

Use of alternative medicine by Norwegian cancer patients

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Tromsø
Terje Risberg

If dedicated to anyone,..... then dedicated to all my colleagues struggling to give cancer patients a better life.

List of papers

- I Risberg T., Lund E. and Wist E. Use of non-proven therapies. Differences in attitudes between Norwegian patients with non-malignant disease and patients suffering from cancer. *Acta Oncol* 1995, **34**, 893–8
- II Risberg T., Wist E. and Bremnes R.M. Patients opinion on and use of non-proven therapies related to their view on cancer aetiology. *Anticancer Res* 1997, **18**, 499-506
- III Risberg T., Bremnes R.M., Wist E., Kaasa S. and Jacobsen B.K. Communicating with and treating cancer patients: How does the use of non-proven therapies and patients' feeling of mental distress influence the interaction between the patient and the hospital staff. *Eur J Cancer* 1997, **33**, 883–90
- IV Risberg T., Lund E., Wist E., Dahl O., Sundstøm S., Andersen O.K. and Kaasa S. The use of non-proven therapy among patients treated in Norwegian oncological departments. A cross sectional national multi-centre study. *Eur J Cancer* 1995, **31A**, 1785–9
- V Risberg T., Wist E., Kaasa S., Lund E. and Norum J. Spiritual healing among Norwegian hospitalised cancer patients and patients' religious needs and preferences of pastoral services. *Eur J Cancer* 1996, **32A**, 274–81
- VI Risberg T., Kaasa S., Wist E. and Melsom H. Why are cancer patients using non-proven therapies? A cross-sectional national multicentre study. *Eur J Cancer* 1997, **33**, 575–80
- VII Risberg T., Lund E., Wist E., Kaasa S. and Wilsgaard T. Cancer patients use of non-proven therapy. A five year follow-up study. *J Clin Oncol* 1998, **16**, 6-12

Contents	Page
Acknowledgement _____	1
List of papers _____	3
1. Background: use of alternative medicine _____	6
Terminology of alternative medicine	
Patients' use of alternative medicine	
Methodological problems, different studies	
Cultural differences	
Study design	
Data material	
Definitions of alternative medicine	
Why do cancer patients use NPTs	
Effect on the disease	
Positive general effect	
Psychological aspects	
Factors influencing patients' use of NPTs	
Demographic factors	
Disease related factors	
Other factors	
2. Study design: methods of administration _____	14
Interview	
Advantages	
Disadvantages	
Mailed questionnaires/self-report questionnaires	
Advantages	
Disadvantages	
3. Reliability and validity _____	16
Reliability	
Validity	
4. Aims of the thesis _____	17
5. Materials and methods _____	18
Study population and design	
The follow-up study	

	The comparative study	
	The national study	
	The reliability study	
	The first interview study	
	The second interview study	
6.	Main results _____	25
	Number of users of NPTs	
	Types of NPTs	
	Information about NPTs, opinions on and trust in the treatment	
	Factors predicting use of NPTs	
	Other characteristics of users of NPTs	
	Effects, side effects and costs of treatment	
	Survival	
7.	Statistical methods _____	27
8.	Discussion _____	27
	Methods and definitions	
	Validity of the reported results	
	Can NPTs be optional within Norwegian hospitals?	
	Factors influencing patients' use of NPTs	
	Geographical, sex, age, former use of NPTs	
	Disease-related factors	
	Other factors	
	Patients' motivations for use of NPTs	
	Importance of information/communication, opinion on life-style	
	NPTs and survival	
9.	Conclusions _____	36
10.	References _____	38
11.	Errata and reanalysis _____	43
12.	Papers I–VII	
13.	Appendix: English translation of the questionnaires	

1 Background: use of alternative medicine

Now and then medicine makes real progress. The understanding that patients suffering from pernicious anaemia could eat liver, not raw as they had done for years, but fried, was such a leap forward.

During medical school I understood that often disease could be different entities for the patient and for the doctor. The suffering and the feeling of illness were often forgotten in our search for cure and understanding of the patients' disease.

Later, as a young doctor in the Norwegian Radium Hospital I sensed the exciting world of science and the hopes of a break-through in cancer treatment. Each time a new compound was introduced our hopes were sky-high and our belief in science immense. At the same time we met suffering and broken hopes on such a scale that often I wondered how it was possible to survive. Every day we discovered the enormous powers that we each hold inside ourselves. I learned that patients lived their lives of misery and disease with hope and unbelievable strength. Patients' gratitude to nurses and fellow doctors was enormous and their help greatly appreciated.

In 1988, a colleague, Erik Wist, asked me to join him at the Department of Oncology in the University Hospital of Tromsø. I am still grateful for that invitation.

The concept that size is not always the most important aspect of life came true in Tromsø. The atmosphere in the Department was excellent for both patients and those of us working there, with an openness that allowed expression of curiosity. Even with up-to-date medical treatment and good intentions as caretakers, there was still a lot to learn about the lives of our cancer patients. We had many semi-philosophical discussions about our patients' lives and about how we could improve our skills. In many areas our knowledge was scarce or simply lacking. We wanted to investigate whether patients had opinions about the causes of cancer other than those given by health authorities and to relate patients' opinions about lifestyle changes with other aspects of life with cancer. Communication and information were important aspects of our daily work with patients. The extent to which patients wanted to have all available knowledge was not, however, studied among Norwegian cancer patients.

Our ambitions for our patients were high. We wanted to be able to get close to them in such a way that we could help and comfort them with their personal and private problems.

It surprised me that one problem presented by many patients maybe was more difficult for me than for them. There have been discussions over many years about how to deal with the use of alternative medicine in cancer. Most doctors took a position coloured by a firm belief that no such method could have any effect on cancer and by any legal regulations covering treatment of the sick which stated that only doctors could treat cancer. The answers that I gave my patients to different questions about alternative medicine did not satisfy me. So, during the winter of 1989–90, we decided to start a study about patients' use of alternative medicine or non-proven therapies (NPTs).

Terminology of alternative medicine

Alternative medicine is one of many terms used to refer to a wide variety of methods of treating disease that fall outside the bounds of mainstream or conventional medicine. Some confusion exists between different countries within Europe of what constitutes alternative medicine: 50 techniques have been identified in France and 58 in Germany; the British Medical Association reported 67 different therapies in the UK, whereas the Swedish Medical Association reported as many as 200 different methods¹. In an effort to categorise the vast number of alternative

methods, the American Office of Alternative Medicine (OAM)² grouped them into seven categories (1) diet and nutrition, (2) mind–body techniques, (3) bioelectro-magnetics, (4) alternative systems of medical practice (or traditional and folk remedies), (5) pharmacological and biological treatments, (6) manual healing methods, and (7) herbal medicine.

In USA all reported remedies used as alternative medicine since the 1940s have been reviewed by a formal committee, the American Cancer Society (ACS). The committee investigating this use also reported on methods that no longer were in official use in the US. In 1986, they identified 51 therapies that were placed on the inactive list. However, many of these methods or remedies like Koch's glyoxylide³ and Hoxsey's cancer cure⁴ were still given in countries like Mexico and were therefore available to cancer patients. Another observation reported by Holland and others⁵ is that many methods recycle every few years, making the total registry of treatments identified throughout the last 50 years numerous. In Norway The «Nitter-kur»⁶ might be an example of this recycle effect with its great popularity in the seventies and again in 1991 to 1993.

Through out Europe different comities has collected articles on a big variety of unproven cancer therapies. An example might be the Swiss Cancer League's study Group ⁷ that has reported on the methods in use in Europe. The most common used therapies in the German - speaking regions of Europe were: mistletoe preparations (Iscador and others) and anthroposophically oriented medicine, various unproven diets, herbal teas and high dose vitamins, oxygen therapy, enzymes, organ extracts and bioelectronic methods ^{8,9}.

Very recently the Norwegian government appointed a comity (Aarbakke kommiteen) giving them a mandate to broadly evaluate aspects of use of alternative medicine, within and outside official Norwegian health care. Conclusions will be available in December 1998.

Terms used by proponents of alternative medicine include: alternative, complementary, non-toxic, holistic, natural and non-invasive. Those used by critics include: non-proven, unproven, questionable, dubious, quackery and fraudulent.

A definition of alternative medicine is given by the American Cancer Society (ACN).

Those diagnostic tests or therapeutic modalities which are promoted for general use in cancer prevention, diagnosis, or treatment and which are, on the basis of careful review by scientists and/or clinicians, not deemed proven nor recommended for current use.

In view of the fact that only duly tested medicines are used in the Department of Oncology in Tromsø, the term non-proven therapies (NPTs) was chosen in the present study. At the time when this term was chosen (1989), the implied criticism in this term was not known to me. If the study were to be started now, a more neutral term would have been chosen.

Use of non-proven therapies by cancer patients

Number of users of non-proven therapies (NPTs)

The number of users of NPTs among Norwegian cancer patients is uncertain. Two studies from the late 1970s reported the number of users as being from 16% to over 50%^{10, 11}. In a smaller study of outpatients seen at Ullevål Hospital¹², 44% were found to be users. In a Finnish survey from 1980¹³, 45% of the participating cancer patients reported use of NPTs. As in the Norwegian study where most of the participants were users, the most popular remedy was extract of birch ash. In a recent large Danish study with the research question aimed at patients' use of Q10¹⁴ a similar number of users was found.

Studies from Germany, Austria and Switzerland^{9, 15, 16} have also shown high number of users among cancer patients (40–50%). Other European studies, however, report few patients who have used NPTs (15–16%)^{17, 18}. An investigation in Poland discovered that more than a quarter of cancer patients used NPTs¹⁹. A Canadian study reported only 7% of 190 interviewed cancer patients as users of NPTs²⁰. In the USA, studies report use of NPTs in cancer patients of 9–15%²¹⁻²⁵. Some major studies are shown in Table 1.

Table 1 Some central surveys describing cancer patients' use of NPT

Research group	Country	<i>n</i>	Percentage ever-users	Prominent types of NPT
Gjemdal (1978)	Norway	100	57	Birch ash
Arkko (1980)	Finland	151	45	Birch ash, vitamins, homeopathy
Eidinger (1984)	Canada	315	7	Not specified
Cassileth (1984)	USA	300	13	Metabolic therapy, diet, megavitamins, Simonton therapy, spiritual healing, immunotherapy
Clinical oncology group (1987)	New Zealand	463	12	Diets
Beaufort (1988)	Austria	295	51	Vegetable juice, tee, vitamins, homeopathy
Berger (1989)	Switzerland	161	44	Diet, Iscador, faith healing, vitamins
Lerner (1992)	USA	5047	9	'Mind therapies', diets, drugs
Damkjaer (1994)	Denmark	769	45	Q10, homeopath, diets
Zouwe (1994)	The Netherlands	949	15	Diet therapy (Moerman)
Downer (1994)	England	600	16	Healing, relaxation, visualization, diets, homeopathy, vitamins/herbs

Modified after Zouwe ¹⁷.

Methodological problems connected with the number of users in different studies

Cultural differences/regulations and time-specific differences

Within Europe two main views are practised regarding the regulation of alternative medicine ²⁶. In southern Europe, France, Belgium and Luxembourg, only physicians are allowed to treat disease, in contrast to the countries in northern Europe, including the Nordic countries, where anyone, in principle, can treat disease. In some of these countries, the health market is regulated by laws that make it illegal to treat certain diseases. (From 1936 the Norwegian 'Kvaksalverloven' states that only physicians may treat cancer and a number of other diseases.) In some countries (England and Ireland), it is legal to treat any disease as long as the practitioner does not advertise him- or herself as a physician if this is not the case ²⁶.

In some countries, such as Switzerland and Germany, alternative methods, thought to be supportive and adjunctive to mainstream treatment, are more acceptable within conventional medicine and are therefore widely used. In Germany anthroposophic and homeopathic remedies are accepted and included among other medicines. In other countries, such

as China and Russia, alternative medicine is placed side by side with scientific medicine; in other countries only official medical treatment may be used in cancer treatment ²⁶. Some reports have published differences in the use of NPTs within the same country ^{17, 21}.

Different types of NPTs have gained popularity at different times. In the late 1970s and the early 1980s, extract of birch ash was very popular among cancer patients in Scandinavia ^{11, 13}. In the USA, laetrile ²⁷ was very popular in the 1970s, and metabolic therapies, special diets, high-dose vitamins and mental imagery in the 1980s ²⁸. Now, in the 1990s new substances have appeared such as shark cartilage ²⁹. However, the major change in the last decade has been the sharp delineation of quackery from complementary, supportive treatments, which could have important implications for the status of alternative medicine in the future.

Study design

Different methods of data collection could account for some of the differences found in different studies ³⁰. In most cases quantitative methods were chosen: structured interview or questionnaire-based studies. In both these methods an anonymous approach or a promise of patient confidentiality could be chosen. In many anonymous studies, the response rates are very low,

sometimes below 50%^{9, 15}, whereas in studies that are not anonymous authors worry about the willingness of patients to respond to sensitive questions³¹.

Data material

Whether the sample of patients studied is representative of the general cancer patient population is of great importance. Disease-related and demographic factors are not always known in the patient samples studied. Patients who are cured of their disease are in a different situation from those for whom there is no cure. The location of the study also has to be known – whether in hospital, at home, with practitioners of NPTs.

Definition of non-proven therapy

If the researcher defines an NPT in ways that differ from the definition used by the participants, the results might be confusing. In studies carried out by Beufort (1988)¹⁶, Hauser (1981)³² and Obrist (1986)³³, patients described using vegetable juice, raw vegetables and different teas as NPTs. It is, however, possible that patients in other surveys changed their diet in minor ways but did not report them as NPTs. The researcher and participating patients must therefore share a common definition of NPTs.

Why do cancer patients use NPTs?

The most important reason for patients with cancer to use NPTs is the fact that many patients cannot be cured by conventional medicine^{34, 35}. Apart from this, different studies have reported a variety of reasons for the use of NPTs by patients.

Effects on the disease

Patients' expectations of NPTs can vary from no effect to full cure^{13, 24, 36, 37}. Some patients start using NPTs to help with pain or other effects of the disease or to help with side effects of the treatment^{15, 32}. Some patients hope to prevent progression or metastatic disease^{15, 32}. Only a few believe that NPT could cure their disease^{13, 15, 24}.

Positive general effects

There is a view among some patients that 'as long as the treatment has no ill effect then why not try it'^{13, 37}. Others believe that, by using NPTs, their immunological defence system will be improved. The opinion is prevalent among many patients that many types of NPT have only good effects and no ill effects.

Psychological aspects

Feelings of hopelessness may be closely related to patients' feelings of having no control over the cancer^{18, 38, 39}. This feeling of loss of control might be counteracted by the use of NPTs. To avoid these feelings of helplessness and depression which patients may develop when they are told that they have a potentially life-threatening disease, they may try to assert control over their own health by turning to alternative therapies, that is, the use of NPTs may be an important coping strategy for many cancer patients. The observation that information and advice are given to the patient mainly by family and close friends has been found in several studies and supports the use of NPTs as a coping measure^{15, 17}. In other cases, advice from family and friends might take such a form that a patient feels under pressure to use NPTs.

Cassileth et al. reported, in 1984²⁴, that patients who used or had used NPTs might differ substantially in their beliefs about illness from those patients who used only conventional therapy. One major factor associated with patients' use of NPTs was the belief that their cancer could have been prevented and that the cancer might be reversible through the same means. Other studies have also shown that cancer patients using alternative medicine have a stronger

belief in the importance of environmental and lifestyle factors as causes of cancer^{15, 17}.

Factors influencing patients' use of NPTs

Demographic factors

The sex of patients does not separate users from non-users of NPTs in most studies^{17, 24}. However, in two Scandinavian studies from 1978 to 1980, and in the English study reported by Downer in 1994, women were users more often than men^{11, 13, 18}. However, Obrist et al. (1986)³³ found, on the contrary, a higher prevalence of use among men. This weak relationship between sex and use of NPTs is somewhat surprising because women seem to use NPTs more often for diseases other than cancer¹⁷. Most studies report a lower mean age and a higher educational level among users of NPTs than among non-users^{15, 16, 24, 32, 37, 40}. Whether patients are married or not seems to be irrelevant¹⁸.

Disease-related factors

Most of the reported studies have not demonstrated any significant correlation between different cancer types and use of NPTs^{15, 17, 24}. However, in the large American survey reported by Lerner and Kennedy, in 1992²¹, use of NPTs was more prevalent for certain types

of cancer. Downer et al.¹⁸ found that more patients with malignant lymphomas were users than patients with other cancer types. After adjusting for the different seriousness of different cancers, this weak or lack of correlation is somewhat surprising. In most studies, stage of disease is not found to be an important factor in predicting patients use of NPTs^{17, 24}. Zouwe did demonstrate a higher degree of use among patients with metastatic disease and those being treated for reasons of palliation. Most studies do not demonstrate any correlation between the duration of disease and patients' use of NPTs^{17, 24}. Hauser et al.³² observed a longer duration of disease among users than among non-users, but his study had only a limited number of patients.

Other factors

Some studies demonstrate that patients using NPTs have less confidence in and are less satisfied with the conventional medical treatment than non-users^{15, 17}. In other studies all patients reported very positive opinions about general practitioners and specialists in hospitals, and no differences were found between users and non-users¹⁸. A correlation has been reported between side effects of treatments, such as radiotherapy and chemotherapy, and use of NPTs²⁴. Patients who had more side effects were less

confident about the benefits of treatment, were more afraid about the negative effect and were more prone to use NPTs^{24, 33, 40}.

