

Interactions among physicians, patients, and first-degree relatives in the familial screening of colorectal cancer in France

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Aims: To characterize determining factors for compliance with colonoscopy recommendations in the familial screening of colorectal cancer through exploration of individual psychosociological factors and issues relating to patient/physician/sibling communication.

Methods: A qualitative approach involving a review of the literature and interviews with general practitioners, specialists, patients, and their siblings.

Results: A confrontation of the content of interviews with data from the literature made it possible to confirm the relevance of classic prevention models, the Health Belief Model and the Theory of Planned Behavior in the French cultural and healthcare environments, as well as their ability to identify the main individual factors liable to motivate or to discourage familial screening. The family network plays a decisive part in the transmission of information from the patient towards siblings. Physicians have expectations relating to communication aids and backup. This study above all highlights the difficulty in determining who is best suited to giving information to the patient, and when and how to relay this information to first-degree relatives.

Conclusion: In view of the many difficulties in establishing interaction between patient, physician and siblings that is liable to lead on to efficient screening, we propose the study of the usefulness of a health-counseling intervention aimed to tailor and follow-up the delivery of screening information to the first-degree relatives.

Keywords: colorectal cancer, targeted screening, siblings, prevention, health promotion

Introduction

Colorectal cancer (CRC) is the most frequently occurring cancer after prostate cancer in men and breast cancer in women. In France, while incidence rates have increased, from 35 to 42/100,000 in men and from 22 to 27/100,000 in women between 1985 and 1995, the specific death rate has decreased in both men and women. This trend can be explained by earlier diagnosis and by improvements in treatment (Remontet et al 2003). Between 1998 and 2002, CRC was associated with an annual mortality rate of 16.1 deaths per 100,000 person-years (Chérié-Challine and Boussac-Zarebska 2007). First-degree relatives (FDR) are at increased risk of CRC with an associated relative risk of 2.24 (Butterworth et al 2006). Every year, around 7000 cases of CRC, amounting to 25% of overall numbers, are diagnosed in high or very high-risk populations. Had these patients been identified sufficiently early, they could have had the benefit of a monitoring program as described in guidelines. Despite screening campaigns, 5-year mortality is still around 55%, reflecting inadequate detection of lesions at the pre-neoplasm stage, or early-stage invasive cancer.

The clinical guidelines for colorectal cancer screening are endorsed by several professional associations such as the American Cancer Society, the American

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College of Gastro-Enterology, the American Society for Gastro-Intestinal Endoscopy, or the French “Société Nationale de Gastro-Entérologie”. All recommend screening in subjects over 50, but while they agree on the need for stricter recommendations among high-risk subjects, recommendations can differ slightly (Walsh and Terdiman 2003). According to French clinical practice guidelines, screening colonoscopy is recommended in subjects with a history of CRC in a FDR occurring less than 60 years of age, and if there are two or more instances of a family history in a FDR, irrespective of age of cancer diagnosis. Surveillance should start at age 45, or 5 years before the age at which colorectal cancer was diagnosed in the index case (ANAES 2004). Application is nevertheless still difficult because these guidelines tell nothing of the respective roles of primary care, oncology, and surgical clinicians, or when and how to transmit adequate information.

Surveys on clinical practice suggest that recommendations are not widely complied with (Denis et al 2003; Lemon et al 2003; Bleiker et al 2005). In a French study, while each patient had 3 to 4 individuals presenting high risk among their relatives, only two-thirds of these individuals were aware of their level of risk, and only 10% were adequately monitored (Ponchon and Forestier 2005), but this estimate derived from a practitioner-based sampling may be biased and actual screening rate remains unknown. Factors encourage FDR of a patient with CRC to submit to screening, while other factors discourage them from doing so, or affect the circulation of relevant information. Few studies have looked for these factors, but none in France (Colombo et al 1997; Harris and Byles 1997; Harris et al 1998; Hunt et al 1998; Rawl et al 2000; Shvartzman et al 2000; Jacobs 2002; Manne et al 2003; Gili 2006). These factors are thought to operate at four distinct levels (Madlensky et al 2003): i) at individual level, ii) at family level, iii) via relations with the physician, and iv) via the social environment.

