FROM NURSE TO NODAL POINTS

The Rationale of a Questionnaire and Database to Collect, Validate and Exchange Information on Familial Cancer

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ABSTRACT

The process, by which information on cases of cancer among relatives of probands with malignancies will be transmitted from sources to the Nodal Points of the UICC Familial Cancer and Prevention Project (FCPP), requires the compilation of a standard questionnaire. The subsequent stage involves data coding and transferring to a relational database which allows information exchange within the FCPP framework.

Key words: Cancer; family history; questionnaire.

INTRODUCTION

Aggregation of cases of cancer in families may be caused by chance association, inherited genetic mutations, common exposure to environmental agents or a combination of these factors. Studies on familial cancer are a key to understanding the gene-environment interactions and the mechanisms of carcinogenesis. They also make it possible to identify persons at high risk of cancer and to take targeted preventive and therapeutic measures (1).

THE FAMILIAL CANCER AND PREVENTION PROJECT

The Familial Cancer and Prevention Project (FCPP) (Chairman: Dr. W. Weber) is one of the seven projects of the Program for Epidemiology and Prevention (Chairman: Dr. S. Tominaga) of the International Union Against Cancer (UICC). It will consist of an international database

network and a worldwide information exchange system (2). Its nucleus are the three Nodal Points: one in Japan for Asia and Oceania (Chairman: Dr. J. Utsunomiya), one in the U.S.A. for North America (Chairman: Dr. J.J. Mulvihill), and one in Switzerland for Europe and Africa (Chairman : Dr. W. Weber). The FCPP objectives are summarized in Table 1.

THE FAMILY HISTORY CODE SHEET

Since the first FCPP preparatory meeting held in 1991 in Lugano, Switzerland, there has been a general agreement on developing a standard questionnaire to collect, validate and exchange information on familial cancer (3).

In 1992 G.N. Stemmermann, on behalf of the FCPP, developed the "Family History Code Sheet" (Table 2) as a tool to obtain information from cancer patients on the occurrence of malignancies among their first-degree relatives, and to validate the information by comparing them with data stored in a general population-based cancer registry covering the patients' area of residence.

On the code sheet the interviewer enters the proband's and relatives' names and cancer diagnosis in longhand, while a cancer registry clerk writes the code of the malignancies as it is recorded in the registry file, according to the ninth revision of the International Classification of Diseases (ICD-9) (4).

In 1992 the "Family History Code Sheet" was used by Stemmermann at the Kuakini Medical Center, Honolulu, Hawaii, to interview 40 unselected cancer patients (probands). Information on cases of cancer among their 333 first-degree relatives was compared with data from the Hawaii Tumor Registry (5). Out of the 33 cases of cancer reported by probands 17 were true positive and 16 false positive. Moreover, it was discovered that 14 cases had not been reported by probands. The information provided by probands showed a specificity of 95% and a sensitivity of 52%.

THE PILOT STUDIES IN BASEL AND TRIESTE

Information on malignancies among first-degree relatives was collected from unselected probands in Basel, Switzerland, by Mussio and Weber during 1993, and in Trieste, Italy, by Brunetti and coworkers during 1994 (Table 3). This was then compared with the data stored in the respective general population-based cancer registries (5, 6).

The information supplied by probands showed a high accuracy (Table 4). These results were in accordance to those reported by other studies (7-10), which, however, documented a lower accuracy of information on cancers that occurred in second- and third-degree relatives (7, 9).

THE FCPP NETWORK

Through the dissemination among scientists of information on cancer aggregation in families and of biologic specimens in order to improve the knowledge on gene-environment

interactions in cancer aetiology, the ultimate goal of each FCPP Nodal Point is to help the greatest number of nurses and general practitioners (GPs) all over the world in cancer control activities.

In the information flow from families to scientists, and in the flow of new discoveries from scientists to families, nurses and GPs are the keystones of this network (Fig. 1). Only they are able to ensure that the information flow keeps up-to-date in the most cost-effective way. This is because families are dynamic groups, environmental exposures modify in time as well as the health status of each person. At the same time, they can transfer to their patients, without excessive delay, the new knowledge received from scientists through the Nodal Points.

