Development of multidisciplinary committees for decision making and care management in hereditary colon cancer: the French state of the art

Souria Aissaoui · Hanaa Aissaoui · Sophie Giraud ·
Stéphane Pinson · Alain Calender

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Abstract Multidisciplinary Committees (MDC) in France were established by the Institut National du Cancer for the management of therapeutic cancer treatment. We wanted to know if this approach is being utilized in Cancer Genetics, in particular for patients with a digestive cancer predisposition. A questionnaire was sent to the 33 French oncogenetic centers. Responses were received from all clinics. We found that 76 % of centers regularly use MDCs for the management of hereditary digestive cancers. Familial colon cancer cases were the most common situation, in which MDCs were utilized. Participation of various medical specialists was reported as follows: geneticists (100 %), gastroenterologists (76 %), genetic counselors (84 %), surgeons (32 %), and biologists (36 %). Twenty percent of centers consult MDCs for every patient compared to 80 % of centers that use MDCs only for select cases. MDCs represent a multidisciplinary approach for patients affected by inherited cancers and may optimize follow-up for genetic screening and further care management.

Keywords Risk assessment · Colorectal cancer · Genetic diagnosis · Multidisciplinary decision making · Familial cancer management

Introduction

The use of multidisciplinary committees (MDC) was introduced by the Institut National du Cancer (INCa; French National Institute of Cancer) in their 2004–2005 National Cancer Plan. The aim of MDCs is to bring together the best medical cancer specialists to assist in the development of a treatment

plan for patients. In cancer genetics, the number of oncogenetic consultations has steadily increased since 2003. For example, an increase of 12.1 % was observed between 2008 and 2009 (7,734 consultations in 2009 compared with 6,901 in 2008) (French INCa 2009). Specific recommendations and criteria for patient follow-up in oncogenetics are given by the INCa report. But there are also various rare cases to study and think over. Genetic testing must be decided and patient care monitored. We were interested to analyze how geneticists manage their cases in the Lyon region, as well as nationwide.

Oncogenetic MDC is shown to be paramount to follow-up familial cases in France and covers the whole territory. It is simple to categorize at risk families, to manage the cases, and provide advice; however, there are some borderline and atypical cases to think over. There exists a heterogeneity in the points of view of clinical experts from one case to another. In order to synchronize our methods and standardize the genetic counseling, the French oncogenetic institutions decided to come together for a discussion of MDC practices. The MDC globally is the site of decision making. Following the INCa recommendations, MDCs analyze, case by case, every difficult clinical situation. The members of MDCs collaborate daily through interactions in clinic and the laboratory. In general, oncogenetic counseling is performed based on established criteria published for the diagnosis of familial adenomatous polyposis (FAP) (Ed Bosman et al. 2010) and the two major consensus conferences, validated by INCa, focusing on hereditary nonpolyposis colorectal cancer (HNPCC)-related digestive cancers: Amsterdam criteria and Bethesda guidelines (Lynch et al. 2004; Lipton et al. 2004).

This study is an evaluation of strategies of patient follow-up used by MDC in France focused on colon cancer and related syndromes. In our clinical center in Lyon, a multidisciplinary consultation for colorectal cancer predisposition, primarily FAP

S. Aissaoui (✉) · H. Aissaoui · S. Giraud · S. Pinson · A. Calender
Hôpital Edouard Herriot, Lyon 03, France
e-mail: souria.aissaoui@chu-lyon.fr

and HNPCC, is held monthly. To our knowledge, no previous studies have been conducted to assess the conditions and benefits of MDC on this particular type of cancer.

Methods

Our study is based on a questionnaire sent to all oncogeneticists and genetic counselors (GCs) in the 33 French oncogenetic centers that perform primary consultations for digestive cancers, during the years 2011/2012. Each center was asked to return a single response based on the collective involvement of their entire staff. A complete list of potential collaborator centers was obtained via the updated French map of the INCa Report 2009 (Fig. 1). Questions about existence of MDC, its role, its organization, members, and types of cases discussed were requested. If no response was obtained

within 2 months, clinicians and counselors were contacted a second time to complete the form. This was done every 2 months. To be exhaustive in the response rate, a final phone call was placed to those centers that did not respond by mail. We obtained responses from 100 % of the centers. For 10 % of the centers, some responses were left blank. In these cases, we recontacted the centers to complete the answers.