This led us to study the models on which prevention campaigns are based, where the focus is on individual behaviors, and to set up a qualitative study involving all the protagonists in the familial screening process (the patient suffering from CRC, FDR, and medical practitioners). This was intended to ascertain whether these theoretical models could be transposed to the French environment, and whether they could be applied to the context of familial screening. The objective of the study was to characterize determinants for adherence to colonoscopy for the purpose of familial CRC screening, using individual psychosocial aspects and features of patient/physician/sibling communication.

Methods

Literature review

Prevention models

As the first step of this study, a systematic review was conducted on all studies published in English or French indexed in the Medline database, meeting one or more of the following criteria: CRC screening, factors associated with compliance, FDR of patients with CRC. The selection field was widened following examination of the bibliography identified by the above search, and literature was located using online search engines such as Google. Our analysis of the literature also focused on conceptual models of prevention and on social networks relevant to the context of screening strategies (individual or familial).

Psychosocial models

Psychosocial models have been drawn up to explain the mechanisms whereby social and cognitive variables can have an influence on the attitudes towards screening (Champion 1984; Jacobs 2002; Gorin 2005). Two of these models are widely used to apprehend psychosocial motivations underpinning compliance with screening (Soler-Michel et al 2006), the Health Belief Model (HBM; Janz and Becker 1984) and the Theory of Planned Behavior (TPB; Ajzen and Fishbein 1977; Ajzen 1991).

Only the HBM was developed for and within the field of health. Individuals undertake a health procedure if they perceive they are at risk (perceived susceptibility), the seriousness of possible consequences (perceived severity), if they recognize both the advantages (perceived benefits) and any obstacles to it (perceived barriers), and if they have encouragement or incentive (cues to action) to undertake it (Rosenstock 1974; Rosenstock et al 1988; Glanz et al 2002). Encouragements or incentives can be internal (symptoms) or external (advice of the family doctor, information campaigns in the media). The HBM also postulates that individuals feel able to overcome barriers to taking action if they feel confident in themselves, or if they have confidence in others (Wardle et al 2000; Hay et al 2003; Janz et al 2003; Gipsh et al 2004; Gorin 2005). According to the TPB model, it is the intention to adopt a given behavior that is decisive. In the elaboration of the intention there is an interaction of cognitive, social, and moral factors. The TPB takes account of the part played by the close circle (family and friends) and by social pressures in the adoption of behaviors. This theory complements the HBM by integrating a normative dimension and a behavioral control dimension.

Other factors, not integrated in the above models, have been described, such as awareness for issues concerning CRC, colonoscopy screening, information on the symptoms of CRC (Gorin 2005; Soler-Michel et al 2005), health system barriers (Denberg et al 2005; Ogedegbe et al 2005; Dujoncqouy et al 2006), sociodemographic factors, personal medical history (Champion 1984; Jacobs 2002; Gorin 2005; Trauth et al 2005), as well as attitudes towards health, family medical history, experience of cancer (Jacobs 2002; Trauth et al 2005), and fatalistic attitudes in relation to cancer (Powe 1995, 1997).

Social network

The social network comprises two aspects, the structural aspect characterizing its range, and the functional aspect characterizing its level of support (Berkman and Syme 1979; Suarez et al 1994; Berkman 1995; Suarez et al 2000; Koehly et al 2003; Kinney et al 2005). A structural indicator of social integration explores three types of relationship, marital status, contacts with family and friends, and membership of an association on a voluntary basis (Berkman et al 2004). Indicators for the functional aspect include emotional support and material assistance (Melchior et al 2003). The social network can have a major influence on compliance with screening recommendations (Gili et al 2006; Ng et al 2007).

These conceptual models underpinned the theoretical frameworks of the interviews.

Qualitative study

Sample selection

We studied a regionally based cohort of all consecutive patients who underwent surgery for CRC less than 60 years of age between January 1st, 1999 and December 31st, 2002 in two areas in western France (Vienne and Deux-Sèvres, with 768,000 inhabitants as of 2005). The French data protection authority approved the protocol for patient inclusion. The recruitment period was chosen to allow 5 years delay, a sufficient delay for the FDR to perform screening colonoscopy. The study was focused on siblings, since parents were mostly dead, and children were below the screening recommended age. Among 237 patients identified by the surgeons, 179 met the inclusion criteria, among them 32 could not be contacted and 19 (11%) refused to participate.

