

Screening Intention and Practice among First-Degree Relatives of Colorectal Cancer Patients in Southern Israel

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Abstract

Background: First-degree relatives of colorectal cancer patients are the largest groups of individuals at increased risk for colorectal cancer.

Objective: To assess the knowledge, attitudes and behavior to disease prevention and colorectal cancer screening among first-degree relatives of colon cancer patients.

Methods: A descriptive, point-prevalence epidemiological study was conducted among 215 first-degree relatives of survivors of colorectal cancer in the southern (Negev) region of Israel. Variables included perceived health status, knowledge about cancer screening, compliance rates with colorectal cancer screening, and interest in participation in early detection programs in the future.

Results: The mean age of the respondents was 47.9±11.2 years, and 54% were males. Only 58 (27%) remembered having been encouraged to undergo an early detection test. In the previous year only 15% underwent fecal occult blood tests, while 9% had a barium enema and 14% an endoscopic examination of the colon by sigmoidoscopy or colonoscopy. A total of 49% of the asymptomatic respondents were unaware of recommendations for screening, and only 38.3% expressed any interest in participating in early detection programs in the future. Only 19% of respondents over the age of 50 and 8% of respondents over age 60 were interested in participating compared with 49% under the age of 50 ($P<0.0001$).

Conclusion: A minority of first-degree relatives of colorectal cancer patients reported having been counseled to undergo screening, although most had seen their family physician in the previous 3 years. Primary care physicians should be more active in informing at-risk patients and encouraging them to undergo periodic screening.

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prevalent types of malignant disease; more than 2,200 new cases of colorectal cancer are diagnosed annually and over 1,100 individuals die from it each year. Colorectal cancer is particularly suited for early detection since there is a pre-malignant lesion (polyp) that can be identified and excised with existing procedures [5]. Five-year survival rates are significantly higher in patients in whom the tumor is identified at any early stage. Modeling methods have shown colorectal cancer screening to be cost effective [6,7].

Governmental and public organizations have recommended screening of average-risk individuals above the age of 50 [8-11]. There is a consensus that all individuals at high risk for colorectal cancer should be encouraged to participate in an early detection program. The largest group of individuals at high risk comprises first-degree relatives of colorectal cancer patients [12-14].

Compliance rates with recommendations for colorectal cancer screening are critical factors in cost-effectiveness models [6]. However, compliance rates of first-degree relatives with screening recommendations are not high [15-20], and no good strategies to improve these rates have been formulated and tested.

The objective of the present study was to survey first-degree relatives of patients diagnosed with colorectal cancer in southern Israel between 1988 and 1993, and evaluate their knowledge, attitudes and behavior to disease prevention in general and to screening for colorectal cancer in particular. The study was conducted in 1996. The years 1988-93 were chosen in order to include survivors of recently diagnosed colorectal cancer who had already completed acute-phase therapy and initial surveillance.

Materials and Methods

The 1,000 bed Soroka Medical Center in Beer Sheva is the only hospital serving southern Israel whose population is approximately 500,000. A list of all patients diagnosed with colorectal cancer at the Soroka Medical Center between 1988 and 1993 was obtained from the Israel Ministry of Health Central Cancer Registry. Of approximately 800 listed patients we identified 250 patients alive and still residing in the Beer Sheva area. All eligible patients were included in the study and no exclusions were made on the basis of age

Colorectal cancer is a leading cause of death in Israel and the developed world [1-3]. It affects both sexes equally and increases with age, particularly above age 50 [4]. In Israel, breast cancer and colorectal cancer are the two most

or other demographic characteristics. The reason for this was twofold – to make the study as comprehensive and all inclusive as possible, and because the study concerned first-degree relatives and not the patients themselves. By including older patients we were able to increase the number of sons and daughters who had already reached screening age. The family physicians of these patients were contacted and, at our request, gave their permission for the study team to approach their patients. After appropriate explanations, the patients were contacted and asked to prepare a list of at least one first-degree relative to be interviewed by the study team. This process was adopted because it guaranteed that no ethical codes were violated. Such an approach could not have been implemented with families of deceased colorectal cancer patients.

First-degree relatives were contacted by phone and interviewed by a trained nurse interviewer using a structured questionnaire. The questionnaire included questions on sociodemographic status, knowledge of the relative's disease, health-related knowledge and beliefs, attitudes to medicine and disease prevention, and willingness to enter a screening program for the early detection of colorectal cancer. The interview was conducted by telephone and not in person, since it was technically impossible to conduct personal interviews with relatives living all over Israel and we did not consider such an interview significantly better than a telephone interview.

The data were analyzed with the SPSS-PC and Epi-Info 6.01b computer software. The chi-square statistic or *t*-tests and ANOVA were used, as appropriate, for comparison of proportions or means. Logistic regression was used for multivariate analyses. Statistical significance was set at $P < 0.05$ throughout. Means are reported as \pm SD.