Clinics were asked to respond to the questionnaire based on their consultation with patients affected by familial colon cancers (FAP or HNPCC) based on established clinical criteria and family history.

Results

A comprehensive overview of the use of MDCs in France suggests that of the 33 hospitals studied in our survey, 25

Fig. 1 Geographical distribution of French oncogenetic consultations (French Inca 2009) and French state of the art MDC by region. In blue are regions that propose MDC, in yellow are those that does not propose

MDC, and in green are regions where some centers (institutions of a town) propose MDC and some others not

(76 %) developed a MDC for digestive cancers associated with FAP and HNPCC syndromes. A map showing French MDCs by region is shown below (Fig. 1). The answers will further influence our results in the evaluation of MDC in terms of organization and quality.

Organization of MDC

The majority of clinical centers (60 %) staff the MDC externally by bringing together clinicians and biologists from across France. Some centers (20 %) organize consultation meetings with personnel working within their own institution. The others (20 %) convene either external or internal MDC (Fig. 2). For clinical centers organizing regional (multicentric) consultation and meetings, videoconferencing is mainly used (55 %). Specialists also often have to travel to the meeting place (40 %). Some patient situation is discussed by phone (5 % of centers). In some regions and/or large clinical centers, regional cooperative networks have been established such as Comité d'experts en Oncogénétique Digestive d'Ile de France in the Paris/Ile de France area, and Groupe Rhône-Alpes des Polyposes Adénomateuses (GRAPA) in the Rhône-Alpes region around Lyon.

Who are the participants of MDC?

This multidisciplinary approach requires an agreement among the specialties of each committee member, so that the joint decision is most beneficial for patients and/or family members when a predisposition to cancer is suspected. The analysis of the rate of participation of different specialists to the MDC meetings showed that, in the context of digestive cancers,

Fig. 2 Organization of French MDC

oncogeneticists are always present. This is probably due to the fact that they are the coordinators of the meetings. In France, oncogeneticists are physicians or biologists with specific training in clinical and laboratory genetics. All French universities offer this discipline, and some provide an opportunity to focus more specifically on cancer genetics. The other participants involved in MDCs are GCs (84 %), gastroenterologists (79 %), graduate students in medicine, pathologists/genetic biologists (36 %), and surgeons (32 %). Genetic counselors receive a masters-level diploma in France. The role of a GC includes the coordination of patient care during an initial consultation, obtaining personal and family histories, and the coordination of molecular and biological testing to the laboratory (microsatellite stability and protein immunohistochemistry test). He or she supports the activities of doctors during the consultation and serves as a liaison between the clinical follow-up of patients and the genetics laboratory.

Some other professions, such as secretaries, medical laboratory technicians, radiologists, or fundamental researchers, occasionally participate (Fig. 3a). In the specialty of colon cancers, gynecologists are not directly implicated in the initial diagnosis and patient follow-up. Traditionally, in France, the physicians/surgeons involved in the diagnoses and treatments of a specific cancer refer patients and relatives for screening, and, therefore, work in close relation with oncogeneticists and genetic counselors.

Participation threshold for decision making

For the purposes of providing quality clinical monitoring and therapeutic management, deciding whether or not to pursue genetic testing in a given patient's case requires a quorum of the various specialists involved in the MDC. We determined from our investigation that a minimum of three skills are necessary for optimal decisions making. Indeed, we observed that when members from less than two specialties are involved, MDCs are not organized and centers do not talk about MDCs. As shown on Fig. 3b, among the seven categories of experts, less than 15 % of MDCs bring together representatives of five or more specialists, about 30 % of MDC meetings involve members from four specialties, and 40 % only involve three specialty representatives.

What is the frequency of MDCs in France?