For the interviews, a panel of index cases was randomly selected from this cohort stratifying on the following criteria to obtain diversity in profiles: living/deceased, male/female, age, rural/urban environment, health facility having provided care for CRC (Table 1). Individuals received a letter which explained the objectives of the study and requested

Table 1 Characteristics of patients and siblings involved in the study (Interviews)

Family	Sex	Age
Family 1		
Index case	Female	58 years
Siblings: 2 brothers	Male	57 years
	Male	44 years
Family 2		
Index case	Male	62 years
Siblings	None	
Family 3		
Index case deceased	Male	26 years
Parent of index case	Female	60 years
Siblings: 1 brother and 1 sister	Female	31 years
	Male	35 years
Family 4		
Index case	Male	54 years
Siblings: 4 sisters	4 Female (not interviewed)	
Family 5		
Index case	Female	58 years
Siblings: 2 sisters	Female	60 years
	Female (not interviewed)	
Family 6		
Index case	Female	42 years
Siblings: 1 brother and 1 sister	Female	49 years
	Male	51 years

their consent for participation. The index case was then contacted by phone to obtain an appointment for an individual face-to-face interview. The siblings were contacted after index subject authorization. If the index subject had died, authorization was sought from the spouse or nearest relative.

Interviews with index subjects and siblings

The interview method enables analysis of the impact of an event or a particular experience on the person involved. We conducted semidirective interviews to provide the different respondents with an environment facilitating free expression but also enabling data collection in relation to a set of interview themes (Miles and Huberman 1994).

Firstly, the index subject's sibling(s) was phoned to obtain an appointment for individual interview. Duration of the interviews ranged between 50 and 90 minutes for patients, and 20 to 30 minutes for siblings.

Interviews with GPs and specialists

We contacted by phone or sent individual invitations to general practitioners (GPs) and hepato-gastro-enterologists (HGEs) practicing in the study areas and invited them to participate in two 1.5 hour-focus groups with a team of

sociologists. Participants were recruited to obtain diverse profiles: location of practice, experience, type of practice, gender. In addition, we conducted 30 minute individual interviews with surgeons and oncologists (see Table 2).

Analysis of interviews

At the beginning of each interview, participants were asked for permission to record the interview and were given a guarantee of the anonymous nature of the data collected. The thematic content analysis method aimed to evidence the social representations or opinions of interviewees from different elements in the discourse.

Results

Factors governing compliance with screening recommendations are approached in three ways: via the patient concerned, via his or her family and social environment, and in relation to communication with the physicians involved. Participants reported most of the factors described in the literature: psychological factors (HBM and TPB themes), family history, personal medical history, health-related behaviors, and sociodemographic characteristics.

Individual factors relating to the person requiring screening

Psychological factors

Perceived susceptibility

Perceived susceptibility reflects subjective perception of the risk of developing a health problem. According to patients and siblings, stress arising from present-day lifestyles is a risk factor for developing CRC. One sibling said, *“For the food we eat, we try to be careful ... We have vegetables from the garden, and things like that.”*

Perceived severity

Perceived severity reflects attitudes and feelings towards the disease. The knowledge about and experience of the disease (unexpectedness, suddenness, care provision) and the image projected by the patient on him or herself has an impact: siblings may have a more positive attitude if a brother or a sister *“stood up to it”* as an index case said. *“I think I managed a lot better when it was me, because then it’s your business, you have to cope, you’re in charge. When it’s someone else you’re just looking on.”* Siblings realize that if their brother or sister had been diagnosed earlier, they could have avoided having to endure this treatment. A sibling said, *“If I were to choose between having colonoscopy and having the chemotherapy she had, I wouldn’t think twice.”*

Table 2 Characteristics of practitioners involved in focus groups or individual interviews

Sex	Age	Speciality
Focus group. General practitioners (n = 4)		
Male	60	General practitioner
Male	30	Resident in general practice
Female	35	General practitioner
Male	60	General practitioner
Focus group. Gastroenterologists (n = 9)		
Female	40	Gastroenterologist
Male	40	Gastroenterologist
Male	65	Gastroenterologist
Female	45	Gastroenterologist
Male	50	Gastroenterologist
Male	45	Gastroenterologist
Male	55	Gastroenterologist
Female	30	Gastroenterologist
Female	35	Coordinator of a cancer screening structure
Interviews. Oncologists and surgeons (n = 4)		
Male	45	Surgeon
Male	45	Surgeon
Female	35	Oncologist
Male	50	Oncologist

