Participation in screening colonoscopy in first-degree relatives from patients with colorectal cancer

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Background: Current guidelines recommend screening colonoscopy in first-degree relatives of patients with colon cancer. The aim of this state-wide study was to investigate the compliance for colonoscopy in first-degree relatives, who were younger than 60 years of age.

Methods: A total of 602 patients were identified from the tumor registry of the public health insurance of Lower Saxony. A questionnaire was sent to these patients, which included a number of different questions regarding their knowledge about the risk of colon cancer for their family members, as well as their participation in screening colonoscopy.

Results: Data from 442 patients and their first-degree relatives (1005 siblings and 354 parents) were available; 178 parents had undergone screening colonoscopy and 344 siblings. Interestingly, the percentage of siblings who underwent screening colonoscopy was significantly higher (27\%) among those siblings where the index patients were aware of the increased risk for the first-degree relatives, in contrast to the siblings of the index patients who were not aware of this risk (20\%).

Conclusion: This study demonstrates that only a minority of first-degree relatives undergo screening colonoscopy and that informing patients about the potential risk for their relatives will increase participation in screening colonoscopy in first-degree relatives of the patients.

Key words: colon cancer, colonoscopy, family history, screening

introduction

Colon cancer is the second most common cause of cancer death in the Western world. The risk of developing colon cancer is 2.5- to 3-fold increased among relatives of those affected \cite{1–3}. However, in most families, no hereditary syndrome can be identified \cite{4}. Thus, no genetic tests can be offered to relatives with an increased risk for colon cancer.

Colonoscopy is generally considered to be the gold standard for the detection of colon adenomas and colorectal cancer \cite{5,6}. A number of studies suggest that screening for colorectal cancer by colonoscopy, with removal of precancerous lesions, reduces the risk of death from colon cancer \cite{7,8}. Colonoscopy and fecal occult blood tests (FOBT) have been recommended as the preferred method of screening for colorectal cancer in expert panel recommendations from various countries \cite{9–12}.

Due to the known familial risk for colorectal cancer, first-degree relatives (parent, sibling or child) of patients with colon cancer or adenomatous polyps are advised to have screening colonoscopy. According to current guidelines, screening procedures should start at age 40 years or 10 years younger than the earliest diagnosis in their family, whichever comes first \cite{9,10}. However, until today only limited information is available about how far these recommendations have become clinical practice. A recent study from France has investigated the compliance for colonoscopy screening in first-degree relatives of patients with large adenoma \cite{13} and has shown a low compliance rate of approximately 18\% among first-degree relatives of individuals with large adenomas. A number of different studies investigated the effectiveness of colonoscopy screening in first-degree relatives from patients with colon cancer \cite{14–17}. However, these studies were done as part of a clinical study or research program, as opposed to our study, which reflects the situation among the general population.

The aim of this study was to estimate the number of first-degree relatives from patients with colorectal cancer (diagnosed before 60 years of age) who undergo colonoscopy. For this,
a questionnaire was sent to more than 600 patients registered at the cancer registry of the public healthy insurance of Lower Saxony, Germany. This questionnaire included questions about the patients themselves, their parents and their siblings in respect to colorectal cancer and participation in colonoscopy procedures.

**materials and methods**

Patients who were diagnosed with stage International Union Against Cancer (UICC) I–III colon cancer at 59 years or younger between January 2003 and August 2005 were identified from the cancer registry of the public health insurance of Lower Saxony, Germany (*Nachsorgeleitstellen der Kassenärztlichen Vereinigung Niedersachsen*). A questionnaire was sent by mail to every patient with a letter explaining the background and significance of this study. Before the questionnaire was sent out to all 602 patients, 10 patients with advanced stage colon cancer, who were treated in our outpatient clinic, were asked to fill out and test the questionnaire in order to verify that all questions were understandable and easy to answer. A translated form of questions in the questionnaire can be found in Figure 1. All questionnaires, which were sent back by mail, were evaluated. Statistical analysis was performed using the SPSS software version 13.0.

