

## USE OF NON-PROVEN THERAPIES

Differences in attitudes between Norwegian patients with non-malignant disease and patients suffering from cancer

TERJE RISBERG, EILIV LUND and ERIK WIST

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**A comparative study was conducted between a group of patients with non-malignant diseases in general practice and a group of cancer patients seen in the Department of Oncology at the University Hospital of Tromsø. The aim of the study was to investigate the prevalent use of 'alternative medicine', here called non-proven therapies (NPTs), among cancer patients and general practice patients, and to investigate whether there are any differences in opinion between the two groups regarding the beneficial effects of NPTs as treatment modalities for cancer. A total of 305 general practice patients and 252 cancer patients were included in the final analysis. In both groups close on 20% had been or were present users of NPTs. Among cancer patients the most preferred NPTs methods were healing by laying on of hands and faith healing. The patients with non-malignant disease expressed a more positive view on the possible benefits of NPTs in the fight against cancer than that expressed by the cancer patients. A total of 63.4% of patients from general practice stated that NPTs ought to be an option for cancer patients within Norwegian hospitals.**

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During the past ten to twenty years there has been much debate concerning the role of 'alternative medicine' or non-proven therapies (NPTs) in the treatment of cancer. The discussion has been going on within both the general population and the medical profession. The debate between supporters, followers, and practitioners of NPTs and physicians defending scientifically based medicine has sometimes been bitter and characterized by lack of will to compromise.

In contrast to these heated discussions concerning the use of benefits of NPTs in the treatment of cancer is the low level of knowledge about many aspects of NPTs use and what people, and in particular patients, think about this matter. A survey conducted in 1978 in the most

northerly part of Norway revealed that 66% of the participating population would consider using NPTs if they contracted a serious or deadly disease (1).

The use of NPTs among cancer patients was not studied on a broad scale in Norway until 1990. However, smaller studies have indicated a 15 to 50% use of NPTs (2, 3).

To obtain more information a questionnaire-based study was set up in June 1990 at the Department of Oncology, University Hospital of Tromsø (4). The use of NPTs among Norwegian cancer patients attending a special cancer treatment unit for the first time was examined. The patients' opinions on the possible effects of such treatments and to what degree NPTs should be an option in Norwegian hospitals were sought. Our aim was to discover whether there was a difference of opinion on NPTs and their use between patients suffering from cancer disease and patients with non-malignant disease consulting general practitioners. The questionnaire was therefore presented to patients with non-malignant disease attending general practices.

The initial results from this study are now presented.

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From the Department of Oncology, University Hospital of Tromsø (T. Risberg, E. Wist), and Institute of Community Medicine, University of Tromsø (E. Lund), Tromsø, Norway.

Correspondence to: Terje Risberg, Department of Oncology, University Hospital of Tromsø, N-9038 Tromsø, Norway.

**Table 1**  
*Characteristics of 305 non-cancer patients and 252 cancer patients*

|                          | Non-cancer patients |      | Cancer patients |      | p-value |
|--------------------------|---------------------|------|-----------------|------|---------|
|                          | n                   | %    | n               | %    |         |
| <b>Sex</b>               |                     |      |                 |      |         |
| Female                   | 163                 | 53.8 | 122             | 48.4 | 0.2     |
| Male                     | 136                 | 44.6 | 130             | 51.6 |         |
| Unknown                  | 6                   | 2.0  |                 |      |         |
| Mean age                 | 50.3 years          |      | 58.3 years      |      |         |
| Range of age             | 19–85 years         |      | 17–89 years     |      |         |
| Age groups (years)       |                     |      |                 |      |         |
| 10–29                    | 14                  | 4.6  | 11              | 4.7  | <0.001  |
| 30–44                    | 105                 | 35.1 | 37              | 14.9 |         |
| 45–59                    | 81                  | 28.2 | 71              | 28.2 |         |
| 60–75                    | 62                  | 22.3 | 110             | 43.7 |         |
| 75–95                    | 26                  | 9.8  | 23              | 9.1  |         |
| <b>Education</b>         |                     |      |                 |      |         |
| Public school            | 193                 | 63.0 | 184             | 74.5 | 0.008   |
| Grammar school           | 63                  | 22.0 | 29              | 11.7 |         |
| University degree        | 47                  | 15.0 | 34              | 13.8 |         |
| <b>Family life</b>       |                     |      |                 |      |         |
| Alone                    | 48                  | 15.8 | 45              | 26.2 | 0.8     |
| With partner             |                     |      |                 |      |         |
| with or without children | 247                 | 81.6 | 200             | 79.4 |         |
| Other                    | 8                   | 2.6  | 7               | 2.8  |         |