2 Study design: methods of administration

The standard assessments used for measuring a phenomenon such as patients' use of NPTs can be based on either interview or patients' self-report questionnaires³¹.

Interview

The interview can be carried out face to face or by telephone.

Advantages

Advantages of the interview, compared with the self-report questionnaire, include the certainty that the actual person is responding to the questions, reduction in the number of items omitted by the respondent and the possibility of helping the respondent with any difficult or confusing questions. Open questions can also be used to collect additional information. It is easier to 'lead' the patient through the questionnaire and thereby omit the problem with 'skip patterns' (where patients are instructed that

they should omit a section of the questionnaire).

The telephone interview has the advantage of being cheap and being administered from one central office.

Disadvantages

Face-to-face interviews are expensive, time-consuming and the interviewers must be well trained^{31, 41}. There is also a risk that characteristics of the interviewer, such as sex, race and age, may affect the response given. If interviewers have opinions about the subject in focus their preferred answers might be communicated to patients. Some patients will be very 'eager to please' – the so-called 'yea sayer' – and will seek the answer that they believe the interviewer wants.

Another disadvantage of the telephone interview is that some people might not have a telephone (people with low incomes) or have an unlisted number (middle-class/rich people). A major problem with the telephone interview is the difficulty with questions that require the person to choose from various options. A possible solution is to send the respondent a list of alternatives (if the respondents are a known group of people) before the interview, or to ask them to write the alternatives on a piece of paper.

Mailed questionnaires/self-report questionnaires

Advantages

The main advantage is the low cost and the coordination of the study from one central office. Further, as no interviewer is present, bias of social desirability tends to be minimized.

Disadvantages

The subject might not return the questionnaire or could omit some of the items. If the study is anonymous, all participants have to be sent reminders to ensure an acceptable response rate. This increases the cost of the survey. Another important problem could be that people other than the participants might influence or actually answer the questionnaire. This reduces the validity of the reported results.

3 Reliability and Validity

It is necessary to discuss the possible errors in a conducted study in order to ascertain whether the study measured what was intended.

Reliability

This addresses the reproducibility of the results, that is, the instrument measures something in a consistent manner. One study aimed at testing the reliability of the questionnaire used in the national study (identical with the fourth and fifth questionnaire in the follow-up study) is described in 'Materials and methods' (study D). There exist various possible sources of error, such as misunderstanding of questions and coding errors.

A possible approach to measuring reliability is to administer the questionnaire to the same sample of patients on two occasions. This method is called test-retest reliability^{31, 42}. The time separating the two questionnaires must be sufficiently short to make the assumption that the underlying condition is unaltered, but long enough to ensure that the respondent does not remember the first response given. The interval in a test-retest procedure can be discussed, but intervals of 2–14 days are usual³¹.

Different methods has been described to measure reliability (analysis of variance, Pearson's correlation and kappa statistics). In the test-retest situation (Self-report questionnaires) kappa statistics may be more appropriate⁴³. The kappa coefficients adjust for the proportion of agreement expected by chance. The coefficient is calculated based on total agreement and does not give credit when responses differ even if only slightly. To adjust for partial agreement, an extension of the kappa approach is used called 'weighted κ '⁴⁴

Validity

This addresses systematic error, that is, whether the questionnaire measures what it was intended to measure. A validation procedure will therefore differ according to the phenomena that are being addressed. Validation of a questionnaire, or a scale, is really a process for determining the degree of confidence that can be placed on inferences made about people from their scores on a questionnaire^{31, 45}. Two validation studies are described under 'Materials and methods' and the reported results are discussed further under 'Discussion'.

4 Aims of the thesis

The main aim of the study was to describe the use of NPTs and how the pattern of use changes throughout the life of Norwegian cancer patients who are hospitalized (inpatients and outpatients).

The following are the other aims of the study:

- To study patients' opinions about the importance of NPTs and whether they should be optional within Norwegian hospitals.
- To analyse the importance of disease-related and demographic factors influencing patients' use of NPTs.
- To assess patients' motivation for use of NPTs and their hopes about the treatment.
- To report on the importance of aspects of information/communication, patients' religious beliefs and their opinions about lifestyle and environmental factors as causes of cancer related to use of NPTs.
- To study patients' use of NPTs in terms of survival

5 Materials and methods

Study population and design

This dissertation is based on responses to three different questionnaire-based studies (A–C),

one reliability study (D) and two interview-based studies (E and F) (Table 2). The questionnaires used in the different parts of the study have been translated into English in the appendix

Table 2 Study population

Study	Number of patients and design	Described in paper
<u>Questionnaire-based studies</u>		
Study A: Follow-up study	252 north Norwegian cancer patients recruited during 12 months answered five questionnaires during 5 years of follow-up	III and VII
Study B: Comparative study	252 cancer patients (baseline study A)/305 non-cancer patients from Health Region V	I and II
Study C: National study	642 cancer patients from all five health regions	IV, V and VI
<u>Reliability study</u>		
Study D: test–retest	28 north Norwegian cancer patients participating in study C, answered the questionnaire twice at an interval of 4 days	page 22
<u>Validating interviews</u>		
Study E: First interview	31 outpatients with cancer: answered the fourth questionnaire at home. Four weeks later, interviewed as outpatients	page 24
Study F: Second interview	73 surviving patients of 252 in study A participated after 5 years of follow-up	VII

Study A

The follow-up study

A longitudinally designed, questionnaire-based study was carried out at the Department of Oncology, University Hospital of Tromsø, during the period June 1990 to July 1996. The main aim of the study was to describe patients' use of NPTs and how their pattern of use changed over the 5-year follow-up study. The study design also gave an opportunity to study survival in terms of patients' use of NPT. Eligible patients, recruited between June 1990 and July 1991, were patients seen at the Department of Oncology or the Department of Radiotherapy for the first time. A total of 263 patients

was invited to participate in the study; 252 (95.8%) accepted. At inclusion in the study, the physician responsible for the patient completed a questionnaire describing the patient's clinical characteristics. The patients themselves filled in a questionnaire giving information about demographic data such as level of education, occupation, marital status and living conditions.

Eligible patients received follow-up questionnaires at 4, 12, 24 and 60 months (questionnaires 2–5) after their first contact with the Department of Oncology. Questionnaires 4 and 5 were identical. The questionnaires covered several topics as indicated in Table 3.

Table 3 Topics in the different questionnaires

Topic	Questionnaire no.	1	2	3	4	5
Patients' perception of diagnostic delay: from their first symptom to treatment		+	–	–	–	–
Patients' opinion on information/communication, before and after the diagnosis of cancer		+	+	–	–	–
Patients' opinion on causes of cancer		+	–	–	–	–
Patients' use of and opinion about alternative medicine in cancer		+	+	+	+	+
Mental distress (measured by GHQ 5*)		+	+	–	–	–
Quality of life (GHQ 20 and EORTC 30)		–	–	+	+	+

*GHQ 5⁴⁶ is constructed by five selected items from GHQ 20⁴⁷.

The number of users of NPTs at baseline in the follow-up study were reported differently in papers I (19.5%), III (18%) and VII (17.4%). In the first paper published in 1995, only patients answering the question about whether or not they were users of NPTs were included in the analyses. However, 16 of 28 non-responders answered all specific questions concerning NPTs negatively. In paper III, these patients are reported as non-users, which gave a somewhat lower estimate of the percentage users of NPTs. In paper VII, describing the follow-up study, all patients are included in the analysis because they could respond to other questionnaires later.

Details about patients' disease-related and demographic factors at the start of the study are reported in papers I and VII. The number of patients participating, non-responders and patients dying during follow-up is described in Table 1 in paper VII.

Study B

The comparative study

In October to November 1990, 400 non-cancer patients, attending four different health centres in the three most northerly counties, were invited to participate in a comparative study, together with the 252 cancer patients included in the follow-up study. A total of 325 patients accepted participation in the study; 20 patients were excluded because of

missing data (six) or present or previous cancer disease (14), leaving 305 eligible participants. The patients were given identical questionnaires about use of and opinions about use of NPTs and their opinions about causes of cancer (questionnaire 1). Based on an interim analysis of the participating cancer patients, the intention was to distribute the questionnaires to an equal number of female and male non-cancer patients. As a result of clerical errors in two of the health centres, the final number of female participants was somewhat higher than male patients (53.8% versus 44.6%). In 2% of cases participants, the sex was not known. Details of the study samples are presented in papers I and II.

Study C

The national study

A nation-wide, questionnaire-based study, initiated by the Norwegian Board of Health, was carried out in December 1992. The aim of the study was to evaluate the use of NPTs among cancer patients in Norway. The study was undertaken at all five Norwegian regional cancer centres to obtain a cross-sectional national sample. The same questionnaires that were presented to patients after 24 and 60 months of the follow-up study were used in the study (questionnaires 4 and 5). At four of the five regional centres, all in- and outpatients attending the centres over one week were invited

to take part in the study. In the fifth centre, the Norwegian Radium Hospital, the study was restricted to one day because of a much larger patient population. The participating physicians at each centre reported the medical characteristics for all patients attending their institutions.

Altogether 911 patients were invited to participate in the study; 101 patients decline to participate and 128 did not return the questionnaire to the investigator. A total of 682 patients (74.9%) answered the questionnaire. Thirty-three patients answered the questionnaire, but did not sign the written informed consent form and so were excluded from the study. Seven patients were excluded because of missing information on age and diagnosis. The final analysis is based on a patient population of 642 (70.5%). The study sample is presented in papers IV–VI.

Study D

Reliability test–retest

All patients included in the national study (Tromsø population) in 1992, who were expected to stay in the Department of Oncology (or the Department of Radiotherapy) for at least 7 days, were invited to participate in a test–retest study. Participants were presented for the second questionnaire 4 days after their initial inclusion in the study.

Of the 28 patients participating in the study, 12 received some help from nurses in the department to fill in the questionnaire. These patients were older than the rest of the patients (mean age 64 years compared with 44 years) and more of them were receiving palliative treatment (67% versus 20%).

Eight patients did not report their use of NPTs in one of the two questionnaires, leaving 21 paired answers. The results are shown in Table 4.

Table 4 Non-proven therapies reported in the two questionnaires

	Questionnaire 1 (<i>n</i> = 21)	Questionnaire 2 (<i>n</i> = 21)
Healing	1	1
Healing by prayers	2	2
Homeopathy	1	1
Diets	0	1
Nitter therapy ¹	1	1
Iscador	1	1 ²
Number of users of NPT	6	7

¹Nitter treatment consists of vitamin B12, γ -globulins, tranexamic acid, multivitamins and nutritional supplement.

²The patient who used Iscador reported additional use of diet in the second questionnaire.

The test–retest reliability is analysed for a number of questions from the questionnaire. If patients were given

opportunities to give more than one answer, kappa analyses were not done (Table 5).

Table 5

Question ¹	All participants (<i>n</i> =28)		Participants receiving no help from staff (<i>n</i> =16)	
	Observed agreement	κ	Observed agreement	κ
1	1.00	1.00	1.00	1.00
3	0.63	0.49	0.73	0.62
4	0.79	0.67	0.81	0.71
5	0.76	0.64	0.75	0.64
33	0.79	0.67	0.79	0.63
34	0.92	0.85	0.87	0.74
37	0.92	0.82	0.93	0.63

¹The numbers represent the numbers given to each questions as given in questionnaire 4.

The test–retest stability of the questionnaire, that is, the reproducibility, was good for most questions. An exception could be question 3 in Table 5 where $\kappa = 0.49$. The wording of this question could be somewhat unclear. Among the patients who did not receive any form of assistance from the staff, observed agreement and κ were higher, implying that younger and more healthy patients had fewer problems answering the question. The difference between the observed agreement (0.93) and the κ value (0.63) in question 37 is explained by a clustering effect because a large majority of the patients reported no pressure from anyone or anything.

Study E

The first validation interview study 1993

The interview was carried out by a specially trained medical student at the outpatient unit, Cancer Department, University Hospital of Tromsø.

Aim

To find out whether the results in a questionnaire-based survey differed substantially from the results found in an interview-based study, carried out with the same patients.

Method

The questionnaire (questionnaire 4 in the follow-up study – see the appendix) were sent to the patients 4

weeks before a planned evaluation at the outpatient unit. At the same time, patients were invited to participate in a personal interview during the evaluation. The questionnaires answered by the patients were stored at the Department of Oncology and were not made available to the interviewer until the interview study had finished. The duration of the interview was from 1.5 to 2.5 hours. It was carried out in a semi-structured manner in which questionnaire number 4 was used as an interview guide and filled in by the interviewer.

Patients

Sixty-eight patients were invited to participate in the study. Of these, 46 (68%) accepted the invitation and returned the questionnaire. However, only 31 patients actually participated in the interview. The discrepancy between patients accepting the invitation and patients being interviewed resulted mostly from administrative difficulties during the time of the interview (changes of evaluation day, the office manager forgetting to report that the patient had arrived to the interviewer).

Results

Similar numbers of users (13 of 31) were found in both the questionnaire-based study and the interview. However, two patients who reported non-use of NPTs in

the questionnaire-based study later reported spiritual healing and use of diet in the interview. In the same manner, two patients who reported use in the questionnaire, both of spiritual healing, did not report use in the interview. Spiritual healing was reported in 10 of 13 cases among users in both studies. The number of users and the methods in use are reported in Table 6.

2. To explore some topics in the questionnaire-based study that were evaluated as sub-optimally phrased or lacking in information.

Method and patients

A questionnaire was constructed. The surviving patients were contacted by letter and invited to participate in the telephone interview. Out of 96 eligible

Table 6 Type of NPTs used by the patients¹

User ²	Questionnaire	Interview
1–2	Spiritual healing	No treatment
3–9	Spiritual healing	Spiritual healing
10	Zone therapy/diet	Diet
11	Nitter therapy	Nitter therapy
12	Nitter therapy	Nitter therapy/Spiritual healing
13	Nitter therapy/Spiritual healing	Nitter therapy/Spiritual healing
14	No treatment	Diet
15	No treatment	Spiritual healing/diet

¹Adjusted after a table from the student thesis⁴⁸.

²13 patients were users of NPTs in the questionnaire-based study and in the interview

Study F

The second interview study 1996

The interview was carried out as a telephone interview by Terje Risberg in November 1996.

patients, 20 rejected the invitation. Altogether 73 patients were reached and participated in the study. The study sample is presented in paper VII.

Aim

1. To find out whether the results in the follow-up survey differed substantially from the results found in an interview-based study, carried out on the surviving patients.

Results

The proportion of agreement between the questionnaire-based study and the telephone interview is 0.96 ($\kappa = 0.92$) for the surviving patients in the follow-up study

concerning their ever using NPTs and is satisfactory. The remainder of the results are presented in paper VII.

6 Main results

Number of users of NPT

The cross-sectional studies show varying number of users, from 13% to 31%, in different parts of Norway (papers IV and V) . The follow-up study (paper VII) carried out in health region V demonstrated the cumulative use, among 45% of the patients, during the 5-year follow-up.

Spiritual forms of NPTs are defined in this thesis as faith healing and laying on of hands. Patients who used combinations of spiritual and non-spiritual healing were defined as users of spiritual healing. This were the situation among fifteen per cent of the users in the follow-up study (paper VII). Patients who defined themselves as non-religious very rarely used spiritual forms of NPTs (paper V).

Table 7 Kinds of NPT used in the different health regions

Health region	Spiritual NPT (%)	Non-spiritual NPT (%)
I and II (Oslo region/ south east)	35.9	64.1
IV (central)	50.0	50.0
III and V (north and west)	71.4	28.6

Types of NPTs

Cancer patients from north Norway used spiritual forms of NPTs more often (paper I), whereas for non-cancer patients non-spiritual forms of NPTs, such as homeopathy, zone therapy and diet treatment, were frequently used. The different kinds of NPTs used by cancer patients differed between the health regions (paper V) and are described in Table 7.

Information about NPTs, opinions about their importance and trust in the treatment

Cancer patients who used NPTs had learned about the treatment from close relatives and friends in 55–64% of cases (papers I and VI). In contrast, only 41% of non-cancer patients seen in general practice reported family and friends as their

main informants. More non-cancer patients believed that practitioners of NPTs had important knowledge about cancer treatment than did cancer patients (61% versus 41–43%). They also believed that NPTs should be optional in Norwegian hospitals (63% versus 43%) (papers I and VI). Both non-users and users of NPTs trusted the information about treatment given by physicians (71% versus 60%), but not promises of cure given by practitioners of NPTs (23% for both groups) (paper VI).

Factors predicting use of NPT

Patients with long-standing disease and those offered only palliative treatment often used NPTs (papers I and IV). Most patients started their use of NPTs either during the first months of disease or later after relapse of disease (paper VII). About 40% of the cancer patients using NPTs had used NPTs previously for non-cancer disease, in contrast to only 13% of the non-users (paper IV). The users reported being given less hope of cure by their physicians (paper VI). More women than men used spiritual forms of NPT, resulting in a higher number of users among women in north Norway (paper VII). Users of NPTs were somewhat younger than non-users with older patients rarely using NPTs (paper IV).