Perceived benefits

Perceived benefits reflect beliefs regarding the efficacy of any possible action to reduce the threat of the disease. Screening reassures, increases chances of recovery, enables early detection of any problem, and avoids having to undergo very demanding treatment. One sibling said, *“I’m convinced that early screening is three quarters of the way to being cured ... I think that if she had been diagnosed earlier, there would not have been all this trouble.”* Individuals who had undergone a first colonoscopy had all subsequently submitted to a second and even a third.

Perceived barriers

Perceived barriers relate to physical, psychological, or financial aspects connected with the screening procedure. Some of these barriers were mentioned in the course of interviews (discomfort and unpleasantness of the examination, time required) while others were not (embarrassment in discussing CRC, increased anxiety, cost). Siblings focused more on the colonoscopy preparation and the anesthesia than on the issue of the examination itself.

Emotional factors

Fears may be viewed as perceived susceptibility if they are moderate in intensity or as an emotional blockage if they are intense. Fatalistic attitudes towards cancer were reported from the interviews: one sibling said, *“Just bad luck, that’s*

life.” The dimension of the family risk for this cancer was not very prominent among siblings, but all stated they were very watchful with respect to their own children.

Cues to action

The advice of medical practitioners, the family and friends constitute outside incentives for screening. Confidence in the quality of the relationship with the medical sphere favors compliance with screening. A FDR said, “*They saved my niece, it’s marvelous what they did for her.... They did what they could for Dad, but there you are, he was diagnosed too late.*”

Intention

The intention to undergo screening is related to subjective attitudes or norms. Some interviewees considered the screening examination as a sort of duty, or obedience towards “medical authority”. One sibling said, “*A year ago I had another colonoscopy, because you should have them every four years.... Like other women of my age I have a mammography every two years.*”

Awareness and knowledge

Awareness and knowledge of the disease and screening requirements. The disease is well identified because of wide media coverage, in particular since the start of the National Cancer Plan in France (Steimle 2005). The idea that CRC is curable, in particular in comparison with other types of cancer, is predominant.

Health-related behaviors

The desire to detect any problem early, and to maintain and improve health by means such as information, diet, sport, and medical check-ups were mentioned in the interviews.

Personal and family medical history

Participants emphasized the influence of a family history of cancer on attitudes to screening. “*In our family, because of past experience, we are careful*” said one sibling. In families who had not experienced cancer, the shock of the diagnosis may have been a determining factor. One sibling said, “*My sister was operated on for cancer in December 2001 and I had a colonoscopy on February 20th 2002 – you see, I didn’t lose any time.*” Siblings mentioned a link with personal medical history and use of medical facilities, including participation in screening programs. None of the interviewees alluded to past experiences (Bentler and Speckart 1979; Codori et al 2001) or negative experiences relating to health-related behaviors (Kahn and Luce 2003).

Sociodemographic characteristics

Among sociodemographic characteristics, gender, age, and professional situation were gathered. The youngest subjects did not include cancer screening among their priorities, despite their family history. Among older subjects with a more stabilized family and professional situation, taking care of health is a priority for this period in life.

Certain factors cited in the literature did not appear in the interviews: income, racial issues, religion and religious practice, health service accessibility, and certain health system barriers (time required to obtain an appointment, proximity of the relevant facility, time to get there).

Family and social factors

The interviews widely touched on the dynamics and the nature of family ties. Relationships among brothers and sisters were a determining factor in the circulation of information. According to patients, emotional closeness, presence of siblings throughout the course of the disease, and easy communication among family members may lead to a more acute perception of the risk of developing cancer among siblings, and foster recourse to screening. One informed patient about screening recommendations by the physician was quick to inform relatives and said, “*My two brothers took my advice soon after my operation and went to hospital for an examination.*” The patient’s behavior can even go as far as to ensure that the examination actually takes place. However, where communication within the family was more difficult and family ties looser, there were few exchanges “*on important things at the time of the illness.*” In these families, screening recommendations were less frequently complied with.