### Material and Methods

In July 1990 a longitudinal questionnaire-based study was set up in the Department of Oncology of the University Hospital of Tromsø. All in-patients at the Department of Oncology and/or patients receiving radiotherapy as out-patients, seen for the first time, who were able to read and understand the questionnaire were eligible for the study. Terminally ill patients (ECOG = 4) were not invited to participate, and only patients who gave informed consent were included. The questionnaires were handed out to the patients by their physician on arrival at the hospital. The questionnaire took the form of multiple choice questions but the patients were invited to add open comments. The patients were promised confidentiality but not anonymity because of the longitudinal design of the study. Patients were asked to respond to four further questionnaires in the subsequent two years. The first questionnaire was designed to evaluate the patients' use of NPTs and their views on the importance of NPTs in the fight against cancer. The concept of NPTs was defined as the use of handling, homeopathy, herbs and diets, zone therapy, the Nitter therapy (vitamin B12-based therapy) and the use of 'seven-star' (local variant). The patients could also add any other types of therapy as a response to an open question. Out of a total of 263 cancer patients who were invited to participate in the study, 252 (95.8%) accepted.

The main goal of the study was to compare the views of a population of cancer patients with those of a population

of patients with non-malignant diseases. A population of 400 patients attending four different health centres in the three most northerly counties of Norway were invited to answer anonymously the same questions about the use of NPTs and to give their views on the degree to which NPTs should be an option for cancer patients within hospitals. They were also invited to add open comments.

A total of 325 (81.3%) general practice patients answered the questionnaire. Fourteen patients had been or were being treated for cancer at the time of the study and six patients did not give any information about prior or present malignant disease. These 20 patients were excluded leaving 305 non-cancer patients (76.3%).

Because of a slight imbalance in age and education between the two groups of patients, the populations were compared after standardization for these variables. The standardization, however, did not alter the results of the study to any significant degree (4). For reasons of simplicity, our results are therefore presented without standardization (SIR). The statistical analysis was carried out using the statistical package SAS with a test for difference between categorical variables with  $\chi^2$  as given in the Proc Freq procedure (5). The study was authorized by the Board of Ethics of health region V.

### Results

The number of users in the different age groups was approximately the same. Crude, not age standardized

**Table 2**

*Prevalence of diagnoses in the study group compared with those of all patients seen in the Department of Oncology (June 1990 to June 1991)*

| Malignancy                | Study population |       | All patients |       |
|---------------------------|------------------|-------|--------------|-------|
|                           | n                | %     | n            | %     |
| Breast cancer             | 52               | 20.5  | 103          | 17.8  |
| Lung cancer               | 40               | 15.8  | 77           | 13.3  |
| Urogenital cancer         | 40               | 15.8  | 81           | 14.0  |
| Malignant lymphomas       | 30               | 11.9  | 72           | 12.4  |
| Gastrointestinal cancer   | 30               | 11.9  | 90           | 15.5  |
| Head and neck cancer      | 15               | 6.0   | 15           | 2.6   |
| Gynaecological cancer     | 13               | 5.2   | 22           | 3.8   |
| Smaller diagnostic groups | 32               | 12.7  | 119          | 20.6  |
| Sum                       | 252              | 100.0 | 579          | 100.0 |

\* Prevalence refers to the number of patients with a diagnosis of cancer seen within the department of cancer in the period 1 July 1990 to 1 July 1991.

numbers were therefore used in this analysis. The characteristics of cancer patients and general practice patients can be found in Table 1.