Other characteristics of NPT users

Cancer patients using NPTs are more likely to believe in environmental factors as a cause of cancer and that lifestyle changes can reduce cancer risk and lead to improvement in the cancer in patients who already have the disease. Among non-cancer patients there was an even stronger difference in opinion between those who did and those who did not believe in NPTs as a useful treatment in cancer (paper II). Users of NPTs expressed the need to have all information available about their cancer (paper III), while at the same time expressing less trust in the treatment administered at the Department of Cancer (paper III).

Effects, costs and side effects of NPT

Most users of NPTs have moderate expectations about the effects of their preferred method of NPT (paper VI). Four of ten believed that NPTs could improve their physical resistance and/or their general condition; one of ten believed that NPTs could cure their disease. However, among users of spiritual treatments, 20% believed in a possible cure (paper V). Three believed they were cured by NPT; four reported side effects of the treatment (paper VI); one had an anaphylactoid reaction resulting in

hospitalisation. The costs of spiritual healing were very low (paper V), while costs of other NPTs ranged from nothing to over £4000 (nine had paid over £1000) (paper VI).

Survival

Use of NPTs did not influence survival among cancer patients seen in north Norway (paper VII).

7 Statistical methods

All data were stored in the database 'Trades' ⁴⁹ and were analysed by the statistical computer program SAS ⁵⁰. The different statistical methods applied are described in each paper. The studies performed were authorised by the Board of Ethics of Health Region V. The Norwegian Data Inspectorate granted permission to store the data from the national study (papers IV–VI).

8 Discussion

Methods and definitions

During the past few years, many authors have started to divide non-proven methods of treatment into alternative and complementary ⁵¹. The importance of this division is to subtract those treatments that are an adjunct to conventional medicine. Typical complementary treatment has the ability to ease patients' symptoms and mental distress, including meditation, relaxing massage techniques, acupuncture for pain and symptom control, or aromatherapy. Most physicians accept the use of such methods and recognise the benefits they can give to patients. However, it must be remembered that the distinction between alternative medicine and complementary medicine is as much a question of the use of methods as it is the differences in the methods. Acupuncture could be given purely for pain control, although some therapists believe that it also treats the underlying disease. If patients believe that techniques of meditation can cure the disease, then meditation is no longer called complementary.

The non-medical method aimed at treating malignant disease which is in most use in the northern and western parts of Norway seems to be different spiritual forms of treatment. The wide spectrum of use and of faith in these methods can be

recognised easily. Many patients who base their lives on religious faith use this for support if endangered by disease. In the national study, we demonstrated that over a fifth of the patients reported a strengthening of their religious beliefs after a diagnosis of cancer. This strengthening of beliefs is one of the most important factors in sustaining patients' hopes after being struck down by a chronic illness or cancer⁵². Even so, in some instances, faith healing is not just a supplement to conventional medicine, but replaces treatment modalities such as surgery, hormone therapy or chemotherapy. In this situation, religious activities would be considered to take life rather than giving support and comfort.

The 'treatment modalities' known as spiritual healing consist of different religious and non-religious healing techniques such as laying on of hands. They represent very different entities from most of the other methods called alternative medicine. The reason for their inclusion in the present studies is their wide use in cancer and the fact that patients often use them to improve or even cure their disease. In retrospect, it would have been better to investigate the use of faith healing in a separate study because most patients do not associate this with alternative medicine. The design of the questionnaire was not optimal for such an investigation. The inadequacy in this method was

one of the reasons that the interview study was carried out among surviving patients in the follow-up study. The questions in this part of the study were designed to shed more light on different aspects of spiritual healing as well as to validate the questionnaire-based study.

Validity of the reported results

It is difficult to evaluate the validity of the information reported in questionnaire-based studies. Very seldom another well documented method, «a golden standard», giving a possibility to compare results from the new method with the established one, do exists. Two studies that addressed validity of the questionnaire-based studies were reported earlier (page 24–26).

The results from the baseline questionnaire used in the follow-up study were also compared with the answers given by participants in the national study (81 patients, November 1992). On inclusion in the follow-up study, 38% of the patients expressed a positive attitude about NPTs being offered in Norwegian hospitals. In the national study 2 years later, 'the Tromsø patients' expressed the same view in 42% of cases.

The number of ever-users in the follow-up study varied from 17.4% to 27.3%. As many as 74% of these patients had used faith healing or laying on of hands, alone or in

combination with non-spiritual forms of NPT. In the national study, 31% reported ever-use and 72% used spiritual forms of NPT. The slightly higher number of users in the national study might be explained by two factors: first, in the cross-sectional study patients had known about their malignancy longer than the participants in the follow-up study (inclusion criteria: first admittance to the Department of Oncology); second, during the period 1991–93, use of alternative medicine and especially ‘Nitter therapy’ had been heavily debated in the media. As a clinician, it was easy to recognize the immense interest that this debate evoked in our patients. The number of patients using ‘Nitter therapy’ was higher in November 1992 (one of six test–retest) and in summer 1993 (three of 13, first interview) compared with baseline data from the follow-up study, in which only one of 44 reported use of ‘Nitter therapy’. Taking account of these factors, the number of users in the studies seems to be comparable.

One of the strengths of the studies presented in this thesis could be the representative nature of the study populations. As far as I know, there has been no other study reported in which patients from all the specialized cancer clinics within one country participated. On the other hand, all the patients from the Norwegian Radium Hospital were recruited during one day whereas

inclusion time for all the other centres was one week. This could introduce a selection bias for estimates of the national use of NPT. Ideally, the inclusion time in the study should have been the same for all the regions.

Another possible bias in the national study is the relatively low inclusion rate among patients recruited at Haukeland Hospital (Health Region III). A similar number of participants, about 150, to the number in the Trondheim area would have been expected. The follow-up study in Tromsø does not have the same degree of selection bias as seen in the national study. However, some patients from the county of Nordland were treated in the Norwegian Radium Hospital, because of problems of capacity in Tromsø.

The follow-up design in the Tromsø study has not been used by others, which has given us an unique opportunity to assess the correlation between use of NPTs and survival, and to look at how this use changes throughout the life of cancer patients. It should, however, be remembered that the data in the Tromsø study are unlikely to be representative of the total cancer population in Norway.

Another bias in the follow-up study is the lack of spiritual healing as an option in the multiple-choice questionnaire at baseline. Spiritual healing was added to the second questionnaire, based on a pre-

liminary analysis of the baseline questionnaire which showed that this method was used frequently in the north of Norway. The reported prevalence of NPTs among cancer patients in the first questionnaire was therefore probably an underestimate. In the national study, three of 81 (3.7%) participating Tromsø patients reported use of faith healing alone. In the follow-up study most of the seven patients, who reported use of 'other' types of NPT, reported use of faith healing, so the underestimate is probably therefore relatively small.

Patients' opinions about the importance of NPTs and whether they should be available in Norwegian hospitals

Our studies show that a little less than half the Norwegian cancer patients believe that practitioners of NPTs could provide useful knowledge in the fight against cancer; even more patients want NPTs to be optional within our hospitals. Thus, a substantial number of patients express the wish to integrate NPTs with conventional medicine. This view was also found among non-cancer patients in north Norway (paper I). Our results are consistent with the findings of a Norwegian study⁵² carried out in 1976 in which 67% of the participating non-cancer patients were prepared to try NPTs in the

hypothetical event of being diagnosed as having a potentially life-threatening disease. Studies among cancer patients from other countries also support our findings. In a survey carried out at the Hammersmith Hospital (UK), two-thirds of cancer patients said that they would accept some form of complementary therapy if it was offered by the hospital¹⁸. Similarly, in a Canadian report from 1984²⁰ only 7% were users of NPTs, but as many as 70% would consider using them. In a recent large Dutch study¹⁷, 50% of the patients expressed an interest in NPTs as treatments for their cancer.

In our studies, the questions about patients' opinions on the importance of NPTs in the treatment of cancer, and whether or not they should be optional in hospitals, were general and not restricted to methods favoured by the patients. Patients' answers could therefore be biased because it is possible that patients believe that their preferred methods should be optional in our hospitals, but that other methods should be excluded.

In an attempt to address this problem, the questions were given in the interviews of surviving patients in the follow-up study; 74% (54 of 73) gave positive responses to NPTs as an option for patients in hospitals. These 54 patients were asked whether all methods of NPTs should be optional to the patients or only selected types: 30% believed that all

types should be optional; 43% only selected methods; and 27% could not answer the question. These figures are probably not representative of the opinions of an average cancer patient, because all the patients participating in the interview had survived their cancer for more than 5 years. In fact, most of the patients defined themselves as cured of their cancer. It is therefore possible that they felt that other patients in a less favourable position should be given treatments of their own choice.

In conclusion, a substantial number of Norwegian cancer patients, a view reported also by many other investigators, have the opinion that NPTs should be optional within Norwegian hospitals.

Factors influencing patients' use of NPTs

Our findings compared with former studies

Geographical factors, former use of NPTs, sex and age

As reported by others^{17, 21}, we found different patterns of use in different parts of the country. Our study gave us the possibility of assessing both number of users and the different methods used in various parts of the country. The finding that spiritual healing is in more common usage in the western and northern parts of Norway (paper V) could have been anticipated as it is common

knowledge that people in these areas have stronger religious beliefs. Former studies conducted among the general population in northern Norway also demonstrated that most participants believed in spiritual healing^{53, 54}. In contrast, only 15% reported the same beliefs in a study conducted in central, southern areas of Norway⁵⁴. This difference in use may explain the high number of women found among users of NPTs from north Norway. Downer et al.¹⁸ also demonstrated in their study that spiritual healing was more commonly used by women.

There is an interesting association between use of NPTs by cancer patients and use by them before developing cancer. We also demonstrated that patients' use of spiritual or non-spiritual forms of NPTs were closely related to their preferred former use of NPTs. The finding that patients who described themselves as non-religious never used faith healing underlines this observation.

Our study confirmed that users of NPTs are on the whole younger than non-users. The very low number of users (5%, paper IV) among patients over the age of 75 years seems to explain most of the differences in mean age between the two groups. These differences should be remembered before interpreting the results of a study such as this one. Older patients differ from younger patients in many aspects: they are more frequently

women and they have received less education. They often perceive less hope of a cure from their physicians and indeed they are more often treated palliatively. Also very young patients show differences in their demographic and disease-related characteristics. In the patient group aged below 30, most have a better education, more curable disease and higher hopes for the future. This 'sigmoid-shaped' curve, with good prognostic factors associated with younger and bad factors associated with older patients, is important to bear in mind in future studies where age might influence the outcome variables.

Disease-related factors

In the national study, as in most other studies, there is no significant correlation between different cancer types and use of NPTs^{15, 24}. However, in the follow-up study, as expected, there are more users of NPTs among patients with cancers that affect women (breast and gynaecological) than among those who have cancers affecting mainly men.

As reported by Zouwe¹⁷, in the national study there are a higher number of users among patients who have metastatic disease or are receiving palliative treatment. At baseline in the follow-up study, patients treated palliatively were more commonly users of NPTs, whereas there was no significant difference between patients with

locoregional disease and those with metastatic disease. During the follow-up study, disease-related factors such as stage of disease and treatment intention, could not be evaluated because these factors were measured only at baseline.

In contrast to the results reported by most other investigators^{17, 24}, the time since diagnosis was an important factor in patients' use of NPTs in our studies. This is clearly demonstrated in the follow-up study, in which only 17.4% used NPTs at baseline, although 45% reported use on one or more occasions during follow-up. This same highly significant difference was found in the national study. One reason why Zouwe did not find significantly more users of NPTs among her patients who knew about their diagnosis for a longer time could be that her cut-off point for her analysis was about 2 years. In other studies, patients sometimes started participating in the study shortly after diagnosis³⁷, so many of these patients could possibly not have started NPTs. Our conclusions are that, in order to test for prevalence of use of NPTs in cross-sectional studies, the time since diagnosis must be at least 6 months.

Other factors

There is no direct evidence in our study to support the statement that patients using NPTs have less confidence in conventional medicine than non-users; 60% of the users and

over 70% of non-users completely trusted a physician who promised them a cure. As many as 90% of the patients stated that their physician had advised neither for nor against use of NPTs. However, users of NPTs did report less satisfaction with the conventional medical treatment received than non-users. They also reported less hope of cure from their physicians than non-users. The primary contact with the physician could, therefore, be of importance in patients' later use of NPTs.

Patients' motivation for use of NPTs and their hopes of treatment

The moderate expectations of treatment which were expressed by the users of NPTs in our study have also been reported by others. Downer et al¹⁸ reported that most patients in their study approached complementary therapy with the expectation of some effect on their disease. Even though these hopes were not fulfilled for most patients, they were still satisfied with the therapies that they had chosen. The use of NPTs could also fulfil an important psychological need, with the difference in perceived hope reported by users of NPTs possibly being one of the reasons why they seek this alternative. This conclusion is strengthened by similar findings in other foreign studies, all of which

stress the importance of giving hope to cancer patients^{18, 24, 39}, again emphasizing the importance of the primary contact with the physician in patients' choice of therapy.

The observation that information and advice given to patients about NPTs came mainly from family and close friends supports the impression that use of NPTs represents a coping strategy for both the patient and family. It must be remembered, however, that another reason for seeking NPTs could be that patients have used this alternative previously in treatment of non-malignant disease, that is, NPTs provide a familiar way of dealing with a health problem.

Aspects of information and communication, patients' religious beliefs and patients' opinions about life-style and environmental factors

The ambition of this dissertation has not been to provide an explanation for patients' decision to use NPTs in cancer treatment, based on personality traits. Other authors¹⁷ have tried to describe health-related behaviours using different models: the Health Belief Model⁵⁶, models describing psychological coping⁵⁷, models describing the health locus of control⁵⁸ and van Aakster's model⁵⁹.

As a clinician I chose to concentrate on aspect important to me in my daily work. From the research of Cassileth and Berger, I knew that patients using NPTs differed substantially in their beliefs about illness from patients using only conventional therapy. One major factor associated with this use of NPTs was the belief that the cancer could have been prevented and its development could therefore be reversed using the same means. Other researchers, however, reported that cancer patients had much vaguer beliefs about the course of their disease than patients with non-malignant disease⁶⁰.

For me, the first part of Orwel's thesis on equality has always meant that, as a doctor, I should strive to give every patient support that is matched to their needs. It is not always necessary to understand why some patients need more communication, information and psychological support than others; it is important, however, to accept this need and to act on it. Whether patients' use of NPTs had an influence on their preferences for information, communication and involvement in their treatment was unknown to me.

A third element that is important to many patients is their spiritual needs. In addition to the traditional psychological coping strategies, many patients use 'alternative medicine' or seek help from God, through 'normal prayer'

or spiritual healing⁶¹. Studies of nurses have indicated that they often assessed their patients' needs inaccurately^{62, 63}. To my knowledge the place of a pastoral service in Norwegian hospitals and how this service should be offered to cancer patients have never been evaluated. I wanted to explore the relationship between patients' religious beliefs and their use of NPTs.

We can conclude from these studies that patients express opinions that can often be understood in the light of their use of NPTs. The positive relationship between lifestyle and use of NPTs that has been reported in other studies²⁴ is not surprising because many methods of NPTs are aimed at improving these factors. The finding that patients who had positive views about use of NPTs in cancer were not completely satisfied with the treatment received is not surprising and nor is the fact that they often wanted more information than other patients. It is also possible to understand that patients diagnosed with a serious disease such as cancer seek support in religion. Another theory is possible: if we look at disease through the eyes of a health economist, the number of religious believers could well go down after diagnosis of serious disease – why did they get sick but their non-religious neighbours are well and fit? In this 'marked theory' a number of patients could lose their faith. However, this 'theory' has proved

wrong. The finding that faith healing is closely connected to patients' personal religious beliefs is important, supporting the impression that patients retain their standards in life even with their serious disease. The adaptation of a religious belief to treat cancer 'intentionally' is probably a very rare event.

Our findings underline the importance of giving information to patients in a form that is understandable and balanced. The importance of good communication cannot be ignored. The ongoing project among Scandinavian oncologists, which is aimed at bettering their communication skills, cannot therefore be underestimated.

Patients' use of NPTs in terms of survival

Through anecdotes and case reports, practitioners of NPTs and their patients and supporters claim success for their regimens in curing cancer. There are, however, few convincing data about the clinical efficacy of NPTs. The relationship between use of NPTs and survival has been studied very little. In a population of patients with breast cancer who attended the Bristol Cancer Help Centre in the late 1980s, survival was analysed⁶⁴. No differences were found between users and non-users of various alternative treatments. The same conclusions were reported by

Cassileth et al.⁶⁵ in 1991 from a study comparing survival rates between late-stage patients receiving the so-called Livingston–Weeler therapy⁶⁶ and patients treated with conventional methods. To our knowledge no prospective follow-up study has been carried out that correlates patients' use of NPTs with survival.

The limitations of our study include the modest number of participants, the many different types of cancer and the fact that all patients were recruited from Health Region V (more patients used spiritual healing than in most other parts of the country). Taking these into account, the results showing no difference in survival between the two groups were convincing. Another factor, not discussed in paper VII, is the finding, also observed in the national study, that older patients (< 75) very rarely used NPTs and had a higher mortality rate than younger patients. This could result in a higher mortality among non-users of NPTs. Reanalysis excluding patients aged over 75 years gave almost identical results, as shown in Table 4 in paper VII, although there was a lower relative risk (RR) of death among better educated patients (RR = 0.5; 95% confidence interval or 95% CI = 0.3–0.9).