Results

The study population comprised 215 respondents, most of whom were sons or daughters of patients (78%); the rest were siblings. The mean age was 47.9 ± 11.2 (SD), and 54% were males. The age distribution is shown in Figure 1. Most of the participants were married (84%), were employed or homemakers (82%), and had at least a high school diploma (95%).

Ninety-nine percent of the respondents perceived their health status as excellent (73%) or good (26%). Thirty-seven respondents (17%) reported recurrent abdominal pain, 35 (16%) reported chronic constipation, 26 (12%) reported at least one episode of rectal bleeding, 7 (3%) said they suffered from lack of appetite, 6 (3%) from chronic diarrhea and 6 (3%) from weight loss. Fifteen percent were very concerned about their health, 31% were somewhat concerned, 18% were slightly concerned and 36% stated that they were not concerned at all about their health.

During the previous year 145 participants (67%) had seen their family physician at least once and 128 (60%) had undergone a physical examination. Serum cholesterol levels were determined in 153 (71%) and blood pressure was

Respondents (N)

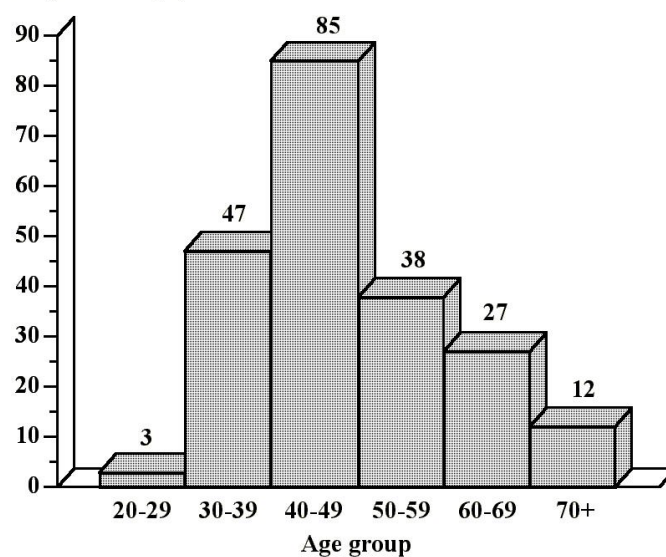


Figure 1. Age distribution of respondents

measured in 196 (91%) at least once over the previous 3 years. In contrast, a minority of the first-degree relatives of colorectal cancer patients had engaged in activities related to prevention of colorectal cancer in the recent past. Only 58 respondents (27%) remembered having been encouraged to have an early detection test. Of these, 35 (60%) were encouraged by their family physician and 17 (29%) by another physician. In the previous year, 28 (13%) underwent a digital rectal examination (for clinical indications such as rectal bleeding in 61%, $P < 0.01$), 31 (15%) had a fecal occult blood test (for evaluation of symptoms in 74%, $P < 0.0001$),

Table 1. Percentage of responders who underwent tests that are used for colorectal cancer screening, or were encouraged to do so

Variable	No.	(%)
Rectal examination (past year)		
Yes	28	(13)
No	183	(87)
Fecal occult blood test (past year)		
Yes	31	(15)
No	181	(85)
Barium enema study (past 3 years)		
Yes	20	(9)
No	195	(91)
Sigmoidoscopy/colonoscopy (past 3 years)		
Yes	30	(14)
No	184	(86)
Encouraged to undergo screening		
Yes	58	(28)
No	151	(72)
Who encouraged?		
Family member (spouse, parent, child)	5	(8)
Family physician	35	(56)
Other physician	17	(27)
Nurse	3	(3)
Other	3	(3)

Table 2. Association of participant variables and symptom variables with procedures over the previous 1–3 years

	Rectal exam (last year)			FOBT* (last year)			Barium enema (3 yr)			Colonoscopy (3 yr)		
	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
Gender	1.9	0.7–5.1	NS	0.85	0.3–2.2	NS	1.46	0.5–4.3	NS	1.4	0.5–3.3	NS
Age	3.6	1.1–11.7	<0.05	6.5	2.1–20.2	<0.01	10.8	3.1–37.8	<0.001	16.0	4.8–50.0	<0.0001
Education level	1.0	0.9–1.2	NS	1.11	1.0–1.3	NS	1.1	1.0–1.3	NS	1.2	1.04–1.4	<0.05
Rectal bleeding	13.3	4.2–42.5	<0.001	3.0	0.9–9.5	NS	7.7	2.4–24.7	<0.001	5.5	1.7–16.7	<0.01
Abdominal pain				4.1	1.5–11.5	<0.01				4.5	1.5–12.5	<0.01
Constipation	0.4	0.1–1.6	NS							0.3	0.07–1.0	NS

FOBT = fecal occult blood test

30 had a barium enema and 20 an endoscopic examination of the colon (barium enema in 75%, $P < 0.0001$, and endoscopy in 57%, $P < 0.05$, for evaluation of symptoms) [Table 1]. Among the respondents who did not undergo any of these tests (most being asymptomatic), 49% stated that they were unaware that early detection tests existed or were available, and 51% avoided them out of fear of the procedure itself or the result.