There were fewer men in the groups of patients with non-malignant disease. These patients were also somewhat younger and better educated than the group of cancer patients.

The distribution of diagnoses among participating cancer patients compared with that of all patients seen in our department during the period June 1990 to June 1991 is presented in Table 2. No significant difference was found.

**Table 3**

*Clinical characteristics of participating cancer patients*

| Characteristics          | n   |
|--------------------------|-----|
| Performance status ECOG* |     |
| 0                        | 125 |
| 1                        | 97  |
| 2                        | 27  |
| 3                        | 3   |
| Stage of disease         |     |
| Localized/regional       | 145 |
| Metastatic               | 107 |
| Months after diagnosis** |     |
| 0-3                      | 174 |
| 4-6                      | 15  |
| 7-12                     | 14  |
| >12                      | 49  |
| Intention of treatment   |     |
| Cure                     | 113 |
| Palliation               | 139 |

\* Performance status according to the Eastern Cooperative Oncology Group.

\*\* Months after diagnosis refers to the interval between diagnosis and administration of the questionnaire

Among men, lung cancer was the most common diagnosis, while breast cancer was the most frequent malignancy among women.

The clinical characteristics of the cancer patients are presented in Table 3. Of the total population, 222 patients (88.1%) had no or only a slight impairment of their performance status (ECOG 0 and 1), and 174 patients (69%) had known about their diagnosis for less than 3 months. In 113 patients (44.8%) the physician responsible had reported the intention of treatment as being curative. Most patients (57.5%) had loco-regional disease.

The attitudes of patients with non-malignant disease and those of cancer patients regarding to what extent they felt that practitioners of NPTs might have useful knowledge in the fight against cancer and whether or not NPTs should be an option for cancer patients in Norwegian hospitals are shown in Table 4. In all, 60.8% of general practice patients expressed the conviction that practitioners of NPTs might have important knowledge in the fight against cancer and 63.4% felt that NPTs should be an option to cancer patients within hospitals. In the group of cancer patients the numbers were 42.5% and 42.9% respectively.

Sixty-seven (21%) patients from general practice and 28 (11%) cancer patients did not answer the question concerning their personal use of NPTs. However, among these non-responding 95 patients, 59 (88%) general practice patients and 21 (75%) of the cancer patients chose to answer the question on whether they wanted NPTs to be available within hospital as well as a question on whether or not they felt practitioners of NPTs had useful knowledge in the fight against cancer. More than 80% of these patients, among both cancer patients and patients with non-malignant disease, expressed doubts with respect to a potential beneficial effect of NPTs in the treatment of cancer (Table 5). Only 3 cancer patients (14.3%) and 8 general practice patients (13.6%) in this group of patients expressed the opinion that practitioners of NPTs might have important and useful knowledge in the fight against cancer and also that NPTs ought to be an option within hospitals.

In the population of 240 general practice patients reporting on the use of NPTs, 55 (22.9%) reported that they were users or had been users of NPTs (95% CI: 17.6%–28.2%). Among the 224 cancer patients who answered the question about the use of NPTs, 44 (19.6%) had used or were using NPTs for their type of cancer (95% CI: 14.4%–24.8%). Among cancer patients, users of NPTs more frequently received palliative treatment ( $p=0.02$ ). Women used NPTs somewhat more frequently than men, but this difference did not reach statistical significance ( $p=0.07$ ). Educational level, performance status and spread of the disease (localized versus disseminated) had no influence on the use of NPTs. In the group of patients with non-malignant disease no specific factor seemed to influence the use of NPTs (data not shown).