9 Conclusion

In seven papers, we have aimed to describe the background and use of alternative medicine or NPTs, among cancer patients in Norway. Different studies have shown us that a substantial number of patients use NPTs once or more. The number of users and their preferred choice of treatment differ throughout the country: the coastal areas in the northern and western parts of Norway are characterized by high use of spiritual healing, whereas patients in more urban areas in the southern part often preferred non-spiritual types of NPTs. We have demonstrated that users of NPTs differ from non-users in various aspects such as opinions about causes of cancer and their need for information and communication. The insight gained from the studies about patients' opinions on causes of cancer, and their preferences for information and communication, is indeed limited, and I hope that other groups will study these areas in more detail in the future.

Many aspects of our studies have confirmed knowledge reported by others, although we have gained new information in other areas. We found that four of ten users of NPTs among cancer patients had used some sort of NPT previously as a treatment for non-malignant disease. With the results demonstrating that the methods used were closely

related to lifestyle and their former choices of NPTs, this study indicated that patients do not change their values even if stricken by serious disease. An example of this consistency was shown by the finding that no patient who defined himself as non-religious ever used faith healing.

I believe that our studies point to some very important relationships between ourselves as practitioners of 'school medicine' and patients. It is important to remember patients' modest expectations of the possible effects of NPTs and their high degree of trust in conventional medicine. This tells us that patients wish to retain the core of conventional medicine, and that telling the truth, professional treatment and imparting of knowledge are greatly appreciated by them. Why then do so many seek to use NPTs? There are probably a multitude of reasons. Modern humans would like to 'live forever'. Many of our patients need to participate in their own destiny – they need a little something, a place to hide away, somewhere that is outwith knowledge and common sense. At the same time, patients wish to be informed about their disease and possible treatment. I believe it is imperative that scientific medicine also in the future hold on to the requirements of exact knowledge and tidy testing routines. In my opinion conventional medicine must keep on being just

that. However, elements of NPTs, known as supportive or complementary treatments, could be important in the treatment of some of our patients.

In the end, I believe that it is important that conventional medicine secures the place of being the best possible treatment for patients, but we have to respect patients' choice in their use of NPTs. The treatment of cancer patients is related not only to diagnosis and the correct use of chemo- and radiotherapy, but also to the provision of optimal patient information and communication so that we can improve patients' ability to cope with a difficult situation and help them adjust to it. Improvement

in this area of doctors' skills may reduce patients' need for NPTs. The patients must be told that our commitments as physicians is to continue care for them even though the goals of the treatment might have to change.

However, as stated by Lerner in 1985 ⁶⁷ different «cures» will continue to appear, whether new or recycled from the past. This will happen until cancer is more generally successfully treated. It is important that those working in oncological centres understand the appeal of NPT to patients and that they deal sympathetically and in earnest with patients questions about them.

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Errata.

The following errors have escaped correction in proof:

Paper I, page 894, Table 1, last paragraph should read:

Family Life

Alone	48	15.8	45	17.9
With partner with or without children	247	81.6	200	79.3
Other	8	2.6	7	2.8

Paper V, page 277, fifth and fourth last lines should read:

- cancer . Of 88 patients who used non-religious NPTs as cancer patients , 33 (38%) had employed NPTs as treatment for an

Recalculations

An inconsistency is found in paper V page 279, last two lines were we reported as follow:

«This study suggested an underreporting of faith healing of more than 30%, but the figures are uncertain due to the small sample population» (Skarshaug, 1994).

The data is interpreted somewhat erroneously. The analysis is shown on page 21 in the thesis. Similar number of users (13/31) were found both in the questionnaire based study and in the interview. There is no underreporting of faith healing, however, there is a misclassification of 2 patients reporting non-use of NPT in both parts of the

Paper I

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

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.

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

	Non-cancer patients		Cancer patients		p-value
	n	%	n	%	
Sex					
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	
Education					
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	
Family life					
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 χ^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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Paper II

Patients' Opinion and Use of Non-Proven Therapies Related to their View on Cancer Aetiology

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Abstract. *Background:* The aim of the study was to investigate patients' attitudes to and use of nonproven therapies (NPTs) in view of their opinions about causes of cancer. *Material and Methods:* A comparative questionnaire-based study was given to patients with non-malignant disease (n=305) seen in general practice and cancer patients (n=252) seen at the Department of Oncology, University Hospital of Tromsø. *Results:* Among non-cancer patients significantly more NPT-positive than NPT-negative patients considered the environment to be an important cancer cause (74% versus 52%) and that food and drink may be carcinogenic (57% versus 40%). For cancer patients, there was no such difference. 60% of non-cancer patients and 35% of cancer patients believed that life style changes could alter the natural course of cancer. In both groups of patients, the NPT-positive believed, to a higher degree than the NPT-negative, that the outcome of cancer could be improved by a change in life style (69% and 48% versus 53% and 29%). *Conclusion:* Patients positive to NPTs have firmer beliefs with respect to the importance of environmental factors than non-believers/users. Moreover, these patients believed more strongly than NPT-negative patients that change of lifestyle may influence the outcome of cancer positively.

Epidemiological studies suggest that environmental factors might be responsible for 80-90% of all cancer in humans (1-3). Health authorities and cancer societies in the western world have responded to this fact. Primary cancer control efforts have been designed to inform the public about the risks of cancer and to encourage risk reduction behaviour.

The cornerstone of any cancer prevention programme is the public's awareness of cancer. However, knowledge alone does

not seem to be enough to make people change their habits and act on the given information. The "health belief model" and its application on public health behaviour as described by Becker (4) suggests that for people to act to prevent a condition, they must, besides possessing the knowledge, see themselves as vulnerable, the condition as threatening, believe in the efficacy of intervention and perceive few difficulties in undertaking the action. The preventive actions taken may also depend on factors such as gender, age, educational level and other cultural and socioeconomic factors.

Cassileth *et al* (5) reported in 1984 that patients who used or had used non-proven therapy (NPT) differed substantially in their beliefs about illness from patients using only conventional therapy. One major factor associated with patients' use of NPT was the belief that their cancer could have been prevented and that the development of the disease may be reversible by the same means. Other studies have also shown that cancer patients using alternative medicine believe more in the importance of environmental factors and lifestyle factors as causes of cancer than others (6,7). Furthermore, the report by Linn *et al* (8) indicate that cancer patients to a greater extent than patients with non-malignant disease have vague beliefs about the causes of cancer.

To our knowledge, comparative studies correlating cancer and non-cancer patients' belief and use of NPT to their opinions on causes of cancer have not yet been performed. The aim of this study was to examine a) whether patients' opinion on the importance and use of non-proven therapies influenced their views on environmental and life style factors as cancer causes, b) if cancer patients hold other opinions on causes of cancer and the importance of life style than patients with non-malignant diseases, and c) whether users of NPTs are more confident that life style change can improve the natural cause of malignant disease.

Materials and Methods

Questionnaire and recruitment of patients. A longitudinal questionnaire-based study (5 questionnaires) was initiated at the Department of

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Oncology, University Hospital of Tromsø in July 1990. A section of the questionnaire was designated to the patients' use of NPT, their views on the importance of NPT in the fight against cancer, and their opinion on causes of cancer. Inclusion in the study required informed consent, ability to read and understand the questionnaire, and a WHO performance status of 0-3. All in-patients and patients receiving radiotherapy as out-patients, who were seen for this first time, were eligible for this study. Patients were recruited over 12 months. The cancer patients were compared to a patient population with non-malignant diseases from general practice. The examining physician and the general practitioner delivered the questionnaire to the patients upon arrival at hospital and the community medical centre, respectively. Since the questionnaire was part of a longitudinal study at the Department of Oncology, cancer patients were assured confidentiality but not anonymity. Since all non-cancer patients in general practice received only one questionnaire, these patients were assured of anonymity.

The part of the questionnaire relevant to this paper is presented in the Appendix.

Use of NPT. The concept of NPT was defined as use of healing by hand, herbs and diets, homeopathy, zone therapy, injection therapies and the use of 'seven star' (local variant). Patients could also add any other types of therapy in response to an open question. More than 60% of the cancer patients used spiritual forms of NPT (healing by hand and faith healing). In contrast, the majority of non-cancer patients used other forms of NPT. Patients' use and opinions of NPT are described in detail in a previous publication (9).

Users of NPT and patients expressing a positive opinion on the usefulness of NPT as treatment for cancer were regarded as NPT-positive (NPT-pos). On the other hand, non users of NPTs and patients expressing negative views on the usefulness of NPTs in the treatment of cancer were defined as NPT negative (NPT-neg).

Cancer patients. Of 263 eligible cancer patients, 252 (96%) participated in the study. The study population consisted of 122 women and 130 men. The mean age was 58 years (range 17 - 89). The majority of patients had an educational level corresponding to elementary school (75 %). Twenty per cent of the patients were unmarried. About half of the study population was presently employed and working. Sixty per cent of patients had localised/regional disease while the rest had locally advanced or metastatic disease.

Assessed by the ECOG performance status (0-normal activity to 4-completely bedridden), most patients were in good general condition (50% WHO 0, 39% WHO 1). The treatment was given with a curative intent in 45% of the cases. For allocation with regard to cancer diagnoses, see Table I.

Non-cancer patients. A population of 400 consecutive patients attending four different community medical centres in the three northernmost counties of Norway was invited to answer identical questions about use of NPTs and causes of cancer as the cancer patients. The selection of community centres were done to secure a geographical spread similar to the cancer patients. A total of 325 (81%) of the non-cancer patients responded. Of these, 20 patients were excluded due to present or previous cancer disease (n=14) or missing data about present or prior malignant disease (n=6), leaving 305 included non-cancer patients (76%). The mean age was 50 years (range 17-85). The study population consisted of 163 women and 136 men. In 6 cases gender was unknown. Sixty-three per cent of patients had an educational level corresponding to elementary school. Sixteen per cent of the patients lived alone.

Statistics. Statistical analyses were performed using the statistical computer program SAS^R, testing for differences between categorical variables with chi-square as given in the Proc Freq procedure (10). Logistic regression analyses were used to simultaneously analyse factors influencing patients' opinions on the importance of environment and life style with regard to the cause and prevention of cancer. Multivariate

Table I. Prevalence of cancer diagnoses.

Malignancy	Cancer patients	
	n	%
Breast cancer	52	20
Lung cancer	40	16
Urogenital cancer	40	16
Malignant lymphomas	30	12
Gastrointestinal cancer	30	12
Head and neck cancer	15	6
Gynaecological cancer	13	5
Smaller diagnostic groups	32	13
Sum	252	100

analyses were performed by Logistic regression analyses after dichotomising the answer categories, as described by Breslow (11). Because of a slight imbalance in sex, age and education between the two groups of patients, the populations were compared after direct standardisation for these variables (SIR) (12). Since the standardisation did not alter the results of the study, our results are shown without standardisation. The different number of subjects within various variables is due to missing data.

Ethics. The patients were informed that all data would be treated confidentially. Furthermore, all patients were explained that refusal to participate in the study would not in any way jeopardise medical treatment or care. The study was authorised by the Regional Ethics Committee.

Results

Among the cancer patients, 28% (n=66) were considered NPT-pos. In comparison, 36% (n=105) of the non-cancer patients were NPT-pos. Among cancer patients, no significant differences concerning gender, age, or educational level were found between the NPT-pos and NPT-neg group. In the group of non-cancer patients, however, NPT-pos patients were more often better educated than the NPT-neg (45% versus 32%, P=0.04). Otherwise, there were no differences between NPT-pos and NPT-neg non-cancer patients with regard to age and gender.

Among cancer patients and non-cancer patients, 54% (n=129) and 60% (n=176), respectively, believed environmental and life style factors were very important in causing cancer (P=0.05). Only 6% (n=15) of cancer patients and 2% (n=6) of non-cancer patients totally rejected environmental factors as possible causes of cancer. There was no significant difference in NPT-pos and NPT-neg cancer

Table II. Factors influencing patients' opinions on importance of environmental influence in regard to cause and development of cancer.

Variable	Cancer patients		Non-cancer patients	
	OR*	95% CI	OR*	95% CI
Sex				
Male	1.00	Reference	1.00	Reference
Female	0.72	0.41-1.24	1.33	0.80-2.23
Age in years				
45-59	1.00	Reference	1.00	Reference
15-29	0.58	0.14-2.37	1.77	0.42-7.47
30-44	1.25	0.34-2.93	1.46	0.75-2.84
60-74	0.81	0.36-1.55	0.73	0.36-1.46
75-91	0.39	0.12-1.21	0.52	0.19-1.42
Education				
Low education	1.00	Reference	1.00	Reference
High education	1.37	0.69-2.75	1.87	1.01-3.46
Positive to use of NPT's				
Not positive	1.00	Reference	1.00	Reference
Positive	1.27	0.69-2.33	2.28	1.28-3.94

*Adjusted for the other variables included in the Table.

patient views on the importance of environmental factors in cancer development. Among non-cancer patients, however, 74% (n=73) of the NPT-pos thought that environmental factors were important, whereas a significantly smaller proportion of the NPT-neg patients (52%, n=98, P=0.004) thought so. In a multivariate analysis among non-cancer patients, higher education and positive attitudes to NPT were found to predict views in favour of environmental factors being important in causing cancer. No such differences were found among the cancer patients (Table II).

Patients who believed that environmental factors were of importance in causing cancer, were asked to rank, in a multiple choice fashion, 7 listed factors with regard to importance (Appendix). Of all patients expressing the opinion that environmental factors are of importance in developing cancer, 45% (n=100) of the non-cancer patients and 41% (n=64) of the cancer patients ranked the factors as requested from 7 to 1. In both groups, 20% marked only the two most important factors, whereas 16% (n=25) of cancer patients and 9% (n=20) of the non cancer patients listed only one factor. The rest of the patients ranked from 3 to 6 factors. Among patients ranking the factors cited air pollution and chemical substances were perceived as the most carcinogenic environmental factors by both non-cancer patients and cancer patients (37% and 36% versus 47% and 34%). The third most

Table III. Patients' opinion on importance of environment with regard to cancer.

Question ¹		Not at all	Only to a small extent	To a great extent	Do not know	Number of responding patients n
		%	%	%	%	
May anything we eat or drink result in cancer?	CP ²	5	26	45	24	244
	NCP ³	4	32	46	19	295
$\chi^2=3.67$ d.f.=3 P=0.3						
Can tobacco or alcohol consumption cause cancer?	CP	2	18	70	10	246
	NCP	1	16	78	5	297
$\chi^2=8.82$ d.f.=3 P=0.03						
Is cancer a contagious disease?	CP	85	3	0	12	251
	NCP	85	5	0	10	301
$\chi^2=2.60$ d.f.=3 P=0.5						
Is cancer a hereditary disease?	CP	18	25	27	30	251
	NCP	22	30	22	26	301
$\chi^2=3.90$ d.f.=3 P=0.3						

¹Questions 3, 4, 5, 6, given in appendix.

²Cancer patients.

³Non-cancer patients.

ranked factor among all patients were exposure to different viruses. No patients in any of the groups believed radiation from high voltage electricity to be the most important cancerogenic factor in the environment. Two to 5 % in both groups ranked radiation from the ground, radiation from computers or radiation from the sun as the most hazardous factors. Among patients listing only one environmental factor, more than 90 % chose air pollution as the most important factor. A larger part of the young and higher educated patients in both groups when compared to the older and less educated made a complete ranking. A tendency were found that these patients more often rated chemical substances as the most carcinogenic. There were, however, no significant differences between the groups.

Among both cancer patients and non-cancer patients we found a significant difference between males and females when asked whether cancer might be a contagious disease or not. Of all patients, 16% (n=41) of male patients and 6% (n=16) of female patients expressed doubt with respect to whether cancer was a contagious disease or not. Furthermore, 6% (n=16) of male and 2% (n=7) of female

Table V. Factors influencing patients' opinions on importance of lifestyle in causing cancer.

Variable	Cancer patients		Non-cancer patients	
	OR*	95% C.I	OR*	95% C.I
Sex				
Male	1.00	Reference	1.00	Reference
Female	0.64	0.36-1.13	0.90	0.80-2.23
Age in years				
45-59	1.00	Reference	1.00	Reference
15-29	0.76	0.17-3.34	1.71	0.41-7.04
30-44	1.60	0.68-3.79	0.96	0.51-1.84
60-74	0.73	0.37-1.46	1.01	0.51-2.00
75-91	0.85	0.27-2.63	0.69	0.27-1.79
Education				
Low education	1.00	Reference	1.00	Reference
High education	0.90	0.49-1.79	2.17	1.19-3.95
Attitudes to use of NPTs				
Not positive	1.00	Reference	1.00	Reference
Positive	2.34	1.27-4.31	1.84	1.07-3.14

*Adjusted for the other variables included in the Table.

patients believed cancer possibly to be a contagious disease. There was no statistical difference between the groups with regard to age, educational levels, or attitudes to NPTs (Table III).