There was no significant difference between males and females with regard to having undergone tests over the previous 1–3 years [Table 2]. Older participants were significantly more likely to have undergone rectal exams, fecal occult blood tests, barium enemas and/or colonoscopies, but they also had significantly more symptoms. Higher education levels were marginally associated with having undergone more colonoscopies, but not the other procedures. Rectal bleeding and abdominal pain were significantly associated with these procedures.

Although the respondents were told that they were at high risk and were informed about screening for colorectal cancer during the telephone contact prior to answering the questionnaire, the overall percentage of respondents who expressed an interest in participating in an early detection program in the near future was 38.3%. There were no significant differences by gender, personal estimate of risk, general perception of health, or whether they had previously been encouraged to participate in a colorectal screening program. Only 19% of respondents over the age of 50 and 8% of respondents over age 60 were interested in participating, compared with 49% under the age of 50 ($P < 0.0001$).

Discussion

The aim of this study was to assess factors affecting participation of first-degree relatives of surviving colorectal cancer patients in early detection programs. This study is unique in that all patients surviving colorectal cancer over a 5 year period in the Soroka Medical Center catchment area were contacted and an inclusive database of first-degree relatives prepared with their consent. The latter comprised the study population.

All participants were at increased risk for colorectal cancer and should have been counseled about this status. Although 92% of the participants had seen their family

physician in the previous 3 years, only 27% reported having been advised to undergo screening. Almost 50% were unaware that they were at increased risk, and the majority of those who knew their status and that early detection programs were available did not undergo any screening procedure for fear of the tests or the results. During the previous 3 years less than 10% had actually undergone a procedure or examination that might be attributed to colorectal cancer screening.

A limitation of this study is that the questionnaire did not include a direct question as to why tests and procedures, which could be interpreted as screening tests, were actually done. However, indirect evidence from the questionnaire indicates that most of the patients who underwent these tests did so for clinical indications rather than for early detection of asymptomatic cancer. A statistically significant proportion of patients undergoing these tests reported symptoms such as rectal bleeding, chronic abdominal pain and/or changes in bowel habit. The tests were conducted significantly more in elderly patients, among whom symptoms were much more prevalent and who were less interested in early detection programs. In any event, exclusion of individuals who underwent tests for clinical indications, had we been able to do so, would only strengthen the evidence that very few first-degree relatives are aware of or undergo early detection procedures.

The mean age of the respondents was under 50, and 24% were below the age of 40. The reason is that we contacted all first-degree relatives of the cancer patients without consideration of age. Since most screening programs are directed at high risk individuals above age 40–45, our group was relatively young and potentially less interested in screening programs. However, our only significant age-related finding on participation in an early detection program was that respondents above age 60 were less interested. There were no significant differences in interest among respondents aged 20–39 and those aged 40–59.

Many factors influence an individual's decision to comply with recommendations for early detection of cancer. We believe that the low rate of interest in screening, a problem reported from many places around the world, stems from the nature of the screening process itself (uncomfortable tests, etc.), fear of the tests and their results, natural inertia, and other known factors. Efforts are indeed being made by the

Israel Cancer Association and professional medical groups to increase interest and improve compliance rates, but these efforts need to be reinforced and backed by public policy and massive educational campaigns.

There is no clear superior strategy to increase compliance rates. Relatives of colorectal cancer patients are not always aware that a family member was diagnosed with the disease, let alone that this confers a high risk status on them [21]. However, in a population in which the majority of high risk individuals are unaware that they are at increased risk for cancer, or that screening procedures that can prevent cancer or detect it at a curable stage are available, compliance may be an irrelevant concept. Since it is now agreed by consensus that colon cancer screening is feasible and cost effective, it is essential not only to increase awareness of official recommendations for early detection, but to train physicians, such as family physicians, gastroenterologists and surgeons who are in regular contact with these at-risk individuals, to initiate counseling and motivate compliance [18,22–24]. The positive effect of counseling by family physicians and primary care providers has been proved in other areas of preventive medicine [25,26]. The advice proffered should be informed by health education theories for determining the proper message and its framing for various groups of patients, e.g., by age, gender, ethnicity, etc. This is particularly important in light of our finding that only 47% of the respondents aged 40–59 and only 8% of those over the age of 60 would be interested in participating in an early detection in the near future.

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What a good thing Adam had. When he said a good thing he knew nobody had said it before.

Mark Twain, American writer (1835–1910)