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# Psychological Effects of Participation in a Prevention Programme for Individuals with Increased Risk for Malignant Melanoma

Yvonne Brandberg, Mia Bergenmar, Christina Bolund, Eva Månsson-Brahme, Ulrik Ringborg, Per-Olov Sjøden

The Swedish Melanoma Study Group runs a programme aimed at prevention and early detection of premalignant and malignant melanoma in families with two or more members having malignant melanoma. Psychological consequences of participation in this programme were studied. A questionnaire containing items concerning cognitive and emotional responses to the programme was completed by 115 consecutive individuals at their first visit to the clinic. The same questionnaire was administered by mail 7 months later. The levels of psychological and psychosomatic problems were relatively low at both points of assessment. No negative psychological effects were found, neither in the group with dysplastic naevus syndrome (DNS) with increased risk for malignant melanoma, nor in the group without dysplastic naevi. Only one variable, "emotional responses to the visit" differentiated between the groups, with higher scores in the group without DNS. A majority of the individuals expressed positive attitudes to the clinic.

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## INTRODUCTION

PREVENTION AND early detection of malignant diseases is a new and growing field in oncology. The aim is to identify individuals having an increased risk of developing a malignant

disease in order to allow primary prevention and treatment of the disease at an early stage [1]. Healthy persons will be informed of their increased risk of developing a life-threatening disease, and medical procedures will be recommended for some. This information and suggestions of preventive medical

procedures may entail psychological effects. Previous research in this field has been sparse [2].

Research concerning psychosocial consequences of measures taken on account of an increased risk is of high concern for a variety of reasons: to increase the knowledge about how individuals cope with having an increased risk; to design medical procedures so as to minimise the negative psychological effects; to provide interventions directed at such effects and to highlight the ethical problems of informing individuals about their increased risk of a life-threatening disease.

Research on psychological effects of preventive procedures in high risk groups has dealt primarily with participation [3–5] and compliance [6–8]. In some studies, however, the main topic has been effects of information about risk [9, 10].

The increase in incidence and mortality due to malignant melanoma has promoted the implementation of screening programmes [1]. Recent studies of families with hereditary malignant melanoma [11] show an almost 100% life-time risk for developing the disease in individuals with dysplastic naevus syndrome (DNS), defined as familial aggregation of dysplastic naevi among members in a family with two or more members with malignant melanoma.

The Swedish Melanoma Study Group currently runs a care programme for cutaneous malignant melanoma. All new melanoma cases in the Stockholm–Gotland area are recorded in the Regional Cancer Registry, and follow-up takes place at the Department of General Oncology at the Karolinska Hospital. This allows identification of families with hereditary melanoma and DNS. 97 families had been identified by August 1991.

A pigmented lesion clinic for the members of melanoma families was organised at Radiumhemmet in 1987. The aims are primary and secondary prevention of malignant melanoma. The probands (the melanoma patients) inform their family members about the DNS clinic. The family members are then invited, usually by letter, to the clinic for a medical examination, which includes skin examination, photographic registration of dysplastic naevi, excision of at least one dysplastic naevus for histological diagnosis and information about malignant melanoma, self-examination and sun protection. At the first visit, family members with DNS are recommended regular skin examinations at the clinic every third or sixth month with the motivation that there is a risk of developing malignant melanoma from dysplastic naevi when you have a family history of this disease. Family members without DNS are not followed. The time scheduled for the first visit is 45 min and 30 min for follow-ups.

The present study reports on psychological consequences of the information and of the medical procedures. The following questions were investigated: are there differences in psychological reactions between a group of persons having high risk of developing malignant melanoma (group DNS) and a group without such a risk (group O)? Are there differences in psychological reactions between the first visit and 7 months later?

## METHODS

### Subjects

The study included all family members ( $n=120$ ) between 20 and 70 years of age (mean 37) visiting the DNS clinic for the first time for skin examination in February 1988–March 1990. Individuals with malignant melanoma or other cancer diagnoses were excluded. 5 family members (4%) rejected participation in the study at their first visit.