The influence of the social network outside the family was also brought up. “*I have a friend who works in a clinic, in a ward specializing in this sort of illness. She had experience of the illness with her father, and her sister was saved in time because she got the screening*” said a sibling.

Transmission of information by medical practitioners

Who gives out the information?

Specialist practitioners (HGE, surgeon, oncologist) all state they provide information, but all finally consider that another practitioner is in a better position to do this. Roughly speaking, according to HGEs and GPs, information on screening should preferably be the job of the surgeons. According to GPs, patients do not talk about receiving information from a HGE but from a surgeon. HGEs consider from experience that oncologists play little part in providing this information.

HGEs regularly receive patients who have been told they should have colonoscopy. However they recognize that in this context they see only those patients who have already decided to undergo the examination. GPs position themselves not as the initiators but as the prescribers. Most of the time the patient comes to the consultation with information, which may be partial, and has already understood that he or she needs the examination in connection with the illness of a sibling. Siblings confirmed that they advised their doctors that their brother or sister had developed CRC and then asked for a prescription for colonoscopy.

When is the information given?

All the physicians stated they reiterated the information. The moment chosen varies according to personal convictions and modes of practice. Thus certain HGEs give the information at the outset because they consider that repetition is important. Opportunities arising for exchanges with relatives, when they visit the patient in hospital, can enable the information to be given directly. Others prefer to give it at a later stage because they feel that the period following the announcement of the diagnosis is unsuitable. Surgeons prefer to provide information in stages, most often several days after the surgical operation, once the diagnosis has been explained. The oncologist informs patients in consultations at the start and end of treatment, or in follow-up consultations, but preferably at the end of treatment, when the patient is more receptive and more likely to remember the information.

What information?

GPs and HGEs consider that the recommendations are relatively straightforward, and that they are well acquainted with them. All however report that even if they are well known, they are not necessarily correctly applied. HGEs consider the recommendations to be too selective.

HGEs emphasize the need for GPs to be convinced of the need for screening. All remember cases where the attitudes of the family doctor discouraged individuals. Certain HGEs do not want to have to use the word “cancer”, with the result that there is a shortfall in information to the family. HGEs voice expectations with respect to information backup that could help patients communicate with their relatives, but they emphasize the need to adapt their issue to each particular instance.

GPs report difficulty in detecting high-risk subjects. Indeed, while they may conduct a detailed exploration of family history in the course of the first consultation, they do not generally update the questioning. A case of cancer may well arise later in the family without the patient informing his

GP. However when the patients themselves ask the question of recommendations for the screening of their children, exchanges on screening siblings are facilitated.

To whom is information given?

The index case’s physician delivers information to the index case him or herself, this person then being expected to hand on the information to siblings, except in occasional situations in which the practitioner meets the family at the patient’s bedside. However practitioners consider it difficult to expect the patient to carry responsibility for preventative screening of siblings. Opinions differ on how far it is possible to urge the sick patient to inform relatives. One surgeon said, “*You can’t go against the person’s wishes, and inform directly ... it would be a breach of confidentiality ... you have to manage to persuade the patient that he should inform his children and siblings.*” Certain practitioners regularly ask their patients if their brothers and sisters have had colonoscopy, but this is not sufficient to actually check that it is the case. Many physicians feel powerless in supporting the patient with his or her role in transferring information; some HGEs make a written reference to the need to screen siblings on prescriptions, hospital reports, and results of examinations. Physicians overall are convinced that the majority of siblings do receive screening.

The circulation of information, which implicates the different specialist practitioners, GPs, patients, and siblings, is summed up by Figure 1.

Discussion

This study has made it possible to confirm the relevance of the prevention models, the HBM and the TPB, in the French cultural and healthcare environment, and their ability to identify the main psychosocial factors coming into play in familial screening of CRC. This study has also highlighted the difficulty in establishing who should carry the responsibility for giving information to the patient, when this should be done, and how to ensure the information is relayed to the patient’s FDR. Establishing communication among the different protagonists is a determining factor in sibling compliance with screening recommendations (Pho et al 2000; Rawl et al 2000; Shvartzman et al 2000; Jacobs 2002; Ruthotto et al 2007).