Considering possible carcinogens in food and drink, there were no statistically significant differences in views between cancer and non-cancer patients (Table III). However, among non-cancer patients, NPT-pos patients believed to a significantly larger extent than NPT-neg patients (57% versus 40%, $P=0.02$) that food and drink may be carcinogenic. This was also the case with younger ($P<0.001$) and higher educated patients ($P<0.001$). In a multivariate analysis adjusted for age, education and attitudes to NPT we found all three factors of statistical significance (data not shown).

In both groups of patients more than 70% believed that stimulants like tobacco and alcohol may cause cancer (Table III). Non-cancer patients expressed a stronger positive opinion and had less doubt about the connection stimulants-

Table IV. Importance of patients way of living as reported by patients being positive or negative to non-proven therapies (NPT's).

	Cancer patients			Non-cancer patients			
	Positive to NPT-s	Negative to NPT s	P	Positive to NPT s	Negative to NPT s	P	
	n (%)	n (%)		n (%)	n (%)		
The way of living is important to the outcome of cancer	To a great extent	32 (48)	49 (29)	0.01	70 (69)	102 (53)	0.02
	Not at all	34 (52)	122 (71)		31 (31)	90 (47)	

cancer. Female non-cancer patients believed more strongly than men in the negative effects of these stimulants ($P=0.03$).

Both groups of patients expressed doubts with respect to whether cancer might be hereditary (Table III). Almost half of the patients believed heredity to be a possibility, while the rest found this doubtful. There were no differences between the groups. Moreover, there were no evident differences between men and women or between patients with different educational levels, though younger patients seemed to believe more in heredity or were less often in doubt than older patients ($p=0.04$).

The majority of cancer patients perceived life style factors to be no importance for the outcome of cancer, whereas the majority of non-cancer patients was of the opposite opinion. As much as 60% ($n=172$) of non-cancer patients strongly believed that a change in lifestyle could have a positive impact on the outcome of cancer compared to 35% ($n=81$) of the cancer patients ($P<0.001$, Table IV). In both groups of patients, NPT-pos patients believed, to a higher degree than NPT-neg patients, that the outcome of cancer would be improved by a change in lifestyle (69% and 48% versus 53% and 29%). By multivariate analysis we found that NPT positivity and negativity were significant predictors for patients' attitudes to life style as cause of cancer (Table V) For non-cancer patients, higher education also seemed to be of significant importance.

According to both patient groups, the changes in lifestyle that would be effective in preventing cancer were cessation of cigarette smoking and a more healthy diet (Table VI). Moreover, NPT-pos cancer patients rated healthy diet higher than NPT-neg patients.

In both groups the NPT-neg patients believed more in the importance to stop smoking than NPT-pos patients ($P=0.02$). Otherwise there were only minor differences between the groups. In fact, no patient mentioned alcohol avoidance as one of the most important changes in life style. A larger proportion of the cancer patients, when compared to non-cancer patients, was in doubt which life style changes would be important in preventing development of malignant disease.

Table VI. Patients' general opinion on which change in lifestyle that would be most important with respect to prevention of cancer.

Factor ³	Cancer patients				Non-cancer patients			
	NPT-pos ¹ (n=65)		NPT-neg ² (n=167)		NPT-pos (n=101)		NPT-neg (190)	
	n	(%)	n	(%)	n	(%)	n	(%)
Only one given factor								
To stop smoking	12	(19)	45	(26)	13	(13)	51	(27)
To eat healthier	15	(24)	26	(16)	9	(9)	19	(10)
To do exercise more	2	(3)	0	(0)	1	(1)	3	(2)
To avoid alcohol consumption	0	(0)	0	(0)	0	(0)	0	(0)
Two factors mentioned								
Smoking/eating	8	(12)	28	(17)	32	(31)	40	(21)
Smoking/exercise	2	(3)	2	(1)	2	(2)	6	(3)
Smoking/alcohol	2	(3)	3	(2)	0	(0)	5	(2)
Exercise/eating	6	(9)	2	(1)	3	(3)	5	(3)
More than two factors mentioned								
	12	(18)	42	(26)	37	(37)	53	(28)
Do not know								
	6	(9)	19	(11)	4	(4)	8	(4)
SUM	65	(100)	167	(100)	101	(100)	190	(100)

$\chi^2=20.60$ d.f.=10 P=0.02 $\chi^2=14.69$ d.f.=10 P=0.20

Missing 32 patients

¹Patients positive to use of NPT

²Patients negative to use of NPT

³The question asked with answer categories are given in Appendix

Discussion

The aim of this study was to examine attitudes to NPTs in cancer and non-cancer patients and to relate these attitudes to their opinion on the value of life style changes and to their opinion on cancer. To our knowledge, no previous study has compared attitudes to NPT correlated to views on cancer aetiology in populations of cancer patients and non-cancer patients.

Because of a slight imbalance in age and education between the two groups of patients the populations were compared after standardisation for these variables. The

standardisation, however, did not alter the results of the study to a significant degree (12,13). Our results are therefore for reasons of simplicity shown without standardisation (SIR).

One may speculate as to whether general practice patients with secured anonymity would answer more freely to sensitive questions like opinions on and use of NPTs than the cancer patients. We have, however, previously shown that fewer non-cancer patients when compared to cancer patients answered questions concerning own use of NPTs (9). On the other hand, cancer patients (no anonymity) due to fear of exploiting unpopular opinions, may under report their use of NPT and appear pseudo-sceptical to use the of NPTs within

our hospitals. The effect of such a bias would be a reduction of the differences between the NPT-pos and the NPT-neg patients in our study. Alas, reported differences between the two groups would then appear smaller than they actually are.

In the study by Cassileth from 1984 (5), users of NPT believed that cancer could be prevented primarily through diet (32% of patients), stress reduction (33%) and environmental changes (26%). In contrast, only 15% of patients treated by conventional therapy alone, believed their cancer to be preventable. The findings of Cassileth seems to support our observations that users and supporters of NPT believe that positive changes in life style may prevent development of malignant disease and improve its course. The positive relationship between life style and use of NPT reported from other studies, may not be surprising since most NPTs are aimed at improving the patients' mental capacity and immunology to counteract illness. Spiritual healing is, however, the most commonly used NPT among cancer patients from northern Norway. The consistent correlation between life style and use of NPT in our study is therefore somewhat surprising.

The observation that non-cancer patients are more dogmatic about the causes of cancer as described by Linn *et al* (8), is also evident in our study. The phenomenon of expressing strong opinions when the consequences have little personal relevance may be demonstrated in our study by the non-cancer patients expressing more positive attitudes towards use of NPT in malignant disease than the cancer patients.

With regard to self-inflicted malignant disease, Linn *et al* (8) postulated that it was likely that cancer patients needed to defend themselves against self-blame as a mean of coping with a potentially fatal disease. Our study was not designed to answer this hypothesis, but we did not find evidence to reject it. What our study did show is that presence of malignant disease influenced the patients' opinion on the importance of environmental and life style factors. Moreover, the absence of malignant disease seems to predict a stronger opinion on the beneficial role of life style changes on the natural cause of cancer.

Environmental factors and life-style factors (like cigarette smoking and alcohol consumption) were analysed separately. The National health authorities have focused on cigarette smoking as the most dangerous life-style factor. Consequently, the possibility that tobacco use would override all other life style factors in a list of potential dangerous environmental factors was therefore expected. However, not more than 41-70% ranked cigarette smoking alone the most important factor in preventing cancer. Interestingly, NPT-pos patients were less likely to indicate cigarette smoking as the most important single lifestyle factor with regard to cancer development. Unfortunately, there are no data in our study showing whether less users of NPT are cigarette smokers compared to non-users. It is possible that users of NPT focus rather more on life style factors easier to change like diet and

exercise. Despite increasing awareness about the carcinogenic effects of cigarette smoking, the number of daily cigarette smokers have remained unaltered in Norway during the last decade. A phenomenon parallel to this was found by Weinstein *et al* (14) in their study on public perception of the risk from radon. They concluded that increased knowledge about radon increased respondents' readiness to acknowledge risks within the community, but had no effect on their willingness to admit that their own homes could be at risk.

Regarding environmental factors as cause of malignant disease, our results may have been influenced by the fixed set of options in the multiple choice list. Given another selection of factors, the results may have differed to some extent. Furthermore, the geographical setting for this study (three northernmost counties in Norway) may have influenced the data since there has been much focus on air pollution from Russia in this region (nuclear weapon testing during the 1960's and today's heavy pollution from industry near the Norwegian border). However, the finding that air pollution and chemical substances were regarded as the most cancerogenic agents in the environment by both groups of patients is consistent with the study by Luther *et al* (15). Moreover, Berger (6) found that about half of the cancer patients in his study believed that environmental contamination could lead to cancer. In the report by Linn *et al* (8), patients with non-malignant disease estimated occupation-related factors the most important, while late-stage cancer patients believed that God's will was even more important as a cancer cause. Eidinger *et al* (16) reported that only 6% of 190 cancer patients considered their cancer as a punishment for their life style or actions that they had committed before developing cancer.

Consistent with Linn *et al* (8), we found that young patients more often believed cancer to be inherited. This underlying cause may be the only «acceptable» reason for young individuals struck by a malignant disease. The reason why males in both patient groups accepted more easily than females the possibility that cancer is contagious can only be a matter of speculation.

In conclusion, this study supports the view that cancer patients appear to have less firm convictions about what is causing cancer than non-cancer patients. It demonstrates that patients using or believing in positive benefits from NPTs have firmer beliefs with respect to the importance of environmental factors than nonbelievers/-users. Moreover, these patients believed more strongly than NPT-neg patients that change of life style may influence the outcome of cancer positively.

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Appendix.

Question (causes of cancer)

1. Do you believe that the environment surrounding us is important as a cause of cancer? Not at all. Yes, but only to a slight degree. Yes, very much so. I do not know.

2. If you believe the environment to be important as a cause of cancer, which environmental factors do you believe are the most important. Please rank the factors given in the list so that the most important factor is given the number 7 and the least important factor is given the number 1. If you believe other environmental factors to be more important, please state so with the name of the factor.

- 1 Air pollution
- 2 Radiation from the ground
- 3 Radiation from high voltage electricity
- 4 Radiation from computers
- 5 Sun exposure
- 6 Chemical substances
- 7 Virus
- 8 Other environmental factors

3. Do you believe that anything you eat or drink might cause cancer? Not at all. Yes, but only to a slight degree. Yes, very much so. I do not know.

4. Do you believe that stimulants (like tobacco and alcohol) might cause cancer? Not at all. Yes, but only to a slight degree. Yes, very much so. I do not know.

5. Do you believe cancer to be a heritable disease? Not at all. Yes, but only to a slight degree. Yes, very much so. I do not know.

6. Do you believe cancer might be a contagious disease? Not at all. Yes, but only to a slight degree. Yes, very much so. I do not know.

7. Do you believe that (a cancer-patient) by changing your (his/her) way of living, in a positive way, would improve on the outcome of your (his/her) disease? Not at all. Yes, but only to a slight degree. Yes, very much so. I do not know.

8. What would be the most important change in life-style for most people to prevent cancer. 1. Stop smoking. 2. Avoid alcohol, 3. More (daily) exercise. 4. Healthier diet. 5. Do not know. Other changes. Please mark them here...

Questions. Opinion on use of alternative medicine.

Alternative medicine

1. Do you believe that others apart from medical doctors (as represented by doctors in hospitals) may have knowledge important in fighting cancer? Examples on such practitioners could be: healers, practitioners of zone-therapy, homeopathy. Not at all. Yes, but only to a slight degree. Yes, very much so. I do not know.

2. Would you like alternative medicine to be optional within hospitals? No. Yes. I do not know.

3. If you use or have used alternative medicine as treatment of your cancer, please state the type of treatment you used (patients were given a list of different forms of NPT).

Paper III



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Original Paper

Communicating with and Treating Cancer Patients: How Does the Use of Non-proven Therapies and Patients' Feeling of Mental Distress Influence the Interaction Between the Patient and the Hospital Staff

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A questionnaire-based study was carried out at the Department of Oncology, University Hospital of Tromsø, during the period July 1990–October 1991. The 252 participating patients received a questionnaire at arrival at the oncology unit and the surviving patients a follow-up questionnaire at home 4 months later. The aim of the study was to assess whether patients' attitudes to information about their malignant disease and satisfaction with the given treatment correlated to their use of non-proven therapies (NPTs) and reported mental distress. Patients under 45 years of age significantly more often preferred comprehensive medical information than older patients (83% versus 52%, $P = 0.001$). Better educated patients were more satisfied with the information given by their general practitioner (GP) ($P = 0.05$) and at their local hospital ($P = 0.02$) than other patients. Of all responders, 81% of the patients treated in the department were completely satisfied with the opportunities to ask questions while 87% reported being given comprehensive information. Only 2% of the patients reported to have received unwanted information. Better educated patients expressed less satisfaction with the information given and the possibility of influencing their own treatment at the Department of Oncology ($P = 0.02$). Patients expressing mental distress wanted less information ($P = 0.05$) and expressed less satisfaction with the quality of the perceived information in the oncology unit ($P = 0.004$). They were also less satisfied with the treatment given ($P = 0.05$) and their own influence on the treatment decision ($P = 0.02$). Users of NPT did not feel the received treatment to be the best possible ($P = 0.04$). © 1997 Elsevier Science Ltd.

Key words: Norway, alternative medicine, mental distress, information, communication, cancer patients

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INTRODUCTION

THE CONCEPT of the patient as a passive receiver of medical information has dramatically changed during the last decades. Recent studies [1] have shown that both patients and their physicians prefer open communication and frankness about disease-related matters. Oken [2] reported 35 years

ago that the majority of physicians (90%) preferred to conceal the diagnosis of cancer from their patients. Eighteen years later, Novack and associates [3] documented a complete change in American doctors' attitudes concerning patient information. Several studies have shown that chronically ill patients, and especially cancer patients, often prefer full disclosure of diagnosis and prognosis. Despite being told "bad news", correct information may provide patients with emotional support, reducing psychological morbidity and enhancing their hopefulness [4–8]. The opinion that the patients should be told the truth has been accompanied by

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an emphasis on involvement of the patients in the decision-making with regard to treatment of the disease. However, a substantial number of patients prefer to receive less than full information and are reserved with regard to partaking in decisions concerning their own treatment [9].

Cassileth and associates [9] described that young and better educated patients more often prefer open communication and full disclosure, and prefer to participate in their own care, compared to older and less educated patients. She found that more optimistic patients often wanted full disclosure of both good and bad news.

One aspect of active participation may be the patients' use of non-proven therapies (NPT). In order to avoid helplessness and depression when told that they suffer from a potentially life-threatening disease, patients may try to assert control over their own health by turning to alternative therapies. Whether the patients' use of NPT influences their preferences regarding information about their disease is largely unknown. As reported by Cassileth [9], patients' feeling of hope, related to their treatment and prognosis, influence their preferences of disclosure with regard to diagnosis and prognosis. In a recent study [10], we presented data demonstrating that cancer patients expressing little hope of beneficial treatment results more often were older, had metastatic disease, received palliative treatment, had known their diagnosis for a longer period of time and were users of NPT. Mental distress may be associated with lack of hope. It is, therefore, possible that mental distress may predict patients who prefer to be less extensively informed than more optimistic and less distressed patients.

The aim of this study was to examine attitudes towards information and active participation in the treatment discussion process among Norwegian cancer patients. Thus, we have assessed both quantity and quality of disease-related information from general practitioners, local hospital and cancer clinics, as viewed by the patients. Furthermore, the impact of mental distress and use of NPT on patients, preferences regarding information and participation in the treatment process were investigated.

PATIENTS AND METHODS

Questionnaires

A longitudinal questionnaire-based study was carried out at the Department of Oncology, University Hospital of Tromsø, during the period July 1990–June 1991. The questionnaires were based on multiple choice questions, but patients also had the possibility of giving open comments.

The two questionnaires dealt with in this paper were part of a larger longitudinal study over 5 years (5 questionnaires). The first questionnaire, presented to the cancer patients on arrival at our oncology unit, was designed to assess patients' attitudes to information about their malignant disease and their use of NPTs prior to admittance to our hospital. This questionnaire also addressed patients' mental distress. Psychological distress was measured using a five-item modification of the 20-item General Health Questionnaire [11].

Four months after discharge from the hospital, patients included in the study received a follow-up questionnaire by mail. This questionnaire focused on possible changes in their use of NPT, mental distress, satisfaction/dissatisfaction with disease and treatment-related information and communication during the hospital stay. Furthermore, they were asked to state their opinion on the quality of the treatment they had received and to indicate whether they took part in the decision-making process regarding their own treatment.

At inclusion in the study, the physician responsible for the patient completed a questionnaire concerning patient diagnosis, time since diagnosis, stage of disease, performance status and aim of treatment (palliative/curative).

Patients

Eligible for the study were all cancer patients who had been referred to the Department of Oncology for the first time. The ability to read and understand the questionnaire were criteria for inclusion in the study. Patients with poor performance status (ECOG = 4) were not eligible.