The final study sample included 115 members of 47 families, 67 women (58%) and 48 men (42%). 70 family members (61%), 39 women and 31 men had DNS. 45 persons (39%), 28 women and 17 men, had no dysplastic naevi, group O. There were no differences between the groups with respect to gender and age. 108 family members (94%) participated by mail in a second assessment, 65 from group DNS and 43 from group O.

### Procedures

Interviews were carried out by a psychologist at the first visit to the DNS clinic, before the medical examination. At that time, the family members did not know whether they had DNS or not. The time to complete the interview and to fill out the questionnaire was about 15 min. The same questionnaire was sent to both groups 7 months after the first visit.

### Instrumentation

The questionnaire, containing 51 items, devised to suit healthy persons and to reveal mild signs of psychological reactions, was tested in a pilot study with 10 family members and found feasible.

*Satisfaction with information.* The family members were asked about satisfaction with information, whether they desired more extensive information and, if so, of what kind. Two items had “yes” or “no” as possible response alternatives, and the last item was open-ended.

*Knowledge of relatives with malignant melanoma.* In order to study to what extent the family members knew which relatives had malignant melanoma, they were asked, “Do you have any relatives with malignant melanoma?” Six categories were provided, parents, siblings, grandparents, siblings of parents, cousins and ‘other’. Data concerning heredity was collected from patient files.

*Emotional responses to the visit.* Five items regarding anxiety, fear and tension at the time of the invitation to the clinic and at the first visit were included in both questionnaires. Five alternative responses were given from ‘not at all’ to ‘very much’ with scores from 0 to 4. The family members were also asked to express their attitudes towards the clinic in an open-ended item.

*Interest in naevi.* “Has your interest in your naevi increased since the information about the DNS clinic?” Five alternative answers were provided from ‘not at all’ to ‘very much’.

*Sick-listed time and medical consultations.* “How many times and for how many days have you been home from work due to illness during the last 6 months?” and “How many times have you consulted a medical doctor during the last 6 months?” Answers were given in four and five categories, respectively.

*Psychological and psychosomatic variables.* Items dealing with physical and psychosomatic complaints and sleep disturbances constituted the following five variables: fatigue (four items with

Correspondence to Y. Brandberg.

Y. Brandberg, M. Bergenmar, C. Bolund, E. Månsson-Brahme and U. Ringborg are at the Department of Oncology, Karolinska Hospital, S-104 01 Stockholm, Sweden; and P.-O. Sjöden is at the Centre for Caring Sciences, Uppsala University, Uppsala, Sweden.

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scores 0–4 regarding weariness, physical condition, dizziness and headache); sleep disturbances (five items with scores 0–5, regarding insomnia, repeated awakenings during the night, restless sleep and nightmares); tiredness (three items with scores 0–5, dealing with difficulties to wake up, not feeling thoroughly rested, and tired at work); psychosomatic complaints (four items with scores 0–4, concerning pain, memory, difficulties in concentration and feeling weak); and nausea (three items with scores 0–4, regarding nausea, non-ulcus dyspepsia and loss of appetite).

The Hospital Anxiety and Depression Scale (HAD)[12], designed for the purpose of detecting anxiety and depressive problems in patients visiting medical hospital out-patient clinics, was included in the questionnaire. The HAD scale is composed of 14 items, seven for anxiety and seven for depression with scores 0–3. It has been found to be a valid instrument [13, 14].

The questions concerning 'satisfaction with information' and 'knowledge of relatives with melanoma' were given as a structured interview at the first visit, and were included as part of the mailed questionnaire. The other items were completed in self-rating form on both occasions.

#### Statistical methods

The Sign test [15] was used to test differences with respect to 'satisfaction with information'.

$\chi^2$  test [15] was employed for evaluating differences in 'knowledge of relatives' and 'sick-leave and medical consultations'. Analyses of variance were performed to test differences between the groups and between points of assessment, as well as their interaction on variables 'emotional responses to the visit', 'concern for naevi' and 'psychological and psychosomatic variables'.