THE FCPP QUESTIONNAIRE AND DATABASE FOR COLLECTING FAMILY DATA

We suggest that the FCPP questionnaire should consist of four areas of information (Table 5), and should be tailored to GPs' and nurses' requirements. Each area corresponds to a relational database compiled with a public domain program, *e.g.*, Epi Info (11).

The FCPP network as a whole and the questionnaire in particular (Table 6) should be validated by a pilot study.

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Table 1. Objectives of the UICC Familial Cancer and Prevention Project

- Use of the family history for cancer control

- Exchange of information, biological material, skills and expertise

- To examine controllable causative factors for familial cancer

- Encouragement of genetic-epidemiology, preventive and therapeutic research

- Discussion of ethical, legal, economic and psychosocial considerations

- To disseminate recent advances in familial cancer studies through a newsletter

Table 2. Sample of the "Family History Code Sheet"

Relationship code ☐ ☐

Relative's name: _____

Date of birth: ☐ ☐ ☐ ☐ ☐ ☐

Cancer(s): _____ _____

ICD-9 ☐ ☐ ☐ . ☐   ☐ ☐ ☐ . ☐

Age at diagnosis (yrs) ☐ ☐ ☐   ☐ ☐ ☐

Relationship code ☐ ☐

Relative's name: _____

Date of birth: ☐ ☐ ☐ ☐ ☐ ☐

Cancer(s): _____ _____

ICD-9 ☐ ☐ ☐ . ☐   ☐ ☐ ☐ . ☐

Age at diagnosis (yrs) ☐ ☐ ☐   ☐ ☐ ☐

Relationship code ☐ ☐

Relative's name: _____

Date of birth: ☐ ☐ ☐ ☐ ☐ ☐

Cancer(s): _____ _____

ICD-9 ☐ ☐ ☐ . ☐   ☐ ☐ ☐ . ☐

Age at diagnosis (yrs) ☐ ☐ ☐   ☐ ☐ ☐

Proband's name: _____

Date of birth: ☐ ☐ ☐ ☐ ☐ ☐

Cancer(s): _____ _____

ICD-9 ☐ ☐ ☐ . ☐   ☐ ☐ ☐ . ☐

Date of diagnosis: ☐ ☐ ☐ ☐ ☐ ☐   ☐ ☐ ☐ ☐ ☐ ☐

Table 3. Information on first-degree relatives supplied by probands interviewed in Basel, Switzerland, and Trieste, Italy

	N. of probands	Total N. for whom data were obtained		Total N. verified	
		Relatives	Cases	Relatives	Cases
Basel	64	375	50	207	23
Trieste	193	752	115	611	99

Table 4. Accuracy of information supplied by probands on cases of cancer among first-degree relatives

	Sensitivity (%)	Specificity (%)	Overall accuracy (%)
Basel	74	97	94
Trieste	85	97	95

Main Goals

Reduction of hospitalization costs. Investment for health promotion, disease prevention and research

Reduction of mortality from cancer

Cancer prevention

Better definition of family problems related to cancer

Increasing of knowledge

Main Activities

To draw up laws which define who are the "keepers" of the genetic information and how the information is to be used