Table 1. Characteristics of 252 cancer patients answering the first questionnaire and 180 evaluable patients answering the second questionnaire

	Patient population			
	Start of study		Follow-up (4 months)	
	<i>n</i>	(%)	<i>n</i>	(%)
Sex				
Female	122	(48)	92	(51)
Male	130	(52)	88	(49)
Mean age (range)	58 (17–89) years		58 (19–87) years	
Age groups in years				
17–29	11	(4)	7	(4)
30–44	37	(15)	27	(15)
45–59	71	(28)	48	(27)
60–75	110	(44)	83	(46)
75–91	23	(9)	15	(8)
Education				
Primary school	184	(73)	130	(72)
Secondary school	29	(12)	22	(12)
University degree	34	(13)	24	(13)
Unknown	5	(2)	4	(2)
Family life				
Living alone	45	(18)	26	(14)
Living with others	207	82	154	(86)

Table 2. Prevalence of diagnoses in the study group and in the remaining patients after 4 months

Malignancy	Population at study start		Population after 4 months	
	<i>n</i>	(%)	<i>n</i>	(%)
Breast cancer	52	(20)	42	(23)
Lung cancer	40	(16)	23	(13)
Urogenital cancer	40	(16)	28	(16)
Malignant lymphomas	30	(12)	25	(14)
Gastrointestinal cancer	30	(12)	18	(10)
Head and neck cancer	15	(6)	11	(6)
Gynaecological cancer	13	(5)	11	(6)
Smaller diagnostic groups	32	(13)	22	(12)
Total	252	(100)	180	(100)

Demographic characteristics of the participating patients at the start of the survey compared to the characteristics of the surviving/responding patients 4 months later are shown in Table 1. Of all eligible patients, 95.8% ($n = 252$) filled out the first questionnaire. 180 patients filled out the follow-up questionnaire. Of the 72 cancer patients who did not respond to the follow-up study, 37 were non-responders and 35 had deceased during the 4 months period. Table 2 shows the distribution of malignant diagnoses among patients responding initially and after 4 months.

69% of the patients had, at the start of the study, been aware of their cancer for less than 3 months. 58% of the patients had localised/regional disease while the rest had locally advanced or metastatic disease. Most patients were in good physical condition. 50% of the patients were classified as ECOG 0 and 39% as ECOG 1. The treatment was given with a curative intention in 45% of the cases. A detailed description of disease-related patient characteristics are described in an earlier published paper [12].

In the group of patients not responding to the follow-up questionnaire, significantly more patients had poor performance status [1-3] and reported mental distress. Otherwise, there were no differences between responders and non-responders.

Patients using NPT

At admittance, 18% (44/240) of the patients had been, or were, users of NPT. These patients are classified as users in analyses from the first questionnaire. In the second questionnaire, 36 patients reported that they had started using NPT between the first and the second questionnaire. These are the patients classified as new users from the second questionnaire.

General Health Questionnaire (GHQ 5)

In order to estimate patients' mental distress, five questions from the GHQ 20 questionnaire were answered by the patients in the first and the second questionnaire. Due to an administrative flaw, only the last 179 patients in the first part of the study were given the GHQ 5 questionnaire. In the follow-up study, all participants were given the five selected questions. The five items were selected in cooperation with an experienced psychiatrist [13].

The items selected were:

- Been able to concentrate on whatever you're doing?
- Felt that you are playing a useful part in things?
- Found everything getting on top of you?

Been feeling unhappy and depressed?

Been feeling nervous and strung up all the time?

The items were scored continuously according to the Likert scoring procedure where the score on each question ranged from 1 to 4 [11] thereby obtaining a total score theoretically ranging from 5 to 20. To obtain comparable results with other demographic and disease-related factors, such as educational level and stage of disease, degree of mental distress was ranked from 1 to 3. Patients scoring from 5-9 were analysed as having little mental distress, from 10-14 as medium distress and patients scoring from 15-20 as expressing high mental distress. A score based on a few items has been shown to rank the subjects adequately according to mental distress [11].

Statistics

The statistical analyses were performed by the statistical computer program SAS [14] testing differences between categorical variables as given in the Proc freq procedure. Multivariate analyses were done by logistic regression analyses after dichotomising the answer categories, as described by Breslow and Day [15]. Due to missing data, the number of participants may vary for some of the questions. The study was authorised by The Board of Ethics of Health Region V.

RESULTS

Patients' opinion on information received prior to admittance to the Department of Oncology

Forty-three per cent of the available patients (106/247) reported being well informed to the time of admittance to the Department of Oncology, while 34% (84/247) reported that they had received some information. Nineteen per cent (46/247) of the patients felt they had received insufficient information and 4% (11/247) no information at all with regard to their cancer.

Patients were asked whether their GP and/or their physicians at the local hospital might have concealed information regarding their malignant disease. Seventy-one per cent of patients (170/239) believed that their GP had given them all the available information and 74% of patients (170/231) expressed the opinion that doctors at the local hospital had informed them fully. The rest of the patients reported that they had received some or no information prior to admittance to the oncology unit.

Questioned whether they wanted all available information concerning their disease, including information on treatment

Table 3. Patients* opinions on the importance of comprehensive information and whether or not their GP and/or their local hospital had withheld information before admittance to the Department of Oncology

Variable	n	Patients want full information		GP gave full information		Local hospital gave full information	
		OR	95% CI	OR	95% CI	OR	95% CI
Sex							
Male	80	1.0	Ref	1.0	Ref	1.0	Ref
Female	76	1.3	0.6-2.7	1.8	0.8-4.2	1.1	0.5-2.6
Age in years							
17-44	39	5.0	1.7-14.9	0.5	0.2-1.7	0.5	0.2-1.7
45-59	50	1.0	Ref	1.0	Ref	1.0	Ref
60-91	67	1.3	0.6-2.9	1.2	0.5-3.1	0.9	0.4-2.2
Education							
Elementary school	108	1.0	Ref	1.0	Ref	1.0	Ref
More than elementary school	48	1.0	0.4-2.4	5.2	1.6-16.7	3.9	1.3-12.2
Use of NPTs							
No use of NPTs	125	1.0	Ref	1.0	Ref	1.0	Ref
Use of NPTs	31	2.4	0.9-6.3	0.8	0.3-2.1	0.5	0.2-1.4
Mental distress							
Low (5-9)	34	1.0	Ref	1.0	Ref	1.0	Ref
Medium (10-14)	86	0.3	0.1-0.9	1.1	0.4-3.1	1.0	0.4-2.7
High (15-20)	36	0.4	0.1-1.3	0.5	0.1-1.6	0.9	0.3-3.1

*Mutually adjusted. Also adjusted for performance status (ECOG) and treatment intention.

and prognosis, 58% of the patients (138/236) wanted full information while 40% preferred only the necessary information. Only 2% of the patients felt that detailed or even cursory information could be harmful. A significantly larger portion of patients aged 17-44 years (83%, 40/48) preferred to be fully informed when compared to patients above 45 years of age (52%, 98/188) ($P=0.001$). Users of NPT tended more often than non-users to prefer comprehensive information (68%, 27/40 versus 57%, 111/196).

The patients' preferences of information compared to their perceived level of information when first seen in the oncology department were as follows: of 11 patients who said they had not been given any information, 10 (91%) wanted to be fully informed, while 1 patient wanted only necessary information. Of 42 patients who replied that they had received inadequate information, 28 (67%) wanted all the available information and 14 (33%) only the necessary information. 81 patients said they had received "some information" and of these, 48% would prefer to be fully informed while 52% thought it enough to receive the necessary information. Among patients who reported being well informed, 61% (60/98) wanted all available information, 37% all necessary information. Two well-informed patients reported being given unwanted and possibly harmful information.

Patients' views on disease-related information given by their GP and local hospital before admittance to the oncology unit and their opinion on importance of such information were analysed, adjusted for gender, age, education, level of mental distress and use of NPT (Table 3). The calculations were restricted to the 179 patients that had received the GHQ 5 questionnaire. Disease-related factors, such as time since diagnosis, stage of disease and treatment intention (curative/palliative), were not associated with any of the dependent variables. Young age was the most important factor in patients wanting full disclosure while patients

expressing mental distress were satisfied with less than full information. Users of NPT more often expressed a wish for full disclosure (68% versus 57%), but the differences between users and non-users did not reach statistical significance ($P=0.2$). Patients with higher education reported being better informed by their GP ($P=0.05$) and by doctors at the local hospital ($P=0.02$) than patients with less education.

Patients' opinion of information and communication offered them in Department of Oncology

The follow-up questionnaire given to the patients 4 months after being discharged from the Department of Oncology dealt with the extent of disease and the treatment-related information patients received while staying in the hospital (Table 4). Of all responding patients, 81% (146/180) were completely satisfied with the opportunities to ask questions during their stay, and 87% of patients (156/179) reported being given comprehensive information. Moreover, 79% (142/179) believed that all available information was given to them, while 13% believed some information was withheld. Only 2% felt that most information was withheld. Two per cent (4/179) of the patients felt they had received unwanted information, but only to a small extent. 70% (126/179) of the patients were satisfied with their level of information, while 23% felt only partly so. Six per cent of patients felt they had received insufficient information.

Thirty-five per cent (61/173) of the patients reported that they had a satisfactory influence on the choice of treatment within the Department of Oncology. Thirty-two per cent (56/173) reported some influence, while the same number of patients felt they had little or no influence on the treatment choice. Seventy-two per cent (128/178) of the patients felt they had received sufficient information about the treatment. Eight per cent of the patients felt they had been given

Table 4. Patients' opinions on the quality of information about disease and treatment given at the Department of Oncology

	Not at all		Only to a small extent		To a great extent		Do not know					
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)				
Opportunities to ask questions (<i>n</i> = 180)	3	(2)	25	(14)	146	(81)	6	(3)				
Were you given information in an understandable way? (<i>n</i> = 179)	2	(1)	19	(11)	156	(87)	2	(1)				
Was information held back? (<i>n</i> = 179)	142	(79)	24	(13)	4	(2)	9	(5)				
Was unwanted information given to you? (<i>n</i> = 180)	173	(96)	4	(2)	0	(0)	3	(2)				
Was the best available treatment given to you? (<i>n</i> = 179)	0	(0)	1	(1)	100	(56)	78	(44)				
How well did you feel informed after the stay in the Department on Oncology? (<i>n</i> = 179)	No information	0	(0)	Insufficient information	11	(6)	Some information	42	(23)	Satisfactory information	126	(70)
How well was the treatment given to you explained? (<i>n</i> = 177)	3	(2)	11	(6)	35	(20)	128	(72)				
How much did you influence the treatment given to you? (<i>n</i> = 173)	No influence	51	(29)	Insufficient influence	5	(3)	Some influence	56	(32)	Satisfactory influence	61	(35)

none or only insufficient information regarding their medical treatment. While 56% (100/178) of the patients felt that they had received the best available treatment, as many as 44% (77/178) were not sure. One patient felt that he had received suboptimal treatment.

Influence of demographic and disease-related factors on patients' satisfaction with information and treatment given at the oncology unit

The level of mental distress had an impact on the patients' satisfaction with the opportunities to ask questions and the quality of medical information given in the oncology unit. Among patients expressing little mental distress, 92% (47/51) were satisfied with the opportunities to ask questions in the department while 77% (92/120) of the more distressed patients were satisfied. Patients' satisfaction with the quality of the information given was much less among the distressed patients (82%, 98/119) than patients expressing less mental distress (98%, 50/51) ($P = 0.004$). Better educated patients seemed less satisfied with opportunities to ask questions (74%, 34/46) than less educated patients (84%, 109/130), but the difference between the two groups did not reach statistical significance ($P = 0.06$). There were no differences as to patients' satisfaction with opportunity and quality of information given in the Department of Oncology with regard to gender, age or use of NPT. Disease-related factors such as stage of disease or treatment-intention did not have any impact on patients' satisfaction. In a multivariate analysis, mental distress and higher level of education were found to predict low satisfaction with different aspects of information in the Department of Oncology (Table 5).

Mental distress was also found to be a strong predictor for patients not being satisfied with the treatment given. The less distressed patients were satisfied with the treatment in 69% of cases (35/51) compared to 52% (61/118) of patients expressing more mental distress ($P = 0.05$). Only

29% (33/115) of distressed patients reported satisfactory participation in the treatment discussions compared to 51% (26/51) of the less distressed patients ($P = 0.02$). New users of NPT reported a lower confidence regarding receiving the best available treatment compared to non-users (40%, 14/35 versus 59%, 74/125) ($P = 0.04$). Better educated patients reported less influence on the choice of treatment modalities (25%, 9/36 versus 40%, 49/123; $P = 0.02$), but their satisfaction with the treatment was the same as that expressed by patients with less education. Multivariate analysis suggests that the most important factors with regard to patients' opinion on treatment quality and influence on administered treatment are mental distress and educational level (Table 6).

DISCUSSION

According to recent American [4, 9] and Northern European studies [1, 16], most cancer patients prefer full information about their cancer. Whether or not this is the case among Norwegian cancer patients has been largely unknown. Our results, where 58% of the patients preferred detailed information whereas 40% wanted only general and necessary information, indicate that Norwegian cancer patients wish to be informed, but not necessarily in all details. In a recent Norwegian study by Loge and associates [17] on physicians' attitudes towards informing the cancer patients, 81% favoured a full disclosure of the diagnosis and prognosis.

Geographical and sociocultural differences may explain some of the differences between previous studies and our study. In 1987, Newall and associates [18] reported that patients in the U.S. demanded more comprehensive information about their illness than U.K. patients. However, in a recent U.K. study among newly diagnosed lung cancer patients, Sell and associates [19] found that 92% felt that being fully informed about their diagnosis was correct. Reports from other parts of the world, such as Japan [20]

Table 5. Patients' reported opportunities to ask disease-related questions and quality of the information received in the Department of Oncology (answers dichotomised as excellent opportunities/less than excellent; and very good quality/less than very good quality)*

Variables	n	Opportunities to ask questions in the Department of Oncology		Quality of the information given in the Department of Oncology	
		Excellent opportunities OR	95% CI	Very good information OR	95% CI
Sex					
Male	77	1.0	Ref	1.0	Ref
Female	74	1.0	0.4-2.7	1.0	0.5-2.0
Age in years					
15-44	28	0.5	0.1-2.1	0.6	0.2-1.8
45-59	39	1.0	Ref	1.0	Ref
60-90	84	0.4	0.1-1.4	1.4	0.6-3.2
Education					
Elementary school	112	1.0	Ref	1.0	Ref
More than elementary school	39	0.2	0.1-0.8	1.0	0.2-4.0
New users of NPT					
No	120	1.0	Ref	1.0	Ref
Yes	31	2.3	0.6-9.1	2.3	0.4-12.7
Mental distress (GHQ 5)					
Low (5-9)	48	1.0	Ref	1.0	Ref
Medium (10-14)	82	0.2	0.1-0.8	0.4	0.2-1.0
High (15-20)	21	0.1	0.1-0.6	0.1	0.01-0.07

*Mutually adjusted. Also adjusted for performance status (ECOG) and treatment intention.

and Southern Europe [21], describe opinions among physicians and patients comparable to opinions reported from U.S. and Northern Europe in the 1950s and 1960s.

All recruited participants in our study were from Northern Norway. Whether these data are representative for the general Norwegian population is not clear. However, a previous National cross-sectional study [10] did not reveal geographical differences in patients' perceptions of promises given by physicians. This may indicate that patients' opinion

on general information concerning their disease is similar throughout the nation.

Age distribution may influence study results. In our study, young patients when compared to older patients preferred, to a much greater extent, to be told all the details about diagnosis and treatment. These results are identical to those reported by others [4, 9].

Differences in the wording of questionnaires issued to patients may also influence the results. Multiple choice questions issued in Cassileth's [9] and Blanchard's study [4]

Table 6. Patients' opinion on the quality of received medical treatment and own influence on the treatment in the Department of Oncology (answers dichotomised as very good quality/less than very good quality; and very good influence/less than very good influence)*

Variable	n	Quality of the treatment given in the Department of Oncology		Influence of the treatment given in the Department of Oncology	
		Very good quality OR	95% CI	Very good influence OR	95% CI
Sex					
Male	76	1.0	Ref	1.0	Ref
Female	74	0.9	0.4-1.9	1.2	0.5-2.5
Age in years					
15-44	27	0.5	0.1-1.4	1.5	0.4-4.9
45-59	39	1.0	Ref	1.0	Ref
60-90	84	0.5	0.2-1.2	1.5	0.6-3.9
Education					
Elementary school	111	1.0	Ref	1.0	Ref
More than elementary school	39	0.8	0.3-1.9	0.4	0.1-1.0
New users of NPT					
No	120	1.0	Ref	1.0	Ref
Yes	30	0.5	0.2-1.1	1.8	0.7-4.4
*Mental distress (GHQ 5)					
Mild (5-9)	48	1.0	Ref	1.0	Ref
Moderate (10-14)	81	0.5	0.2-1.0	0.4	0.2-0.9
Severe (15-20)	21	0.2	0.1-0.6	0.1	0.03-0.6

*Mutually adjusted. Also adjusted for performance status (ECOG) and treatment intention.

has been compared (Appendix). The wording and the number of choices are not equivalent.

Consistent with recent American and European reports [9, 19], we found that only 2% of the patients believed that detailed information could be harmful. In contrast, physicians refractory to full disclosure claim that the wish to protect the patients is the main reason for not giving full information. However, studies have shown that physicians favouring only restricted information to patients would prefer full information if they were patients themselves [22].