## RESULTS

#### Satisfaction with information

89 family members (86%) obtained information about the visit from a relative and 14 were informed through mass media and called the clinic on their own initiative. The first 10 persons included in the study did not receive this item and 2 persons could not remember.

86 family members (86%) were satisfied with the information about the clinic at the first visit, but 25 individuals (25%) would have preferred more extensive information. The proportion satisfied with the information increased significantly to 102 individuals (97%) in the second questionnaire ( $P < 0.05$ , Sign test). The proportion who would like extensive information decreased from 25 (25%) to 13 family members (13%) ( $P < 0.05$ , Sign test). No differences between groups were found, either concerning satisfaction with information, or desire for further information ( $\chi^2$ ). 15 individuals failed to complete this item at the first visit and 10 did so in the second questionnaire.

#### Knowledge of relatives with malignant melanoma

45 persons (44.6% at the first visit, and 43.7% in the second questionnaire) could correctly indicate their relatives with malignant melanoma. The number of correct and incorrect answers in each category was calculated (Fig. 1). Replies not reporting on actual relatives with melanoma, or reporting false positives were regarded as incorrect.

There were no differences in knowledge between the first and the second questionnaire, or between groups ( $\chi^2$ ). The knowledge of closely related melanoma patients (parents and siblings) was high (>80%), while the knowledge of "other relatives" was poor (<40%). The proportion of incorrect replies

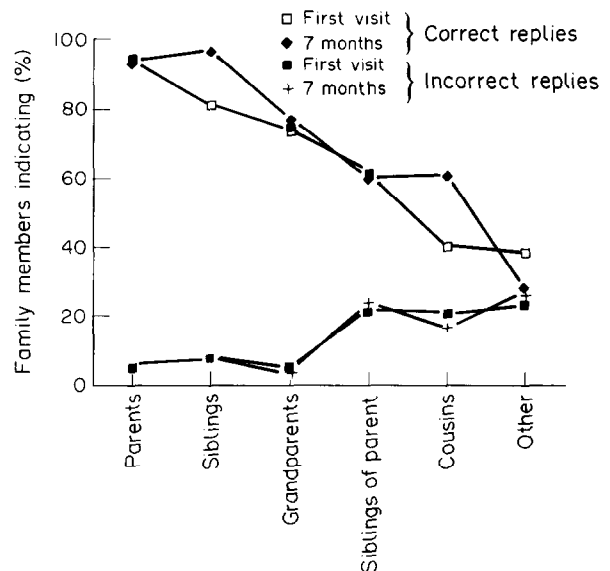


Fig. 1. Knowledge about relatives with malignant melanoma on two occasions

in this category was also high (>20%). 10 persons in the first interview, and 8 in the second questionnaire did not answer this item. Data were missing for 4 persons.

#### Emotional responses to the first visit and attitudes to the clinic

The scores on the second questionnaire represent retrospective data. They were asked about the responses to the first visit. Although these mean scores indicated low levels of emotional responses, they were significantly higher than at the first visit [ $F(1,88)=8.02$ ,  $P < 0.01$ ]. In both questionnaires, mean scores were higher for group O (0.677 and 0.881) than for group DNS (0.443 and 0.528). The between group difference was significant [ $F(1, 88)=4.77$ ,  $P < 0.05$ ]. No interaction was found between groups and points of assessment.

A majority of the family members expressed positive attitudes to the DNS clinic on both assessments. 84 individuals (78%) answered this item in the second questionnaire. They all expressed positive attitudes. 24 individuals (22%) were positive to prevention, 8 to medical check-ups and 7 to information. 2 patients were positive but pointed out that the procedures could cause unnecessary anxiety.

#### Interest in naevi

A decrease in the proportion of individuals 'not interested at all' was seen from the first to the second questionnaire. The interest in naevi increased [ $F(1, 96)=17.9$ ,  $P < 0.0001$ ] (Fig. 2). Mean scores at the first visit were 1.12 for group DNS and 1.13 for group O. Corresponding figures after 7 months were 1.50 and 1.67. No differences were found between the groups.

