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# Living with a Hereditary Form of Cancer: Experiences and Needs of MEN 2 Patients and Their Families

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*Unlike the purely medical research done in multiple endocrine neoplasia type 2 (MEN 2) families, little work has been done on the psychosocial aspects of the disease. To assess the severely stressful influences and the consequences of that stress on the family network, a small-scale survey was carried out during a national meeting. The goal of the study was to obtain more information about the experiences and needs of MEN 2 patients and their relatives. Of the 59 respondents, 85% were satisfied with the medical information provided, 81% were satisfied with the medical knowledge of the specialist, but only 12% were satisfied with the medical knowledge of the general practitioner regarding MEN 2. Furthermore, 63% of the parents had difficulties in talking about the disease with their children. The need expressed for contact with fellow sufferers and their families is expected to lead to the establishment of an interest group for MEN 2 families. (Henry Ford Hosp Med J 1989;37:164-6)*

In November 1987 a working group composed of patients, partners of patients, and two professionals was formed. This group was formed because of the expressed need for answers to questions from families of multiple endocrine neoplasia type 2 (MEN 2) patients in the outpatient clinic of the Utrecht University Hospital and the desire for contact with other families in the same situation. A short preliminary questionnaire was distributed to members of these families. Approximately 40 relatives responded and indicated that they would be interested in attending a nationwide information day. The results of this survey led the working group to organize a nationwide project intended primarily to provide medico-technical information and to exchange experiences. The preparation for this national meeting took almost one year, and the first national day for MEN 2 families in The Netherlands was held in October 1988. A total of 74 first-degree relatives including nine children under the age of 15 years participated. All the participants were requested to complete a questionnaire. In this way the working group hoped to get an impression of the experiences and needs of MEN 2 families to identify those areas that require special attention (1-6).

The survey was designed to find answers to the following questions:

1. Are MEN 2 patients and their families satisfied with the medical information and the guidance they receive? What are the reasons for their satisfaction or dissatisfaction?
2. Where and to what extent are problems encountered in talking about the disease in their social network?
3. What forms of contact pertaining to MEN 2 are considered desirable by the patients and their relatives? In what activities do they wish to participate?

In this article we will discuss mainly the answers to questions 1 and 2.

## Background Data of the Respondents

### Sociodemographic data

The questionnaire was completed by 59 relatives. The study group included 23 men (39%) and 36 women (61%). The age range of the respondents was 11 to 74 years, with a mean age of 40 years. No significant age difference was noted between patients and nonpatients. Forty-five (76%) of the respondents were married or living with a partner, ten persons were single, three were widowed, and one was divorced.

Of the 59 respondents, 32 were patients. Of the 27 who were relatives or partners of the patients, four were at risk and 23 were not at risk. The low percentage of the at-risk group is striking, since the proportion in the population at large is higher.

### First contact with MEN 2

The respondents had been informed of the disease for an average of seven years. Two respondents had known about the disease since 1975, and 27% of the respondents had known since before 1980. In most cases the respondents had been informed

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**Table**  
**Sources of Learning About the Hereditary Character of MEN 2**

Source	Respondents			Total
	Patient	At Risk	Not At Risk	
General practitioner	1			1
Specialist	20		10	32
Partner/family	11	2	12	25
Literature			1	1
Total	32	4	23	59

about the hereditary character of MEN 2. The majority of the cases (56%) had been informed by a specialist and 41% by a relative (Table).

## Results

### Satisfaction with medical contact

Regarding the expertise of the specialist, 98% were satisfied and only 2% were dissatisfied (Fig 1). In general the respondents were very satisfied with the contact with the specialist.

The various aspects of the yearly screening were evaluated positively by 86%, but 12% were not satisfied, and 24% expressed extremely negative opinions regarding how they were informed of the screening results. The main objections included prolonged delay of reporting of the results, insufficient information about the meaning of the results, and inadequate handling of the children at the screening.

Regarding contact with the general practitioner, 71% were satisfied or very satisfied and only 14% were very dissatisfied. Some relationship was found between the satisfaction with the functioning of the general practitioner and the estimate of his expertise ( $r = 0.25$ ,  $P = 0.04$ ). No difference was found between the patients and nonpatients regarding their satisfaction with the general practitioner.

Regarding how they had been informed about MEN 2, 85% were satisfied or very satisfied and 10% were dissatisfied.

