
	Incomplete bowel emptying	636 (26.7)	563 (30.2)	52 (15.7)	21 (11.4)	<0.001
	Change in bowel habit	675 (28.4)	578 (31.0)	73 (22.0)	24 (13.0)	<0.05
	Tiredness/anaemia	658 (27.7)	540 (29.0)	77 (23.2)	41 (22.3)	0.109
	Bloody stool	965 (40.6)	794 (42.6)	120 (36.1)	51 (27.7)	0.845
	Total (mean number recalled)	3.41	3.66	2.77	2.01	<0.001

\*a: Some cells had an expected count of less than 5, so chi-square tests could not be performed

**Table 3. Analysis of Covariance Showing Demographic Predictors of Recall and Recognition of Nine Warning Signs of Cancer**

		Number of warning signs recalled		Number of warning signs recognised	
		Estimated marginal mean (95% confidence interval)	Significance	Estimated marginal mean (95% confidence interval)	Significance
Age	18-24	0.47 (0.22-0.72)	F(5,893)=2.530 P<0.05	3.99 (3.30-4.67)	F (5,905)=4.857 P<0.001
	25-34	0.71 (0.51-0.91)		3.96 (3.41-4.51)	
	35-44	0.65 (0.50-0.80)		3.52 (3.10-3.93)	
	45-54	0.45 (0.33-0.58)		3.16 (2.81-3.51)	
	55-64	0.56 (0.41-0.70)		3.50 (3.09-3.91)	
	>65	0.30 (0.10-0.50)		2.23 (1.67-2.79)	
Sex	Male	0.44 (0.35-0.53)	F(1,897)=10.240 p=0.001	3.12 (2.88-3.35)	F(1,909)=10.455 P=0.001
	Female	0.67 (0.56-0.78)		3.77 (3.46-4.07)	
Ethnic group	Malay	0.54 (0.46-0.62)	F(2,896)=1.781 P=0.169 (NS)	3.66 (3.45-3.86)	F (2,908)=17.030 P<0.001
	Chinese	0.58 (0.41-0.75)		2.77 (2.29-3.25)	
	Others	0.38 (0.13-0.55)		2.01 (1.42-2.60)	
Marital status	Single	0.52 (0.33-0.72)	F(3,895)=0.065 p=0.978 (NS)	3.28 (2.73-3.83)	F(3,907)=0.972 P=0.405 (NS)
	Married	0.52 (0.45-0.60)		3.37 (3.16-3.59)	
	Divorce	0.60 (0.04-1.23)		2.07 (0.30-3.84)	
	Widowed	0.59 (0.25-0.94)		3.80 (2.83-4.77)	
Education	Primary	0.38 (0.26-0.49)	F(3,894)=5.665 p<0.001	3.06 (2.75-3.38)	F(4,906)=3.925 P<0.05
	Secondary	0.69 (0.58-0.79)		3.75 (3.50-4.05)	
	Certificate/Skill	0.36 (0.03-0.70)		3.35 (2.42-4.29)	
	College/University	0.97 (0.62-1.32)		4.03 (3.06-5.00)	
SES	None	0.29 (0.07-0.51)	F(2,896)=0.118 p=0.889 (NS)	2.49 (1.87-3.11)	F(2,908)=2.293 P=0.102 (NS)
	High	0.56 (0.35-0.77)		3.94 (3.37-4.52)	
	Medium	0.53 (0.45-0.62)		3.32 (3.08-3.56)	
Income	Low	0.50 (0.38-0.63)	F(3,895)=6.05 p<0.001	3.22 (2.87-3.57)	F(3,907)=9.232 P<0.001
	<RM500	0.33 (0.19-0.46)		2.68 (2.31-3.04)	
	RM500-RM1000	0.51 (0.40-0.62)		3.37 (3.06-3.68)	
	RM1000-RM2000	0.66 (0.52-0.80)		3.62 (3.23-4.00)	
	>RM2000	0.76 (0.57-0.95)		4.31 (3.80-4.83)	

**Table 4. Ethnic Differences in Percentage of People Reporting They Would Contact a Doctor in <2 Weeks for Each Warning Sign**

Warning signs	All groups (n=2131)	Malay (n=1677)	Chinese (n=308)	Others (n=146)	Significance (p)
Lump or swelling in abdomen	818 (38.4)	665 (39.7)	115 (37.3)	38 (26.0)	<0.05
Abdominal pain	847 (39.7)	700 (41.7)	96 (31.2)	51 (34.9)	<0.001
Unexplained weight loss	752 (35.3)	600 (35.8)	108 (35.1)	44 (30.1)	0.391
Bleeding from back passage	846 (39.7)	706 (42.1)	103 (33.4)	37 (25.3)	<0.001
Back passage pain	553 (26.0)	480 (28.6)	40 (13.0)	33 (22.6)	<0.001
Incomplete bowel emptying	619 (29.0)	541 (32.3)	58 (18.8)	20 (13.7)	<0.001
Change in bowel habit	651 (30.5)	548 (32.7)	78 (25.3)	25 (17.1)	<0.001
Tiredness/anemia	636 (29.8)	519 (30.9)	78 (25.3)	39 (26.7)	0.097
Blood in stools	909 (42.7)	740 (44.1)	121 (39.3)	48 (32.9)	0.013

2324)=5.280,  $p<0.05$ ).