#### Sick-listed time and medical consultations

No differences were found, either between groups or between the first and second questionnaire ( $\chi^2$ ) (Table 1). A majority reported less than three visits and there were no differences between groups or points in time ( $\chi^2$ ) (Table 2).

#### Psychological and psychosomatic variables

The means for all variables were low (Table 3). No differences were found for the following seven variables either between

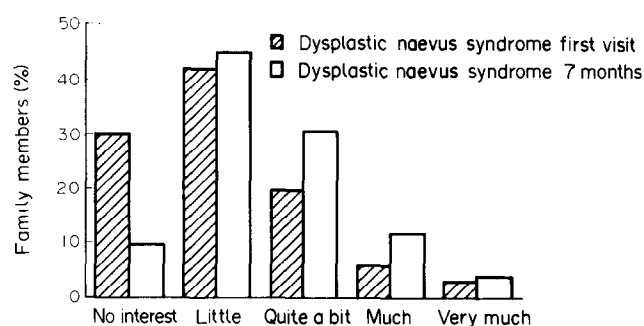


Fig. 2. Percentage of family members responding on each response alternative to item, "Has your interest in your naevi increased since the information about the DNS clinic?" on two occasions.

groups or between points of assessment: fatigue, sleep disturbances, tiredness, psychosomatic complaints, nausea, anxiety (HAD) and depression (HAD).

### DISCUSSION

The assumption that the information of heredity increased risk of developing a life-threatening disease, and the recommendation of medical procedures might entail negative psychological effects was not confirmed. On the contrary, many individuals expressed positive feelings towards the DNS clinic and a sense of security in being monitored regularly by professionals. The mean scores were low on all psychological variables in both groups. Regular inclusion of individuals in a follow-up programme entailing visits to the DNS clinic every 3 or 6 months did not seem to give rise to sleep disturbances, psychosomatic complaints, anxiety or depressive symptoms. These findings are consistent with results from studies showing that care givers systematically overestimate the degree of patients' distress as compared to patients' self-assessments [16, 17].

Many family members expressed the opinion that the regular visits to the DNS clinic was a way to cope with having moles and the knowledge of close relatives with malignant melanoma. Individuals in group O had no dysplastic naevi but their emotional response at the first visit were stronger than those in group DNS. The provision of practical coping advice might have resulted in reduction of the already existent interest in naevi in group DNS. No such interest ought to have been present in group O. The focus on malignant melanoma might have been more frightening for them, not having to cope with dysplastic naevi, although having a history of malignant melanoma in the family.

The information given during visits was formulated in positive terms and designed to be reassuring: "We check on your moles regularly and if any change in moles occurs, it can be detected at a very early stage." The information included instructions for

Table 1. Time off work

Time	First questionnaire (%)		Second questionnaire (%)	
	DNS	O	DNS	O
Not sick-listed	33 (50.8)	17 (39.5)	33 (53.2)	16 (39.0)
≤ 1 week	26 (40.0)	21 (48.8)	20 (32.3)	19 (46.3)
> 1 week–1 month	5 (7.7)	2 (4.7)	7 (11.3)	5 (12.2)
> 1 month	1 (1.5)	3 (7.0)	2 (3.2)	1 (2.4)

Table 2. Medical consultations during the last 6 months

Number of consultations	First questionnaire (%)		Second questionnaire (%)	
	DNS	O	DNS	O
None	38 (54.2)	30 (66.8)	36 (56.3)	25 (58.1)
1–2	23 (32.9)	11 (24.4)	24 (37.5)	15 (34.9)
3–4	9 (12.9)	2 (4.4)	2 (3.1)	3 (7.0)
> 4	0	2 (4.4)	2 (3.1)	0

self-examination and sun protection, giving the family members advice on how to take action against the threat. The satisfaction with information was high compared with other studies [18]. Relevant information concerning actions to be taken is essential when counselling persons who have family histories of cancer [19]. Most family members met the same doctor on both occasions with enough time scheduled to allow the family members to ask questions. The increase in interest in naevi in both groups indicates an effect of the information about self-examination.