Informed cooperation

History taking. Updating information. Collection of biologic specimens

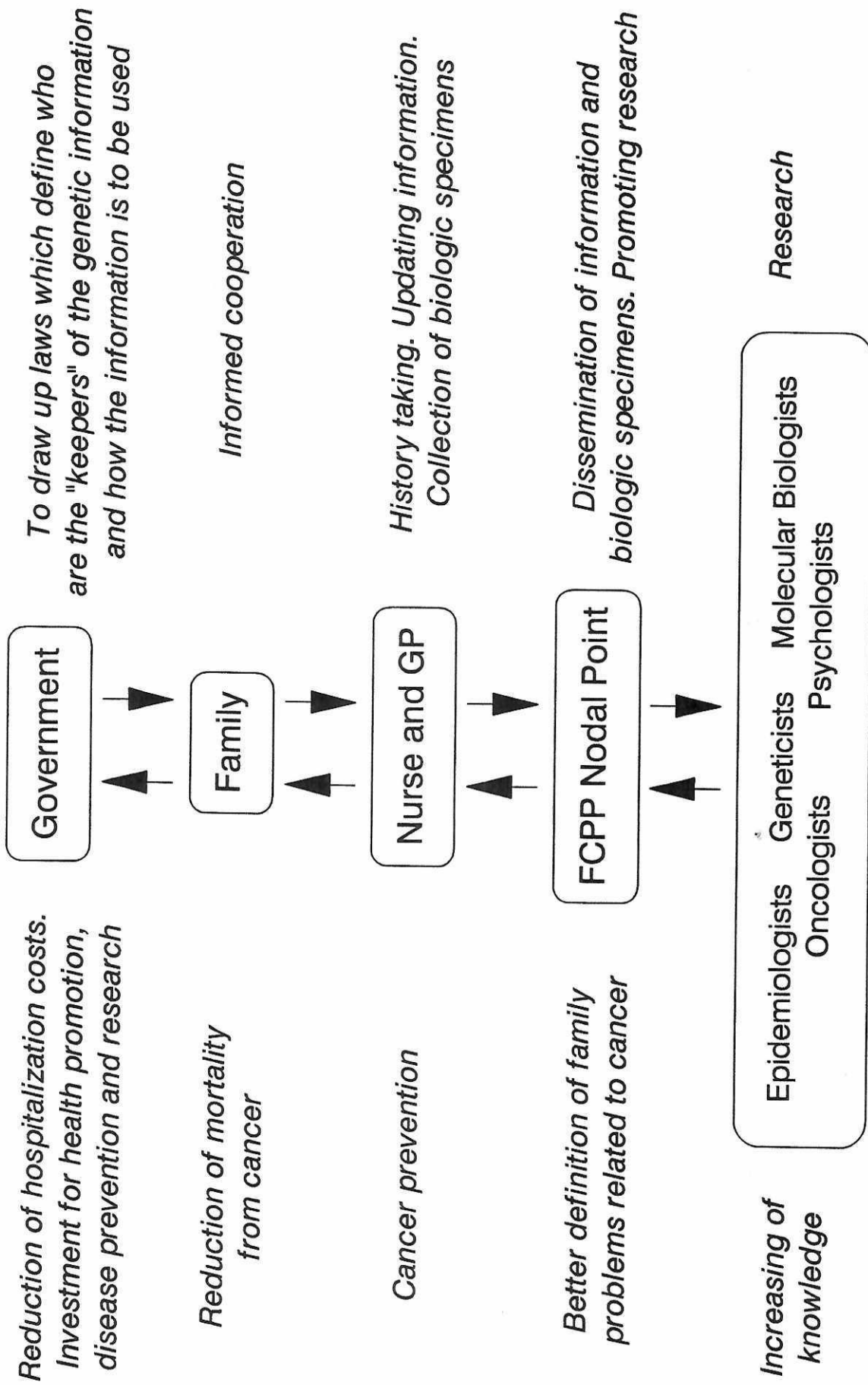*Dissemination of information and biologic specimens. Promoting research*

Research

Government → Family → Nurse and GP → FCPP Nodal Point → Epidemiologists Geneticists Molecular Biologists Oncologists Psychologists

Fig. 1. The FCPP network

Table 5. Areas of information covered by the FCPP questionnaire for collecting family data

- General information on proband/relative

- Malignant and benign neoplasms
  Place where biologic specimens are stored

- Comorbidity

- Environmental exposure

Table 6. Designing and testing stages of the FCPP questionnaire for collecting family data

Stage	
1	First version and user's guide
2	Pilot study
3	Analysis of pilot study results
4	Final version