**Table 4**

*The attitudes of patients with non-malignant disease (GPP) and cancer patients (CP) on the extent to which practitioners of NPTs have useful knowledge in the fight against cancer and whether NPTs should be an option for cancer patients within Norwegian hospitals*

|                                                           |     | Yes  |     | No   |    | Do not know |    | Total | p-value |
|-----------------------------------------------------------|-----|------|-----|------|----|-------------|----|-------|---------|
|                                                           |     | %    | n   | %    | n  | %           | n  |       |         |
| Practitioners of NPTs have important knowledge            | CP  | 42.5 | 103 | 17.5 | 42 | 39.6        | 95 | 240   | <0.005  |
|                                                           | GPP | 60.8 | 177 | 6.5  | 19 | 32.7        | 95 | 291   |         |
| NPTs should be an option for cancer patients in hospitals | CP  | 42.9 | 100 | 18.4 | 44 | 38.2        | 89 | 233   | <0.005  |
|                                                           | GPP | 63.4 | 185 | 7.9  | 23 | 28.7        | 84 | 292   |         |

Forty-seven cancer patients (26.1%) who, so far, had not used NPTs as treatment for cancer reported that they possibly would consider using NPTs.

Homeopathy, herbs diets and zone therapy were the most popular NPTs methods used by patients seen in general practices. Healing by laying on of hands was the most popular method among cancer patients. Other treatments consisted mainly of acupuncture among general practice patients and religious types of treatment among cancer patients (Table 6).

Both groups reported that their main information about NPTs came to them from close friends and family. This was more predominant among cancer patients. As many as 54.9% of the cancer patients reported that family and friends were the main informants on NPTs compared with 41.1% among general practice patients. The difference between the groups did not reach statistical significance ( $p = 0.09$ ). Very few cancer patients (7.8%) reported that they were put under pressure by family, friends or others to use NPTs.

**Table 6**

*Non-proven therapies used by cancer patients and patients with non-malignant disease*

|                      | Non-cancer patients (n = 305) |      | Cancer patients (n = 252) |      |
|----------------------|-------------------------------|------|---------------------------|------|
|                      | n                             | %    | n                         | %    |
| Healing              | 4                             | 1.7  | 21                        | 9.4  |
| Homeopathy           | 12                            | 5.0  | 7                         | 3.1  |
| Zone therapy         | 6                             | 2.5  | 1                         | 0.4  |
| Herbs/vitamins/diets | 11                            | 4.6  | 3                         | 1.3  |
| Others               | 6                             | 2.5  | 7                         | 3.1  |
| Combinations         | 16                            | 6.6  | 5                         | 2.2  |
| Number of patients   | 55                            | 22.9 | 44                        | 19.5 |
| Missing information  | 65                            | 21.3 | 28                        | 11.3 |

## Discussion

The use of NPTs by patients with different diseases is heavily debated in Norway but the documentation of their

**Table 5**

*Attitude towards use of NPTs and feeling that NPTs are important for cancer patients in the group of patients that did not state whether they were users of NPTs or not*

|                     | Positive |    | Negative |   | Do not know |    | Total |    |
|---------------------|----------|----|----------|---|-------------|----|-------|----|
|                     | %        | n  | %        | n | %           | n  | %     | n  |
| Cancer patients     | 14.3     | 3  | 4.8      | 1 | 81.0        | 17 | 8.3   | 21 |
| Non-cancer patients | 13.6     | 8  | 1.7      | 1 | 84.8        | 50 | 19.3  | 59 |
| Total               |          | 11 |          | 2 |             | 67 | 14.4  | 80 |

Missing information in 7 cancer patients and 8 patients in general practices.

Positive: Patients stating that NPTs should be an option with hospitals and that practitioners of NPTs might have important knowledge in the fight against cancer.

Negative: NPTs should not be an option within hospitals, practitioners of NPTs have no important knowledge in the fight against cancer.

Do not know: Patients who answered 'Do not know' and patients who were positive to one but negative to the other question.

use is limited. Our findings that 19.6% of cancer patients and 22.9% of general practice patients were or had been users of NPTs is, however, comparable with earlier reports.

In a Norwegian study of a general population from 1978 comprising 808 patients, Brusgaard et al. reported that 20% were using NPTs (1). The use of NPTs in the general population of Denmark and Sweden is reported to be of the same magnitude (6, 7). A recent report from the USA discloses that in a non-selected group of 1 539 subjects, 34% of the respondents had used at least one unconventional type of therapy during the previous year (8). This study showed that the prevalence and frequency of use of unconventional methods differed in relation to the principal medical conditions. The frequency of use of non-proven methods was highest for back problems (36%), anxiety (28%), headaches (27%), chronic pain (26%) and cancer (24%). A total of 28% of patients who consulted a medical doctor for a medical condition were users of unconventional therapy. In Norway the use of NPTs among patients with rheumatic disease was studied in 1980 (9). As many as 61% had been or were using NPTs.