Familial screening is indeed positioned in an individualized information process (Marcus et al 1999; Glanz et al 2007) which is very different from the promotion of large-scale screening by campaigns with wide media coverage. Few studies have explored determinants for compliance

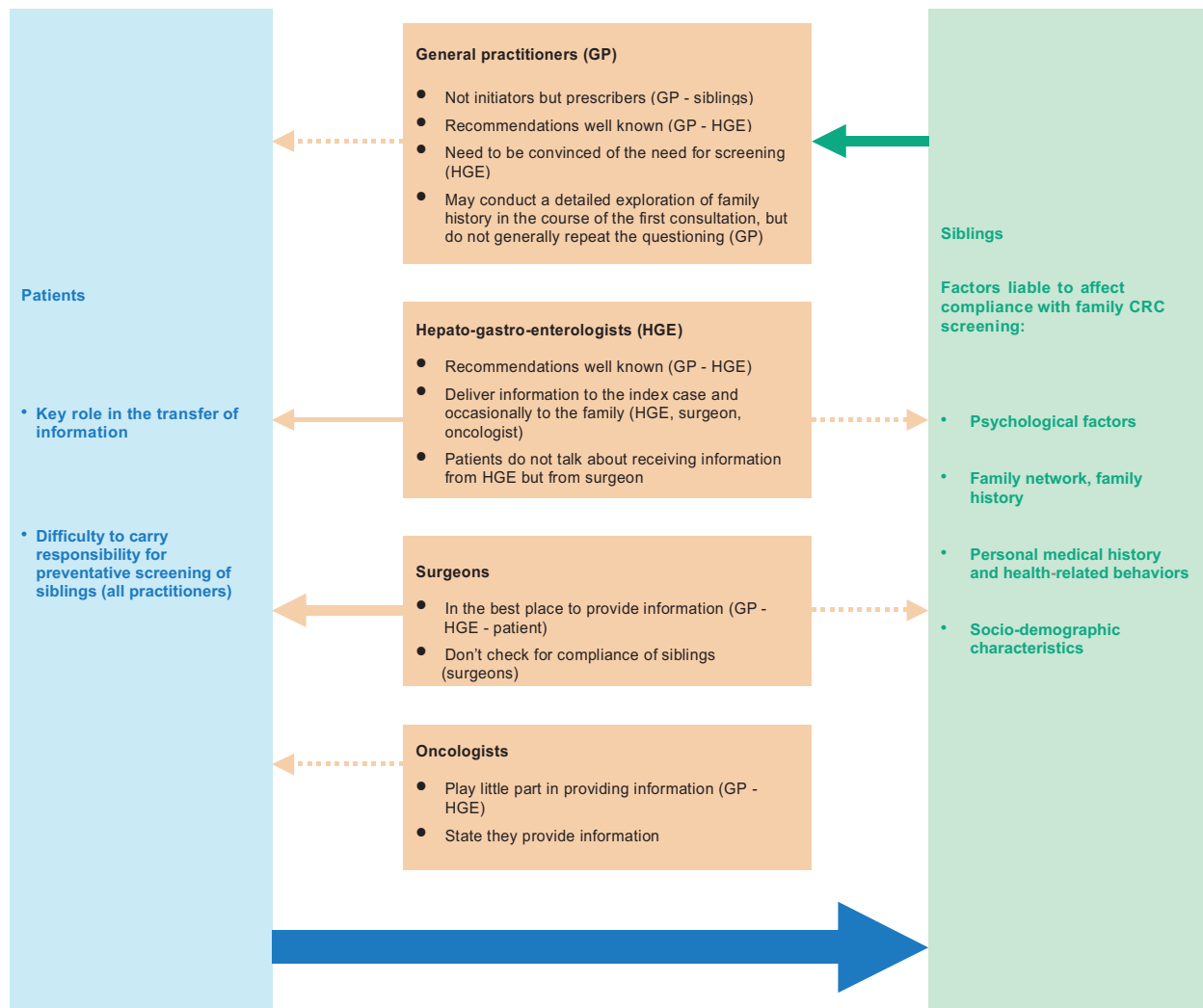


Figure 1 Interactions among physicians, patients, and first-degree relatives.

with screening recommendations using colonoscopy, unlike CRC screening in the general population using Hemocult[®] (Codori et al 2001). The dual approach used in this work, ie, a bibliographic search focused on prevention models and a qualitative exploration using interviews, made it possible to apprehend the multiform nature of determinants that come into play, despite inherent limitations due to the uncertain representativeness of the study sample. For the physicians, the group interview method enabled peer discussions on practice; the resulting dynamics led each participant to take the other further in his or her argumentation, and to deeper self-questioning.