The frequency of MDC meetings in French centers was shown to vary from monthly meetings in the majority of cases (>61 %), to bimonthly (<27 %), and four times a year (<12 % of centers). In some geographic areas, the MDC are scheduled two to three times per year or when required for a specific group of patients and/or families. In Lyon, for example, the meetings of the FAP-specific multidisciplinary group, GRAPA, are organized twice a year (Fig. 3c).

Fig. 3 Main results of the investigation

Which cases are followed in MDC, and what is the objective of MDC?

All centers report reviewing cases, but, globally, only 20 % of centers discuss all patient cases that are suggestive of a pre-disposition to digestive tumors. The typical or obvious cases are directly approved for genetic testing by oncogeneticists. So, a selection of cases for discussion by the MDC is generally made. The clinicians' busy schedules, as well as human and technical resources (videoconferencing material for example), could explain this need for selection. Furthermore, depending on the clinical center, the heterogeneity of strategies used in multidisciplinary management, the geographic localization, and the size of hospitals may all contribute. These arguments are highlighted in the commentary that accompanied the completed questionnaires.

More than half of centers (55 %) are only interested in borderline clinical situations in a familial context or when a familial predisposition was highly suspected, where Amsterdam/Bethesda criteria are met but for which we have methodological difficulties, suggesting that tools must be developed. For example, what to do for a family covering Amsterdam criteria but where the potential index cases are not available to be tested? Should a center propose a genetic test for a proband having no cancer and for every relative?

Some centers (19 %) restrict their cases to those probably leading to the patient/family follow-up and care management, and some others (4 %) only use MDC for achievement of genetic testing validation.

We more globally observed that, in the current situation, over 50 % of patients and/or related family members benefit from the MDC. The results of the questionnaires, thus, show that in less than the half of the cases, decision making is performed by clinicians and oncogeneticists without the need for the MDC, since these cases are deemed to be more typical.

Discussion and conclusion

This study shows that this practice is steadily planned by teams of experts so as to give an added value to the monitoring of a given case with the presence of a large panel of experts (oncogeneticists, gastroenterologists, genetic counselors, biologists, surgeons, etc.). French practice conforms to the definition of multidisciplinary. It is difficult to standardize MDC, probably since genetics is an evolving field. Another possible reason for this lack of uniformity in practice may be the lack of time (cases are selected beforehand in the majority of centers) and technical hurdles, which may be resolved through videoconferences for instance. The true goal of MDC is the

improvement and optimization of patient care. Thus, MDC will be useful in cases of rarer pathologies (like for breast and ovarian cancer predisposition, planned twice a month in our clinical center in Lyon).

In France, the personalized monitoring of cancer patients and the importance of multidisciplinary are crucial in medical practice. The first essential question in hereditary cancers, including cancers of the colon as in our study, is the decision making of whether to offer genetic analysis. This decision is primarily based on Amsterdam criteria and Bethesda Guidelines but is often complex, given the number of genes involved in FAP (2; *APC*, *MYH*) and HNPCC (>6; *MMR*). The other critical question is the care management and therapeutic follow-up recommendations for the patient and its family. Less than 20 % of all clinical centers discuss all clinical cases. The balance between quality of MDC on selected patients and the complexity of the management of unselected patients is difficult to establish. Our results show that videoconferencing is widely used in centers wishing to bring together regional experts and some hospitals as in Grenoble since 2001 (Guillem and Cancer 2011).

In this study, it also appears important to consider two categories of cases as follows: (1) homogeneous groups of patients presenting Amsterdam/Bethesda criteria and (2) groups of patients having a clinical presentation that do not meet these criteria and that may present difficulties and problems of differential diagnosis. It is important to standardize professional practices and promote homogeneous decision making by MDC. Monitoring and adapting patient follow-up thanks to national guidelines might be facilitated by enforcing the means and the progressive computerization and networking of regional consultations.

Based on this local experience, it seems also interesting to perform a study at the national level with the aim to achieve an assessment and improvement of global decision making and genetic counseling organization. Our work provides us some

guidelines to improve our efficiency and maybe, in a further goal, to define some quality criteria.

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