In 1986 practitioners of NPTs claimed that 700 000 patients in Norway had been treated by chiropractors (10) and that 150–200 000 patients were treated yearly by homeopaths (11).

In anonymous studies low response rates are sometimes a problem. This was seen in a German study from 1989 where only 33% of the invited patients returned the questionnaire (12) and in an anonymous Swiss study from 1991 where 53.3% of the invited patients answered their questionnaires (13). A response rate of more than 80% among the invited patients from general practice in our study is therefore very satisfactory.

A possible biasing factor in our study is that the study populations were treated differently with respect to anonymity. Some of the cancer patients may consider the hospital staff to have negative attitudes to NPTs. Because of a lack of anonymity they may underreport their use of NPTs and also be more reluctant to admit that they support their use within hospitals.

One might postulate that the patients in general practice would answer the questions about use of NPTs more freely than the cancer patients. This could result in a lower number of missing values in the questionnaires from general practice patients on such sensitive questions. We find, however, that in the anonymous part of the study there are more patients who do not answer the questions concerning their use of NPTs. The reason for this discrepancy is unknown. There may be doubts in the general population regarding the concept of anonymity. General practice patients may, on the other hand, also feel free not to answer any questions.

The number of patients that use NPTs as cancer patients differs in different studies. In the USA three major surveys

show the number of users as ranging from 9% to 15% among hospitalized cancer patients (14–16). A Canadian study reported only 7% users of NPTs out of 190 interviewed cancer patients (17). Recent studies from Germany and Switzerland indicate that as many as 40 to 50% of cancer patients may be users of NPTs (12, 13) whereas only 15.2% of the participants in a large Dutch study with cancer patients were reported to be users of NPTs (18). Scandinavian studies on cancer patients' use of NPTs are few. A Finnish survey from 1980 reports a 45% use (19). In Norway smaller studies have shown a use of between 15 and 50% in cancer patient populations (2, 3). Recently, an extensive Danish study was published showing a 44.6% use of NPTs (20).

The treatment of a number of diseases is regulated by law in Norway. Among the diseases that only authorized physicians are permitted to treat are cancer, diabetes mellitus, infectious diseases and diseases in children. It is known that many cancer patients consult practitioners of alternative medicine. In 1976 a study from the most northerly county in Norway revealed that as many as 66% of the study population expressed the view that they would possibly use NPTs if they contracted a deadly or very serious disease (21). Studies from other countries have shown that more than 50% of the population would consider NPTs in such a situation (17, 18). Our findings that 60% of patients with non-malignant disease believe that practitioners of NPTs might make an important contribution in the fight against cancer and that 63.4% wanted NPTs to be a treatment option in our hospitals is in agreement with this. Cancer patients are less likely to want NPTs to be used in hospitals. They have less confidence in practitioners of NPTs, but, even so, 4 out of 10 cancer patients would be willing to introduce the use of methods other than those based on science within hospitals. This contrast with the opinion of the health authorities and the medical profession. According to Norwegian law, only safe and duly tested medicine, defined as scientifically based medicine, should be used in the treatment of cancer.

There are differences between the attitudes of patients with non-malignant disease and cancer patients. This is true both with respect to how important they think NPTs are in the treatment of cancer and with respect to the kind of NPTs they are using.

One explanation for general practice patients having a more positive attitude towards the use of NPTs in cancer disease might be that such an opinion has no bearing on them personally. It may be easier to voice strong opinions when the consequences have no personal relevance. Because of the personal implications, cancer patients may be more circumspect in their opinions.

Homeopathy and diet therapy are the most frequently used treatments among patients with non-malignant disease. Cancer patients use treatment modalities such as healing by laying on of hands and healing by prayer.

Cancer patients from northern Norway seem to choose alternative treatment involving an element of miracle and magic.

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