The strong association in our study, between growing mental distress and less satisfaction with the quantity and quality of medical information, is in accordance with previous reports [9, 23]. These reports confirm that lack of information increases stress and anxiety. Adequate information will in most cases prevent depression and actually assist many patients in sustaining optimistic attitudes. However, whether mental distress was precipitated by lack of information, or whether patients perceived information as inadequate because of their mental distress, cannot be addressed in a cross-sectional designed study.

Fifty-five per cent of the patients reported that they had received the best possible treatment. Scarce information about available alternative treatments may explain the somewhat low number of patients expressing strong confidence in the received treatment. However, the strongest predictor of little satisfaction with the received treatment and influence on the choice of treatment is patients' reported mental distress. This finding is consistent with the reports by Cassileth and associates [9], where hopefulness predicted patients' growing desire to participate in decisions regarding their own treatment.

It has been shown that patients in critical situations rely on different coping strategies. Denial of the consequences of a malignant disease, if not the diagnosis itself, may help patients to be more optimistic [9, 23]. Many patients are known to seek support from relatives and close friends [9]. Raleigh [24] studied patients with chronic illness or cancer, and found that the most important factors in sustaining hope were family, friends and religious beliefs.

The use of NPT may be an important coping strategy for many cancer patients. In a previous report, 41% of non-cancer patients reported family and friends to be their main informants of NPTs [12]. Two studies among Norwegian cancer patients has shown that 55% and 64%, respectively, reported family and close friends as the most important informants of NPT [10, 12]. The observation that NPT related information and advice are largely given by family and close friends has been shown by others [25, 26]. In order to cope with malignant disease in everyday family life, it is comprehensible that patients take advice from close friends and family rather than others. This mechanism represents a way of living with their cancer together with their close ones. Patients using NPTs tended to want more comprehensive information than non-users. To our knowledge, this has not been reported previously. Zouwe and associates [26] found, however, that users of NPTs believe less in the administered treatment and found the relationship with the treating physician less supportive. Stoll [23] concluded in 1993 that the growth in use of NPTs among relatively well-educated European patients reflected two major factors: (1) their increasing awareness of the uncertainties of orthodox cancer therapy, (2) the increase in full disclosure of infor-

mation to the patients. Patients' use of NPT might thus reflect a need to avoid awareness of the consequences of their cancer. The finding that older patients more seldom than younger patients use NPTs seems to support this theory [9, 27]. As reported by others [4, 9], we found that younger patients wanted comprehensive information regarding their disease significantly more often than old patients. In an earlier report [28], we found that among young patients using NPTs, significantly more patients would use healing by hand or spiritual healing than among middle-aged and older patients. Furthermore, patients believing that NPT could cure the disease were often young patients. These findings may reflect a greater need of "miracles" among the younger cancer patients where only cure of disease would be acceptable in view of their family situation and long normal life expectancy.

In conclusion, clinicians treating cancer patients must be aware of the difficulties related to patients' feelings of mental distress and their opinions on use of NPT. Communication with the patients might profit from such awareness and give the patients a better possibility to comprehend the medical information.

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APPENDIX

Cassileth/Blanchard [4, 9]

- a. I want only the information needed to properly care for myself.
- b. I want additional information only if it is good news.
- c. I want as much information as possible, good or bad.

Risberg et al. (present)

- a. It is important for me to know all details about my disease, to the extent this information exists.
- b. It is important for me to possess all the necessary information concerning my disease, without necessarily knowing all the details. The physicians will in any way treat me in the best possible way.
- c. It is not important with full medical information.
- d. Comprehensive information might be harmful.

Paper III





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Original Paper

Communicating with and Treating Cancer Patients: How Does the Use of Non-proven Therapies and Patients' Feeling of Mental Distress Influence the Interaction Between the Patient and the Hospital Staff

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A questionnaire-based study was carried out at the Department of Oncology, University Hospital of Tromsø, during the period July 1990–October 1991. The 252 participating patients received a questionnaire at arrival at the oncology unit and the surviving patients a follow-up questionnaire at home 4 months later. The aim of the study was to assess whether patients' attitudes to information about their malignant disease and satisfaction with the given treatment correlated to their use of non-proven therapies (NPTs) and reported mental distress. Patients under 45 years of age significantly more often preferred comprehensive medical information than older patients (83% versus 52%, $P = 0.001$). Better educated patients were more satisfied with the information given by their general practitioner (GP) ($P = 0.05$) and at their local hospital ($P = 0.02$) than other patients. Of all responders, 81% of the patients treated in the department were completely satisfied with the opportunities to ask questions while 87% reported being given comprehensive information. Only 2% of the patients reported to have received unwanted information. Better educated patients expressed less satisfaction with the information given and the possibility of influencing their own treatment at the Department of Oncology ($P = 0.02$). Patients expressing mental distress wanted less information ($P = 0.05$) and expressed less satisfaction with the quality of the perceived information in the oncology unit ($P = 0.004$). They were also less satisfied with the treatment given ($P = 0.05$) and their own influence on the treatment decision ($P = 0.02$). Users of NPT did not feel the received treatment to be the best possible ($P = 0.04$). © 1997 Elsevier Science Ltd.

Key words: Norway, alternative medicine, mental distress, information, communication, cancer patients

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INTRODUCTION

THE CONCEPT of the patient as a passive receiver of medical information has dramatically changed during the last decades. Recent studies [1] have shown that both patients and their physicians prefer open communication and frankness about disease-related matters. Oken [2] reported 35 years

ago that the majority of physicians (90%) preferred to conceal the diagnosis of cancer from their patients. Eighteen years later, Novack and associates [3] documented a complete change in American doctors' attitudes concerning patient information. Several studies have shown that chronically ill patients, and especially cancer patients, often prefer full disclosure of diagnosis and prognosis. Despite being told "bad news", correct information may provide patients with emotional support, reducing psychological morbidity and enhancing their hopefulness [4–8]. The opinion that the patients should be told the truth has been accompanied by

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an emphasis on involvement of the patients in the decision-making with regard to treatment of the disease. However, a substantial number of patients prefer to receive less than full information and are reserved with regard to partaking in decisions concerning their own treatment [9].

Cassileth and associates [9] described that young and better educated patients more often prefer open communication and full disclosure, and prefer to participate in their own care, compared to older and less educated patients. She found that more optimistic patients often wanted full disclosure of both good and bad news.

One aspect of active participation may be the patients' use of non-proven therapies (NPT). In order to avoid helplessness and depression when told that they suffer from a potentially life-threatening disease, patients may try to assert control over their own health by turning to alternative therapies. Whether the patients' use of NPT influences their preferences regarding information about their disease is largely unknown. As reported by Cassileth [9], patients' feeling of hope, related to their treatment and prognosis, influence their preferences of disclosure with regard to diagnosis and prognosis. In a recent study [10], we presented data demonstrating that cancer patients expressing little hope of beneficial treatment results more often were older, had metastatic disease, received palliative treatment, had known their diagnosis for a longer period of time and were users of NPT. Mental distress may be associated with lack of hope. It is, therefore, possible that mental distress may predict patients who prefer to be less extensively informed than more optimistic and less distressed patients.

The aim of this study was to examine attitudes towards information and active participation in the treatment discussion process among Norwegian cancer patients. Thus, we have assessed both quantity and quality of disease-related information from general practitioners, local hospital and cancer clinics, as viewed by the patients. Furthermore, the impact of mental distress and use of NPT on patients, preferences regarding information and participation in the treatment process were investigated.

PATIENTS AND METHODS

Questionnaires

A longitudinal questionnaire-based study was carried out at the Department of Oncology, University Hospital of Tromsø, during the period July 1990–June 1991. The questionnaires were based on multiple choice questions, but patients also had the possibility of giving open comments.

The two questionnaires dealt with in this paper were part of a larger longitudinal study over 5 years (5 questionnaires). The first questionnaire, presented to the cancer patients on arrival at our oncology unit, was designed to assess patients' attitudes to information about their malignant disease and their use of NPTs prior to admittance to our hospital. This questionnaire also addressed patients' mental distress. Psychological distress was measured using a five-item modification of the 20-item General Health Questionnaire [11].

Four months after discharge from the hospital, patients included in the study received a follow-up questionnaire by mail. This questionnaire focused on possible changes in their use of NPT, mental distress, satisfaction/dissatisfaction with disease and treatment-related information and communication during the hospital stay. Furthermore, they were asked to state their opinion on the quality of the treatment they had received and to indicate whether they took part in the decision-making process regarding their own treatment.

At inclusion in the study, the physician responsible for the patient completed a questionnaire concerning patient diagnosis, time since diagnosis, stage of disease, performance status and aim of treatment (palliative/curative).

Patients

Eligible for the study were all cancer patients who had been referred to the Department of Oncology for the first time. The ability to read and understand the questionnaire were criteria for inclusion in the study. Patients with poor performance status (ECOG = 4) were not eligible.

Table 1. Characteristics of 252 cancer patients answering the first questionnaire and 180 evaluable patients answering the second questionnaire

	Patient population			
	Start of study		Follow-up (4 months)	
	<i>n</i>	(%)	<i>n</i>	(%)
Sex				
Female	122	(48)	92	(51)
Male	130	(52)	88	(49)
Mean age (range)	58 (17–89) years		58 (19–87) years	
Age groups in years				
17–29	11	(4)	7	(4)
30–44	37	(15)	27	(15)
45–59	71	(28)	48	(27)
60–75	110	(44)	83	(46)
75–91	23	(9)	15	(8)
Education				
Primary school	184	(73)	130	(72)
Secondary school	29	(12)	22	(12)
University degree	34	(13)	24	(13)
Unknown	5	(2)	4	(2)
Family life				
Living alone	45	(18)	26	(14)
Living with others	207	82	154	(86)

Table 2. Prevalence of diagnoses in the study group and in the remaining patients after 4 months

Malignancy	Population at study start		Population after 4 months	
	n	(%)	n	(%)
Breast cancer	52	(20)	42	(23)
Lung cancer	40	(16)	23	(13)
Urogenital cancer	40	(16)	28	(16)
Malignant lymphomas	30	(12)	25	(14)
Gastrointestinal cancer	30	(12)	18	(10)
Head and neck cancer	15	(6)	11	(6)
Gynaecological cancer	13	(5)	11	(6)
Smaller diagnostic groups	32	(13)	22	(12)
Total	252	(100)	180	(100)

Demographic characteristics of the participating patients at the start of the survey compared to the characteristics of the surviving/responding patients 4 months later are shown in Table 1. Of all eligible patients, 95.8% ($n = 252$) filled out the first questionnaire. 180 patients filled out the follow-up questionnaire. Of the 72 cancer patients who did not respond to the follow-up study, 37 were non-responders and 35 had deceased during the 4 months period. Table 2 shows the distribution of malignant diagnoses among patients responding initially and after 4 months.

69% of the patients had, at the start of the study, been aware of their cancer for less than 3 months. 58% of the patients had localised/regional disease while the rest had locally advanced or metastatic disease. Most patients were in good physical condition. 50% of the patients were classified as ECOG 0 and 39% as ECOG 1. The treatment was given with a curative intention in 45% of the cases. A detailed description of disease-related patient characteristics are described in an earlier published paper [12].

In the group of patients not responding to the follow-up questionnaire, significantly more patients had poor performance status [1-3] and reported mental distress. Otherwise, there were no differences between responders and non-responders.

Patients using NPT

At admittance, 18% (44/240) of the patients had been, or were, users of NPT. These patients are classified as users in analyses from the first questionnaire. In the second questionnaire, 36 patients reported that they had started using NPT between the first and the second questionnaire. These are the patients classified as new users from the second questionnaire.

General Health Questionnaire (GHQ 5)

In order to estimate patients' mental distress, five questions from the GHQ 20 questionnaire were answered by the patients in the first and the second questionnaire. Due to an administrative flaw, only the last 179 patients in the first part of the study were given the GHQ 5 questionnaire. In the follow-up study, all participants were given the five selected questions. The five items were selected in cooperation with an experienced psychiatrist [13].

The items selected were:

Been able to concentrate on whatever you're doing?

Felt that you are playing a useful part in things?

Found everything getting on top of you?

Been feeling unhappy and depressed?

Been feeling nervous and strung up all the time?

The items were scored continuously according to the Likert scoring procedure where the score on each question ranged from 1 to 4 [11] thereby obtaining a total score theoretically ranging from 5 to 20. To obtain comparable results with other demographic and disease-related factors, such as educational level and stage of disease, degree of mental distress was ranked from 1 to 3. Patients scoring from 5-9 were analysed as having little mental distress, from 10-14 as medium distress and patients scoring from 15-20 as expressing high mental distress. A score based on a few items has been shown to rank the subjects adequately according to mental distress [11].

Statistics

The statistical analyses were performed by the statistical computer program SAS [14] testing differences between categorical variables as given in the Proc freq procedure. Multivariate analyses were done by logistic regression analyses after dichotomising the answer categories, as described by Breslow and Day [15]. Due to missing data, the number of participants may vary for some of the questions. The study was authorised by The Board of Ethics of Health Region V.

RESULTS

Patients' opinion on information received prior to admittance to the Department of Oncology

Forty-three per cent of the available patients (106/247) reported being well informed to the time of admittance to the Department of Oncology, while 34% (84/247) reported that they had received some information. Nineteen per cent (46/247) of the patients felt they had received insufficient information and 4% (11/247) no information at all with regard to their cancer.

Patients were asked whether their GP and/or their physicians at the local hospital might have concealed information regarding their malignant disease. Seventy-one per cent of patients (170/239) believed that their GP had given them all the available information and 74% of patients (170/231) expressed the opinion that doctors at the local hospital had informed them fully. The rest of the patients reported that they had received some or no information prior to admittance to the oncology unit.

Questioned whether they wanted all available information concerning their disease, including information on treatment

Table 3. Patients* opinions on the importance of comprehensive information and whether or not their GP and/or their local hospital had withheld information before admittance to the Department of Oncology

Variable	n	Patients want full information		GP gave full information		Local hospital gave full information	
		OR	95% CI	OR	95% CI	OR	95% CI
Sex							
Male	80	1.0	Ref	1.0	Ref	1.0	Ref
Female	76	1.3	0.6-2.7	1.8	0.8-4.2	1.1	0.5-2.6
Age in years							
17-44	39	5.0	1.7-14.9	0.5	0.2-1.7	0.5	0.2-1.7
45-59	50	1.0	Ref	1.0	Ref	1.0	Ref
60-91	67	1.3	0.6-2.9	1.2	0.5-3.1	0.9	0.4-2.2
Education							
Elementary school	108	1.0	Ref	1.0	Ref	1.0	Ref
More than elementary school	48	1.0	0.4-2.4	5.2	1.6-16.7	3.9	1.3-12.2
Use of NPTs							
No use of NPTs	125	1.0	Ref	1.0	Ref	1.0	Ref
Use of NPTs	31	2.4	0.9-6.3	0.8	0.3-2.1	0.5	0.2-1.4
Mental distress							
Low (5-9)	34	1.0	Ref	1.0	Ref	1.0	Ref
Medium (10-14)	86	0.3	0.1-0.9	1.1	0.4-3.1	1.0	0.4-2.7
High (15-20)	36	0.4	0.1-1.3	0.5	0.1-1.6	0.9	0.3-3.1

*Mutually adjusted. Also adjusted for performance status (ECOG) and treatment intention.

and prognosis, 58% of the patients (138/236) wanted full information while 40% preferred only the necessary information. Only 2% of the patients felt that detailed or even cursory information could be harmful. A significantly larger portion of patients aged 17-44 years (83%, 40/48) preferred to be fully informed when compared to patients above 45 years of age (52%, 98/188) ($P=0.001$). Users of NPT tended more often than non-users to prefer comprehensive information (68%, 27/40 versus 57%, 111/196).

The patients' preferences of information compared to their perceived level of information when first seen in the oncology department were as follows: of 11 patients who said they had not been given any information, 10 (91%) wanted to be fully informed, while 1 patient wanted only necessary information. Of 42 patients who replied that they had received inadequate information, 28 (67%) wanted all the available information and 14 (33%) only the necessary information. 81 patients said they had received "some information" and of these, 48% would prefer to be fully informed while 52% thought it enough to receive the necessary information. Among patients who reported being well informed, 61% (60/98) wanted all available information, 37% all necessary information. Two well-informed patients reported being given unwanted and possibly harmful information.

Patients' views on disease-related information given by their GP and local hospital before admittance to the oncology unit and their opinion on importance of such information were analysed, adjusted for gender, age, education, level of mental distress and use of NPT (Table 3). The calculations were restricted to the 179 patients that had received the GHQ 5 questionnaire. Disease-related factors, such as time since diagnosis, stage of disease and treatment intention (curative/palliative), were not associated with any of the dependent variables. Young age was the most important factor in patients wanting full disclosure while patients

expressing mental distress were satisfied with less than full information. Users of NPT more often expressed a wish for full disclosure (68% versus 57%), but the differences between users and non-users did not reach statistical significance ($P=0.2$). Patients with higher education reported being better informed by their GP ($P=0.05$) and by doctors at the local hospital ($P=0.02$) than patients with less education.