Among siblings, the main determinants of screening compliance behaviors described in the literature were confirmed in the interviews: psychological factors (perceived susceptibility, severity, benefits and barriers, emotional factors), family history, personal medical history, health-related

behaviors, and social networks. The particular context of family screening explains the very important part played by the family network and its workings in relation to the more restricted role of the social network. In this context, further social network analyses will require to distinguish family from close friends. Other factors, with a smaller impact, were not brought up in the interviews, for instance conditions of access to healthcare (accessibility of facilities, time needed to obtain an appointment, access time, cost) and past experiences. Other factors again are not part of the European culture, such as income, or have a lesser impact in Europe than in the US context (race, or religion and religious practice). The analysis of perceived barriers and benefits affords the opportunity of targeting information and communication campaigns (Rawl et al 2000), or even of personalizing information to be given to siblings via better knowledge of their feelings and attitudes (Glanz et al 2007).

Specialist physicians (HGE, surgeon, oncologist) all state that they deliver information to patients, although all consider that they are not in the best position to do this. A study conducted in the Boston Medical Center showed that out of 79 patients with CRC, only 18 had been informed of the risks for their FDR, and most of those who had this awareness had obtained it from sources other than their physician (Pho et al 2000). GPs report that, while there is a detailed exploration of family history at the time of a first consultation with a patient, they do not generally return to this, and this finding was also observed in other studies (Denis et al 2003). In a later study it was noted that family history of CRC was recorded in only half the medical files (Denis et al 2007). The direct transmission of information by the physician to siblings appears from the present study only to occur in a small number of situations. According to our results physicians often rely on the patient to deliver information on screening recommendations to FDR, while at the same time they acknowledge that this is a difficult task for the patient. They note that systematic screening campaigns such as Hemocult® could foster targeted screening via better awareness about CRC in the general population, thereby rendering siblings presenting a risk more receptive to the information provided by their relative. The development of an information sheet delivered to the patient by the HGE to be handed on to siblings has already been tested in France (Ponchon and Forestier 2005), showing good acceptance by patients. However a recent study in the USA found that this type of information document “had no influence on self-perceived risk of developing colorectal cancer or uptake of screening activities” (Stephens and Moore 2008). The deontological issues need to be addressed: the physicians delivering care to the index subject do not feel authorized to contact siblings or the family doctors of these siblings directly for the purpose of giving information, in particular for reasons of medical confidentiality.

The patient plays a key role in the transfer of information, and according to one study “knowledge of the sibling’s illness is the strongest predictor” of screening compliance (Gili et al 2006). Depending on individuals, one wishes to inform family members themselves and on their own, or with the help of the physician, or entrusts the delivery of information to a third party using a “family medical information” procedure; patients may refuse to give any information to relatives, or even not be themselves informed of the diagnosis. For information to have every chance of reaching the family members, it seems essential to look for strategies for accompanying physicians as well as patients in this process.

Future research is needed to confirm our results from a quantitative study targeting the cohort of patients and their siblings, with the objective to describe the screening rate and to analyze the respective impact of determinant factors. Moreover, a better knowledge of perceived barriers and benefits may help to focus an individually “tailored risk counseling”, which has previously proved to increase compliance with screening guidelines among FDR of CRC patients (Marcus 1999, Glanz et al 2007) but has never been evaluated in a European context.

Acknowledgments

Authors are gratefully indebted to patients, siblings, and practitioners who participated in the study interviews, to Angela Swaine-Verdier for her freely translated verbatim French into English to give an idea of both content and tone, to our clinical research assistants Laetitia Becq Giraudon, Nicolas Mériaux, and Christelle Routelous, and for the financial support of the Caisse Nationale d’Assurance Maladie des Travailleurs Salariés and the Ligue Nationale contre le Cancer.

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