**results**

A total of 602 patients, who were 59 years and younger and diagnosed with colorectal cancer, were identified from the cancer registry of the public healthy insurance of Lower Saxony, Germany, and questionnaires were sent to all of these patients. Altogether, 442 (73.4%) patients returned the questionnaire within 7 months (Table 1). The median age of diagnosis of colon cancer in the index patients was 51.4 years (range 26–59). Of these, 141 (32.1%) patients indicated that their colorectal carcinoma was diagnosed through a screening procedure. However, only 23.7% of the patients had undergone screening colonoscopy. Of the index patients, 43.9% answered that they were aware of an increased risk for the development of colon cancer for their first-degree relatives, and 62.5% of the patients indicated that they had undergone some type of cancer-screening procedure (including screening for cervical cancer breast carcinoma and others) before diagnosis of colon cancer was made.

**prevalence of colon cancer in parents and siblings of patients with colon cancer**

It is known that first-degree relatives of patients with colorectal carcinoma have an increased risk of developing colon cancer.

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**Questions regarding yourself:**

1. Did you know about an increased risk for the development of colon cancer for first-degree relatives (Parents, siblings, children)?
2. Did you undergo any examination for cancer screening before colon cancer was diagnosed?
3. Did you undergo screening endoscopy before colon cancer was diagnosed?
4. Was colon cancer diagnosed through a screening colonoscopy?

**Questions regarding your parents:**

1. Was any type of cancer diagnosed in your parents before you were diagnosed with colon cancer?
2. Were your parents diagnosed with colon cancer before you were diagnosed with colon cancer?
3. Were your parents diagnosed with colon cancer after you were diagnosed with colon cancer?
4. Do your parents know about the diagnosis of your colon cancer?
5. Did your parents undergo screening colonoscopy before you were diagnosed with colon cancer?
6. Did your parents undergo screening colonoscopy after you were diagnosed with colon cancer?
7. Why did your parents not undergo screening colonoscopy?

**Questions regarding your siblings:**

1. Was any type of cancer diagnosed in your siblings before you were diagnosed with colon cancer?
2. Were your siblings diagnosed with colon cancer before you were diagnosed with colon cancer?
3. Were your siblings diagnosed with colon cancer after you were diagnosed with colon cancer?
4. How many siblings do you have?
5. How old are your siblings?
6. To how many siblings do you have personal contact?
7. How many of your siblings know about the diagnosis of your colon cancer?
8. Did your siblings undergo screening colonoscopy before you were diagnosed with colon cancer?
9. Did your siblings undergo screening colonoscopy after you were diagnosed with colon cancer?
10. Why did your parents not undergo screening colonoscopy?

**Figure 1.** The questionnaire that was sent to patients diagnosed with colon cancer at age 59 years and less.
In our survey, patients indicated that 8.8% of the patients’ parents were diagnosed with colon cancer, supporting previously published data [18]. In 8 cases, the diagnosis of colon cancer in parents was made after the index patient was diagnosed (Table 2). The index patients had a total of 1005 siblings; 909 (90.4%) of them knew about the diagnosis of colorectal cancer in the index patients; 888 siblings (87.9%) had personal contact with the index patients. Colorectal cancer was diagnosed in 28 cases of siblings (=2.8%). This diagnosis was made in 21 cases before and in 7 cases after detection of colorectal cancer in the index patient.

Screening for colorectal cancer in parents and siblings of patients with colorectal cancer

Index patients were asked whether their parents or siblings had undergone colonoscopy. Siblings who were more than 10 years younger than the index patients, were not eligible for colon-cancer screening according to the international guidelines. A total of 354 parents were still alive at the time this survey was taken. Altogether, 178 screening endoscopies were done in the parents, 107 before and 71 after the index patients were diagnosed (Figure 2). A total of 888 siblings were eligible for screening for colon cancer according to international guidelines (Table 3). Only 344 (39%) screening colonoscopies were done in siblings; 109 screening endoscopies were done before colon cancer was diagnosed in the index patients and 235 cases after the diagnosis of colon cancer in the index patients (Table 3).

Figure 2. Information on the parents of the index patients. The total number of parents alive at the time of the questionnaire is shown: 89.5% of them had knowledge of colon cancer in the index patient; 19.8% had done screening colonoscopy; 20% had screening colonoscopy after diagnosis. Therefore, 661 siblings (66%) and 238 parents (68%) did not receive a screening colonoscopy. According to the current guidelines, screening colonoscopy is recommended for all of these individuals.