Responses to the close-ended questions about warning signs were better than recall. Passage of blood in stools was the most-recognised symptom, ranging from 27.7-42.6% recall across the groups. Ethnic differences were significant for four symptoms, i.e. abdominal pain, back passage pain, incomplete bowel emptying, and change in bowel habit ( $p$  value<0.05). The mean number of symptoms recognised was 2.9 (95%CI: 2.8,3.0). Analysis of variance showed a significant between-group differences ( $F(2, 2342)=22.833$ ,  $p<0.001$ ) in total recognition score. There was a strong, positive correlation between scores on the recall and recognition measures, which was statistically significant ( $r_s=0.488$ ,  $p<0.001$ ).

#### *Predictors of warning sign awareness*

Analysis of covariance was used to examine for independent sociodemographic predictors of the total number of warning signs recalled or recognised. For both recall and recognition, younger age, females, higher education, and higher income group were significantly associated with better warning symptom score (Table 3). Ethnicity was associated with recognition, but not recall. Marital status and higher SES were not significantly associated with increased awareness.

#### *Anticipated delay in help seeking*

For all ethnic groups, passage of blood in stools was associated with the least anticipated delay (32.9-44.1% said they would consult a doctor in less than 2 weeks) and back passage pain had the highest anticipated delay (71.4-87.0% said they would wait 2 weeks or more). The chi-square tests showed significant differences between ethnic groups for all symptoms except unexplained weight loss, blood in stools and tiredness or anaemia.

## **Discussion**

This is the first community-based study to explore ethnic differences in awareness of cancer warning signs, and anticipated delay in help seeking in a multi-ethnic rural population using the standardized Colorectal CAM as the mode of assessment. The results from this study confirmed poor knowledge of CRC among the respondents, irrespective of ethnic group. It is not surprising to note the poor knowledge of symptoms across the ethnic groups as Malaysia has yet to introduce a national awareness and screening programme. The vast discrepancy between

recall and recognition of symptoms can be attributed to the effect of priming in recognition which results in increased cognitive fluency and better scores (Alter et al., 2009).

Awareness of warning signs was very poor, especially in the open-ended (recall) format where abdominal pain was the only symptom that was mentioned, unprompted, by approximately 15% of respondents with the rest of symptoms recalled by less than 7% of respondents. In the recognition format, most respondents were only able to recognise two or three of the nine warning signs. The findings also correlate well with another opportunistic screening study in a tertiary care centre by Hilmi et al. (2010) who found that knowledge of CRC symptoms were poor, with over 42% of respondents unable to identify any of the symptoms of CRC. This is also in line with many other studies from more developed countries in Asia (Koo et al., 2012; Wong et al., 2013), in Europe (Keighley et al., 2004) and Australia (Christou et al., 2012).

Rectal bleeding is the most common and important symptom of CRC (Majumdar et al., 1999; Tan et al., 2002) with the highest positive predictive value for CRC than other symptoms (Ferraris et al., 2004). Hence, awareness on this symptom will be crucial to promote early identification of the disease. Although overall mean of recall or recognition for each symptom is generally low, our study noted rectal bleeding as the second most-cited and recognised symptom in all respondents. This may suggest that they were aware of the link between rectal bleeding and CRC.

Recall and recognition had similar correlates, both being higher in respondents who were younger, female, and in higher education or income categories. The greater awareness of CRC symptoms among women than men could be due to increased awareness about bowel habit fluctuation among women from their family roles as carers (Yardley et al., 2000). Women are also closely involved in the care of sick family members and hence, are able to obtain health care information when they accompany them to the doctor.

Although age showed significant associations with both recall and recognition of warning signs, the scores were inconsistent with increasing age. The oldest age group (65 years and over) had the lowest recall and recognition, which is alarming given that this group is at highest risk for CRC. Poorer recall memory after patient education among older patients has previously been documented (Jansen et al., 2008). This may reflect on age-related cognitive decline or greater lifetime experience of

possible cancer symptoms, which proved benign (Brown et al., 2003). A greater awareness in younger generation was not surprising as it has been highlighted in several other studies, although they were not related to cancer (Philipp et al., 1993; Majid et al., 2012).