The family members were aware of malignant melanoma in close relatives, but the knowledge concerning cousins and "other relatives" was much less, which is consistent with the findings from a study of the accuracy of patient report of a family history of cancer [20]. In that study, 121 self-referrals to a cancer prevention clinic for individuals who had at least two relatives with cancer were asked to identify these relatives with cancer. Adequate replies were obtained for 90% first relatives with cancer, 65% for second degree and 49% for third degree relatives.

A new questionnaire was constructed since no instrument was available for the group of persons focused on here. The validity and reliability of this instrument as well as its sensitivity in detecting mild signs of psychological distress should be ascertained. The method of constructing the instrument entailed reviewing the literature and interviewing staff and patients. All the family members were asked five questions regarding the questionnaire at the end of the interview at the first visit. They considered the items to be relevant, easy to answer and not anxiety provoking. This implies a certain face validity. A currently running study uses a similar instrument in a group of patients with malignant melanoma.

This study was carried out at one specific DNS clinic which decreases the generalisability to other clinics. Similar studies are currently carried out at two other DNS clinics in Sweden.

Table 3. Group means on psychological and psychosomatic variables on two assessments

Variable	Group DNS		Group O	
	First visit	7 months later	First visit	7 months later
Sleep disturbances	0.90	0.83	0.86	0.84
Tiredness	1.68	1.82	1.43	1.33
Somatic complaints	0.35	0.40	0.26	0.24
Fatigue	0.77	0.79	0.81	0.60
Nausea	0.14	0.14	0.24	0.18
Anxiety (HAD)	0.67	0.68	0.63	0.60
Depression (HAD)	0.33	0.36	0.26	0.27

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# Fulminant Hepatic Failure in Non-Hodgkin Lymphoma Patients Treated with Chemotherapy

Lay-Tin Soh, Peng-Tiam Ang, Ivy Sng, Eu-Jin Chua and Yong-Wan Ong

**Chemotherapy is the mainstay of therapy for patients with non-Hodgkin lymphoma. Among side-effects associated with the use of chemotherapy, immunosuppression is one which can be potentially fatal. In hepatitis B carriers, immunosuppression permits widespread infection of the hepatocytes and its subsequent withdrawal causes an "immunological rebound" leading to massive necrosis of hepatocytes. 4 patients who died of fulminant hepatitis following chemotherapy are reported. These were patients with positive hepatitis B serology. Caution is advised when treating non-Hodgkin lymphoma in patients from hepatitis B endemic regions.**

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## INTRODUCTION

DESPITE ADVANCED disease, cure is the common goal sought by all who treat patients with intermediate and high grade non-Hodgkin lymphoma (NHL). This has been made possible because of the significant advances made in treatment of lymphoma over the past 15 years. The treatment of non-Hodgkin lymphoma often involves the use of chemotherapy, which, besides suppressing and eradicating the tumour, compromises the immunity of the patient. In certain groups of patients, this

immunosuppression can prove to be fatal. The following is an account of 4 hepatitis B carriers who died from fulminant hepatitis during and after chemotherapy.

## Case reports

**Case 1.** A 55-year-old Chinese man with stage IVB diffuse large cell lymphoma, was treated with MACOP-B (methotrexate, doxorubicin, cyclophosphamide, vincristine, bleomycin and prednisolone). The regimen alternates myelosuppressive with non-myelosuppressive agents weekly for 12 weeks. High-dose steroids (prednisolone, 75 mg daily) are given during this time with tailing of dose from week 10. Liver function tests prior to chemotherapy were normal except for a mildly raised alanine transaminase (79 U/l). Evaluation at the end of chemotherapy showed no evidence of residual disease. 3 weeks after cessation of chemotherapy, the patient developed lethargy, generalised malaise, jaundice and tea-coloured urine. He was

Correspondence to Lay-Tin Soh.

Lay-Tin Soh and Peng-Tiam Ang are at the Department of Medical Oncology, Ivy Sng is at the Department of Pathology, Eu-Jin Chua is at the Department of Therapeutic Radiology and Yong-Wan Ong is at the Department of Haematology, Singapore General Hospital, Outram Road, Singapore 0316.

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