We next investigated whether screening colonoscopies were more frequently performed among first-degree relatives of those index patients who were aware of an increased risk for the development of colon cancer: 193/440 index patients (43.9%) knew about the increased risk for their first-degree relatives;
number of siblings, who underwent screening colonoscopies after diagnosis 438

Yes 7 (1.6 %)
No 357 (81.5 %)
Do not know 23 (5.3 %)
No sibling 51 (11.6 %)

Total number of siblings with knowledge of CRC less than 10 years younger than the index patients 888


discussion

In this study, we have performed a survey about the participation of first-degree relatives of patients with colon cancer in screening colonoscopy. The patients with colon cancer were diagnosed at an age of 59 years or younger. Only less than 30% of the parents and siblings of patients with colon cancer, who were eligible for screening colonoscopy, actually underwent the procedure, demonstrating that this screening process is only performed in a minority of people, with a documented elevated risk for colon cancer.

We used the cancer registry of the Kassenärztliche Vereinigung of Lower Saxony to identify patients with colon cancer. This registry collects data about diagnosis and treatment of cancer patients. In addition, this registry arranges improved cooperation in interdisciplinary treatment and accelerates communication between inpatient and outpatient medical care. Therefore our study differed from other investigations in which relatives from patients with colorectal cancer who invited to enroll in screening colonoscopies [14–17]. The main focus of this investigation was to determine the impact of current screening recommendations in the general population.

Several strengths and limitations of this study have to be emphasized. Due to the design of this study and ethic rules, it was not possible to directly contact first-degree relatives of colon-cancer patients, so that index patients had to respond for their relatives. Therefore, it was not possible to validate patients’ answers and to exclude those patients who only underwent sigmoidoscopy but not complete colonoscopy. One question regarding the contact between the family members was included into this questionnaire, in order to exclude those relatives from our studies, where the index patients could not provide the relevant information. As expected, a number of patients indicated that they were not in contact with their relatives or that the relatives did not know about the patient’s diagnosis of colon cancer. For the same reason, we could also only obtain limited information as to why patients’ relatives had not undergone screening colonoscopy. It is possible that stool tests for occult blood were performed by some of the relatives instead of screening colonoscopy. However, in contrast to the average risk population for which FOBT can still be offered as an accepted screening modality, current guidelines recommend colonoscopy and not other methods as the principal screening procedure, especially for people with an increased risk of colon cancer [17].

A number of previous studies have identified possible predictors for colorectal cancer-screening participation in the US [19] and elsewhere [20, 21]. Different reasons were noted on the questionnaire, including age (in case of parents), fear of the result, age of the parents, lack of knowledge and lack of physical complaints. However, our study also clearly demonstrates that participation in screening colonoscopy after diagnosis in the index patients was significantly higher in those families where the index patients knew about the increased risk
for colon cancer in their families. This observation clearly shows the importance of patient information. In our study, only 44% of all patients were aware of an increased risk for colon cancer for their first-degree relatives. This data indicates that patients with colon cancer are inappropriately educated in Germany and patient education has to be optimized in order to reduce the number of new colon-cancer cases.

It is beyond the scope of this study to determine the reason why the majority of patients did not know about the increased risk for colon cancer in their first-degree relatives. One might speculate that the physicians who diagnosed and treated the index patients, did not explain the increased risk for the first-degree relatives and current screening guidelines for colorectal cancer. However, other factors cannot be excluded [22,23].

In summary, our investigation clearly indicates that less than 40% of eligible first-degree relatives from patients with colon cancer diagnosed at the age of 59 years and younger participate in colonoscopy screening for colon cancer. Our study also demonstrates that only a minority of patients are aware of the increased risk of colon cancer in their first-degree-relatives. However, most importantly, we have shown that in those families who knew about the increased risk, relatives participated more frequently in screening colonoscopy after the diagnosis was made in the index patients. This suggests that better education of colon-cancer patients could translate into an increase in screening colonoscopy, which might reduce the number of colon cancer occurrence in families with an increased risk for this common malignancy.

references