Not surprisingly, respondents with higher education level were more aware of the symptoms. However, differences between ethnic groups were mostly significant and hence, highlight particular gaps in awareness. For instance, only 11.4% of other ethnicities recognised incomplete bowel emptying as a warning sign, whereas awareness was higher (30.2%) among the Malays. After adjustment was made for all significant predictors, the Chinese have poorer recognition of CRC symptoms compared to the Malays despite having the highest incidence of CRC among the three major ethnicities.

Although another study (Hilmi et al., 2010) has reported similar findings among the Chinese, this is nevertheless surprising as the incidence of CRC is highest among the Chinese (Ministry of Health Malaysia, 2007). However, the study cited was conducted in a largely urban setting as opposed to rural population in our study, with a lower percentage of Chinese when compared to our national demographics. This underscores the need for targeted education for the Chinese when colorectal screening is to be introduced to the general population.

In contrast, the Chinese are found to be better at recognising most symptoms when compared to the other ethnic minorities (excluding unexplained abdominal pain and unexplained anal pain). This may, in part, be explained by the cognitive models of cancer and the varying understanding of its symptoms between ethnic groups (Dein, 2004). Further exploratory studies are needed to understand the way in which cancer is conceptualised in different communities, specifically at Chinese cultural views (Hou, 2005).

Most respondents anticipated longer delay (>2 weeks) in help-seeking if they noticed a cancer warning sign. The study also indicated that variations in delay between ethnic groups can be explained by poor awareness of symptoms. For instance, the other ethnicities, which showed poorest recognition of symptoms, were most likely to delay in seeking help. People who identified more emotional or practical barriers to help-seeking were less likely to have seen a doctor for advice on a worrying symptom (Simon et al., 2010). Ignorance, embarrassment (Yardley et al., 2000) and fear of consultation (Smith et al., 2005) probably contribute to delay in seeking advice.

Local evidence indicated a high incidence of CRC above 40 years old (Rashid et al., 2009). Hence, our study effectively captured the high risk population, as the majority of respondents were aged 45 years and above (65.3%). Fortunately, there were few missing data on the CAM items, and therefore responses are representative of the survey population, but generalisation on all adults in Malaysia cannot be assumed because of the differences in ethnic breakdown between the study population and the actual demographics in Malaysia. This study also employs the use of a validated and reliable measure of cancer awareness (Stubbings et al., 2009; Power et al., 2011) which meets standard psychometric criteria, although

strictly there is no perfect measure and both the recall and recognition formats have limitations.

There are several other limitations to this study. Recognition scores tend to be higher than recall scores (Waller et al., 2004), but it is hard to determine which better predicts the concept of cancer awareness. Ajzen and Fishbein argued that the most accessible beliefs are those that can be readily brought to mind. Hence, this would suggest that symptoms that are recalled are more likely to lead to help seeking than those that are merely recognised (Ajzen et al., 2000). Both methods are not free from biases: recall is limited by memory and perseverance, and may underestimate awareness, while recognition encourages guessing and hence overestimates awareness.

Although this study did not assess the perceived barriers to help seeking, nevertheless the literature suggests that being worried about what the doctor might find (Robb et al., 2009), embarrassing screening procedures (Harvey et al., 2011), being busy and not bothered (Yusoff et al., 2012) are potential barriers to seeking early medical advice. The data on recall format is heavily skewed and marked by an abundance of zero values. The mean, as indicated, may not be the best descriptor of such skewed data. Therefore, it has to be interpreted with caution.

Targeted public education should be developed to increase awareness, encourage early help-seeking and improve clinical outcomes. Access to healthcare information should be improved and these programmes should be culturally and linguistically appropriate. Education about CRC should include targeting of higher-risk population groups in whom awareness is particularly lacking, such as middle-aged, lower income males and should emphasise discrimination about the significance of different bowel symptoms.

Health education directed towards increasing public awareness about CRC should emphasize that some common bowel symptoms are not typical of CRC and that combinations of symptoms, such as change in bowel habit with rectal bleeding are of particular importance. Further work should explore the reasons for patient delay in presenting with cancer symptoms and to determine the most useful measures for predicting early detection behaviours.

In conclusion, the level of awareness across all ethnicities in Malaysia is generally low, especially among ethnic minorities, and more prominently among the older age, males, lower education level and lower income group. There is a high level of anticipated delay in seeking medical attention for possible cancer symptoms. Targeted public education, which is culturally and linguistically appropriate, should be developed to increase awareness, encourage early help-seeking and improve clinical outcomes.

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