### Ability to talk about MEN 2

Of the 80% of respondents who had a partner, 70% found it easy or very easy to talk about the disease and 26% found it neither difficult nor easy to talk about practical matters. Difficulties were encountered in speaking about fears and uncertainties about the disease and about anticipation of the birth of children. In 63% of the cases, the respondents had one or more children. Of this group, 37% found it neither difficult nor easy and 26% found it difficult to talk about the subject. In the contact with their children, parents found it easier to talk about practical matters than about emotional problems. Serious problems were not mentioned. Of the 88% who had relatives other than spouses or children, 41% found it easy to talk about the disease within the family, 27% found it difficult to very difficult, and 31% formed an intermediate category. It was considered especially difficult to explain the medical aspects of MEN 2 to acquaintances and people at work. In general respondents found it more difficult to talk about the disease with persons outside the family than with

### Kind of Contact

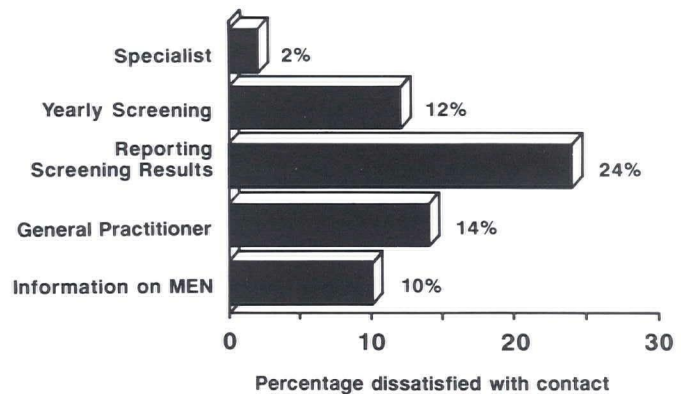


Fig 1—Percentage of patients dissatisfied with medical contacts.

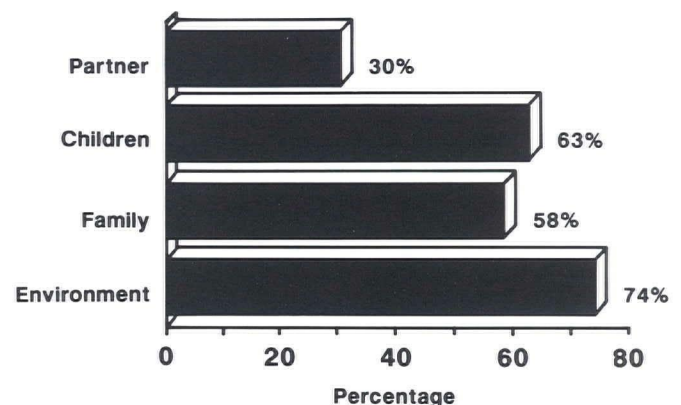


Fig 2—Percentage of patients having difficulties in discussing illness.

relatives (Fig 2). The ability to talk about the disease inside and outside the family was closely related to the estimated knowledge of the general practitioner ( $r = 0.45$ ,  $P = 0.009$ ).

## Conclusions

In general the respondents were satisfied with the information about MEN 2 supplied by physicians. This satisfaction seemed to be proportional to the expertise and the competence of the care provided. The evaluation was usually positive concerning both the specialist's knowledge about the disease and contact with the specialist in general.

The various aspects of the yearly screening itself were evaluated positively, but many of the respondents were less satisfied about the reporting of the results.

There was little contact with the general practitioner about the disease since the specialist played a central role. However, even though there was great satisfaction with the functioning of the general practitioners, their limited knowledge of the disease was

found to be correlated with the problems in talking about the disease both inside and outside the family.

More than one-third of the respondents considered talking about the disease with their social network difficult to very difficult but relatively easy with the partner. Problems with the partner were mainly in emotional areas; it is sometimes difficult for a patient to share insecurities and fears with someone who is closely involved with him or her but who is not at risk.

It is more difficult to talk to children about the disease. In such contact the emphasis is mainly on providing information. Some respondents felt that they knew too little to be able to explain matters well to their children.

The study showed clearly that patients and nonpatients were equally involved in the problems associated with MEN 2.

This study provided a broad base for organization of MEN 2 interest groups.

### Recommendations

The formation of national interest groups should be stimulated. The interest group should supply information to general practitioners. The first step toward solving the problems associ-

ated with reporting of the yearly screening could be to discuss these problems with MEN 2 specialists. Contact with fellow sufferers should be facilitated. Patients and nonpatients equally should be informed and involved in the activities pertaining to MEN 2.

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