Patients' opinion of information and communication offered them in Department of Oncology

The follow-up questionnaire given to the patients 4 months after being discharged from the Department of Oncology dealt with the extent of disease and the treatment-related information patients received while staying in the hospital (Table 4). Of all responding patients, 81% (146/180) were completely satisfied with the opportunities to ask questions during their stay, and 87% of patients (156/179) reported being given comprehensive information. Moreover, 79% (142/179) believed that all available information was given to them, while 13% believed some information was withheld. Only 2% felt that most information was withheld. Two per cent (4/179) of the patients felt they had received unwanted information, but only to a small extent. 70% (126/179) of the patients were satisfied with their level of information, while 23% felt only partly so. Six per cent of patients felt they had received insufficient information.

Thirty-five per cent (61/173) of the patients reported that they had a satisfactory influence on the choice of treatment within the Department of Oncology. Thirty-two per cent (56/173) reported some influence, while the same number of patients felt they had little or no influence on the treatment choice. Seventy-two per cent (128/178) of the patients felt they had received sufficient information about the treatment. Eight per cent of the patients felt they had been given

Table 4. Patients' opinions on the quality of information about disease and treatment given at the Department of Oncology

	Not at all		Only to a small extent		To a great extent		Do not know	
	n	(%)	n	(%)	n	(%)	n	(%)
Opportunities to ask questions (n = 180)	3	(2)	25	(14)	146	(81)	6	(3)
Were you given information in an understandable way? (n = 179)	2	(1)	19	(11)	156	(87)	2	(1)
Was information held back? (n = 179)	142	(79)	24	(13)	4	(2)	9	(5)
Was unwanted information given to you? (n = 180)	173	(96)	4	(2)	0	(0)	3	(2)
Was the best available treatment given to you? (n = 179)	0	(0)	1	(1)	100	(56)	78	(44)
How well did you feel informed after the stay in the Department on Oncology? (n = 179)	No information		Insufficient information		Some information		Satisfactory information	
	0	(0)	11	(6)	42	(23)	126	(70)
How well was the treatment given to you explained? (n = 177)	3	(2)	11	(6)	35	(20)	128	(72)
How much did you influence the treatment given to you? (n = 173)	No influence		Insufficient influence		Some influence		Satisfactory influence	
	51	(29)	5	(3)	56	(32)	61	(35)

none or only insufficient information regarding their medical treatment. While 56% (100/178) of the patients felt that they had received the best available treatment, as many as 44% (77/178) were not sure. One patient felt that he had received suboptimal treatment.

Influence of demographic and disease-related factors on patients' satisfaction with information and treatment given at the oncology unit

The level of mental distress had an impact on the patients' satisfaction with the opportunities to ask questions and the quality of medical information given in the oncology unit. Among patients expressing little mental distress, 92% (47/51) were satisfied with the opportunities to ask questions in the department while 77% (92/120) of the more distressed patients were satisfied. Patients' satisfaction with the quality of the information given was much less among the distressed patients (82%, 98/119) than patients expressing less mental distress (98%, 50/51) ($P = 0.004$). Better educated patients seemed less satisfied with opportunities to ask questions (74%, 34/46) than less educated patients (84%, 109/130), but the difference between the two groups did not reach statistical significance ($P = 0.06$). There were no differences as to patients' satisfaction with opportunity and quality of information given in the Department of Oncology with regard to gender, age or use of NPT. Disease-related factors such as stage of disease or treatment-intention did not have any impact on patients' satisfaction. In a multivariate analysis, mental distress and higher level of education were found to predict low satisfaction with different aspects of information in the Department of Oncology (Table 5).

Mental distress was also found to be a strong predictor for patients not being satisfied with the treatment given. The less distressed patients were satisfied with the treatment in 69% of cases (35/51) compared to 52% (61/118) of patients expressing more mental distress ($P = 0.05$). Only

29% (33/115) of distressed patients reported satisfactory participation in the treatment discussions compared to 51% (26/51) of the less distressed patients ($P = 0.02$). New users of NPT reported a lower confidence regarding receiving the best available treatment compared to non-users (40%, 14/35 versus 59%, 74/125) ($P = 0.04$). Better educated patients reported less influence on the choice of treatment modalities (25%, 9/36 versus 40%, 49/123; $P = 0.02$), but their satisfaction with the treatment was the same as that expressed by patients with less education. Multivariate analysis suggests that the most important factors with regard to patients' opinion on treatment quality and influence on administered treatment are mental distress and educational level (Table 6).

DISCUSSION

According to recent American [4, 9] and Northern European studies [1, 16], most cancer patients prefer full information about their cancer. Whether or not this is the case among Norwegian cancer patients has been largely unknown. Our results, where 58% of the patients preferred detailed information whereas 40% wanted only general and necessary information, indicate that Norwegian cancer patients wish to be informed, but not necessarily in all details. In a recent Norwegian study by Loge and associates [17] on physicians' attitudes towards informing the cancer patients, 81% favoured a full disclosure of the diagnosis and prognosis.

Geographical and sociocultural differences may explain some of the differences between previous studies and our study. In 1987, Newall and associates [18] reported that patients in the U.S. demanded more comprehensive information about their illness than U.K. patients. However, in a recent U.K. study among newly diagnosed lung cancer patients, Sell and associates [19] found that 92% felt that being fully informed about their diagnosis was correct. Reports from other parts of the world, such as Japan [20]

Table 5. Patients' reported opportunities to ask disease-related questions and quality of the information received in the Department of Oncology (answers dichotomised as excellent opportunities/less than excellent; and very good quality/less than very good quality)*

Variables	n	Opportunities to ask questions in the Department of Oncology		Quality of the information given in the Department of Oncology	
		Excellent opportunities OR	95% CI	Very good information OR	95% CI
Sex					
Male	77	1.0	Ref	1.0	Ref
Female	74	1.0	0.4-2.7	1.0	0.5-2.0
Age in years					
15-44	28	0.5	0.1-2.1	0.6	0.2-1.8
45-59	39	1.0	Ref	1.0	Ref
60-90	84	0.4	0.1-1.4	1.4	0.6-3.2
Education					
Elementary school	112	1.0	Ref	1.0	Ref
More than elementary school	39	0.2	0.1-0.8	1.0	0.2-4.0
New users of NPT					
No	120	1.0	Ref	1.0	Ref
Yes	31	2.3	0.6-9.1	2.3	0.4-12.7
Mental distress (GHQ 5)					
Low (5-9)	48	1.0	Ref	1.0	Ref
Medium (10-14)	82	0.2	0.1-0.8	0.4	0.2-1.0
High (15-20)	21	0.1	0.1-0.6	0.1	0.01-0.07

*Mutually adjusted. Also adjusted for performance status (ECOG) and treatment intention.

and Southern Europe [21], describe opinions among physicians and patients comparable to opinions reported from U.S. and Northern Europe in the 1950s and 1960s.

All recruited participants in our study were from Northern Norway. Whether these data are representative for the general Norwegian population is not clear. However, a previous National cross-sectional study [10] did not reveal geographical differences in patients' perceptions of promises given by physicians. This may indicate that patients' opinion

on general information concerning their disease is similar throughout the nation.

Age distribution may influence study results. In our study, young patients when compared to older patients preferred, to a much greater extent, to be told all the details about diagnosis and treatment. These results are identical to those reported by others [4, 9].

Differences in the wording of questionnaires issued to patients may also influence the results. Multiple choice questions issued in Cassileth's [9] and Blanchard's study [4]

Table 6. Patients' opinion on the quality of received medical treatment and own influence on the treatment in the Department of Oncology (answers dichotomised as very good quality/less than very good quality; and very good influence/less than very good influence)*

Variable	n	Quality of the treatment given in the Department of Oncology		Influence of the treatment given in the Department of Oncology	
		Very good quality OR	95% CI	Very good influence OR	95% CI
Sex					
Male	76	1.0	Ref	1.0	Ref
Female	74	0.9	0.4-1.9	1.2	0.5-2.5
Age in years					
15-44	27	0.5	0.1-1.4	1.5	0.4-4.9
45-59	39	1.0	Ref	1.0	Ref
60-90	84	0.5	0.2-1.2	1.5	0.6-3.9
Education					
Elementary school	111	1.0	Ref	1.0	Ref
More than elementary school	39	0.8	0.3-1.9	0.4	0.1-1.0
New users of NPT					
No	120	1.0	Ref	1.0	Ref
Yes	30	0.5	0.2-1.1	1.8	0.7-4.4
*Mental distress (GHQ 5)					
Mild (5-9)	48	1.0	Ref	1.0	Ref
Moderate (10-14)	81	0.5	0.2-1.0	0.4	0.2-0.9
Severe (15-20)	21	0.2	0.1-0.6	0.1	0.03-0.6

*Mutually adjusted. Also adjusted for performance status (ECOG) and treatment intention.

has been compared (Appendix). The wording and the number of choices are not equivalent.

Consistent with recent American and European reports [9, 19], we found that only 2% of the patients believed that detailed information could be harmful. In contrast, physicians refractory to full disclosure claim that the wish to protect the patients is the main reason for not giving full information. However, studies have shown that physicians favouring only restricted information to patients would prefer full information if they were patients themselves [22].

The strong association in our study, between growing mental distress and less satisfaction with the quantity and quality of medical information, is in accordance with previous reports [9, 23]. These reports confirm that lack of information increases stress and anxiety. Adequate information will in most cases prevent depression and actually assist many patients in sustaining optimistic attitudes. However, whether mental distress was precipitated by lack of information, or whether patients perceived information as inadequate because of their mental distress, cannot be addressed in a cross-sectional designed study.

Fifty-five per cent of the patients reported that they had received the best possible treatment. Scarce information about available alternative treatments may explain the somewhat low number of patients expressing strong confidence in the received treatment. However, the strongest predictor of little satisfaction with the received treatment and influence on the choice of treatment is patients' reported mental distress. This finding is consistent with the reports by Cassileth and associates [9], where hopefulness predicted patients' growing desire to participate in decisions regarding their own treatment.

It has been shown that patients in critical situations rely on different coping strategies. Denial of the consequences of a malignant disease, if not the diagnosis itself, may help patients to be more optimistic [9, 23]. Many patients are known to seek support from relatives and close friends [9]. Raleigh [24] studied patients with chronic illness or cancer, and found that the most important factors in sustaining hope were family, friends and religious beliefs.

The use of NPT may be an important coping strategy for many cancer patients. In a previous report, 41% of non-cancer patients reported family and friends to be their main informants of NPTs [12]. Two studies among Norwegian cancer patients has shown that 55% and 64%, respectively, reported family and close friends as the most important informants of NPT [10, 12]. The observation that NPT related information and advice are largely given by family and close friends has been shown by others [25, 26]. In order to cope with malignant disease in everyday family life, it is comprehensible that patients take advice from close friends and family rather than others. This mechanism represents a way of living with their cancer together with their close ones. Patients using NPTs tended to want more comprehensive information than non-users. To our knowledge, this has not been reported previously. Zouwe and associates [26] found, however, that users of NPTs believe less in the administered treatment and found the relationship with the treating physician less supportive. Stoll [23] concluded in 1993 that the growth in use of NPTs among relatively well-educated European patients reflected two major factors: (1) their increasing awareness of the uncertainties of orthodox cancer therapy, (2) the increase in full disclosure of infor-

mation to the patients. Patients' use of NPT might thus reflect a need to avoid awareness of the consequences of their cancer. The finding that older patients more seldom than younger patients use NPTs seems to support this theory [9, 27]. As reported by others [4, 9], we found that younger patients wanted comprehensive information regarding their disease significantly more often than old patients. In an earlier report [28], we found that among young patients using NPTs, significantly more patients would use healing by hand or spiritual healing than among middle-aged and older patients. Furthermore, patients believing that NPT could cure the disease were often young patients. These findings may reflect a greater need of "miracles" among the younger cancer patients where only cure of disease would be acceptable in view of their family situation and long normal life expectancy.

In conclusion, clinicians treating cancer patients must be aware of the difficulties related to patients' feelings of mental distress and their opinions on use of NPT. Communication with the patients might profit from such awareness and give the patients a better possibility to comprehend the medical information.

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APPENDIX

Cassileth/Blanchard [4, 9]

- a. I want only the information needed to properly care for myself.
- b. I want additional information only if it is good news.
- c. I want as much information as possible, good or bad.

Risberg et al. (present)

- a. It is important for me to know all details about my disease, to the extent this information exists.
- b. It is important for me to possess all the necessary information concerning my disease, without necessarily knowing all the details. The physicians will in any way treat me in the best possible way.
- c. It is not important with full medical information.
- d. Comprehensive information might be harmful.

Paper IV

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Original Paper

The Use of Non-proven Therapy Among Patients Treated in Norwegian Oncological Departments. A Cross-sectional National Multicentre Study

T. Risberg, E. Lund, E. Wist, O. Dahl, S. Sundstrøm, O.K. Andersen and S. Kaasa

A national multicentre study was performed to investigate the prevalent use of "alternative medicine", here called "non-proven therapies (NPT)", applied among Norwegian cancer patients. Of 911 patients invited to take part in the study, 642 were included in the analysis. Demographic characteristics were collected for all patients. The participating physicians gave information about the patients' clinical characteristics. Among 630 evaluable patients, 20% had been or were present users of NPTs for their oncological disease. The preferred methods were healing by hand and faith healing. Herbs, vitamins, diets and Iscador were other popular methods. As many as 40% of the users of NPTs had used NPTs earlier for non-malignant diseases. Elderly patients were less likely to use NPTs. Use was high in the northern part of Norway.

Key words: Norway, multicentre study, prevalent use, alternative medicine, non-proven, cancer patients
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INTRODUCTION

THE USE of "alternative medicine" or non-proven therapy is a matter of much debate. Non-proven therapy (NPT), is defined as a remedy or treatment of any type used to treat cancer, but not proven to be effective in cancer clinical trials, and, therefore, not prescribed in public hospitals. Little is known about the use of NPTs among Norwegian cancer patients. Two studies from the late 1970s reported the number of users as varying from less than 20% to more than 50% [1, 2].

In Norway, only authorised physicians are allowed to treat malignant diseases such as cancer. The law that regulates the treatment of cancer is the law against "quackery" from 1936. It covers all aspects of diagnosis and treatment of cancer disease that is not performed by physicians. The law also deals with situations in which the aspect of healing is the main purpose of religious activity. For this reason, healing by prayers is included in the group of NPTs in this report. It is known, however, from

studies in other countries that many cancer patients seek advice and treatment from areas other than the medical profession. The number of users of non-proven cancer remedies seems to vary with regard to several factors such as geographical, socio-economical, religious and cultural [3-5].

In order to assess the use of NPTs among hospitalised cancer patients, a multicentre study, including all Norwegian cancer treatment centres, was performed. The study was designed to answer a broad spectrum of questions about cancer patients and their use of NPTs. In this first report, data on the prevalent use of NPTs and the factors influencing their use, are presented.

PATIENTS AND METHODS

In December 1992, a nationwide questionnaire-based study was initiated to evaluate the use of NPTs among cancer patients in Norway. The study was undertaken at all five regional cancer centres, to obtain a good cross-sectional national sample. An expanded version of a questionnaire developed at the University of Tromsø, Norway was used [6]. The questionnaire was designed by a consensus of experts, and its feasibility tested in a pilot study among outpatients in the Department of Oncology at the University Hospital of Tromsø. At four of the five regional centres, all in- and outpatients attending the centres during one particular week were invited to take part in the study. In the fifth centre, the Norwegian Radium Hospital, all inpatients seen in the Departments of Medical Oncology and Gynaecology on one specific day were included. The study was restricted to 1

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day at this centre because of the much larger sample size due to a wider patient recruitment area. The participating physicians in each centre reported the medical characteristics and intention of treatment for all patients attending during the specified time periods.

Patients able to read and understand the written information and the questionnaire were eligible for the study. The questionnaire was completed by the patients within the outpatient clinics during their scheduled visits, while inpatients completed the questionnaire in their hospital rooms. The patients were asked to answer questions about their thoughts and use of NPTs. Forty-eight of the 50 questions in the questionnaire were multiple choice questions. In two questions, the patients were invited to add open comments.

911 patients were invited to participate in the study. 101 patients declined to participate and 128 patients did not return the questionnaire to the investigator. A total of 682 patients (74.9%) answered the questionnaire. 33 patients answered the questionnaire but did not sign the written consent form and were, therefore, excluded. 7 patients were excluded because of missing information on age and diagnosis. The final analysis is based on a patient population of 642 (70.5%). A total of 374 women and 268 men with a mean age of 58.5 years ranging from 17 to 91 years were included in the study. The clinical characteristics of both participating and non-participating patients are given in Table 1. Sex and diagnoses were evenly distributed. Non-participants were older, had poorer performance status, and were more often inpatients than the participants.

12 patients did not give information on whether or not they were users of NPTs, and were, therefore, excluded in the analysis concerning differences between the population of users and non-users.

Logistic regression analysis was used to analyse simultaneously factors influencing the use of NPTs. Relative risk (RR) with 95% confidence interval (95% CI) was estimated by the Mantel-Haenszel statistics as given in the Proc Freq

Table 1. Characteristics of 642 participants and 269 non-participants in the study

	Participants		Non-participants		P-value	Number of patients with missing data
	n	%	n	%		
Sex						
Female	374	(58.2)	148	(58.1)	0.96	14
Male	268	(41.8)	107	(41.9)		
Age groups in years						
10-29	32	(5.0)	9	(3.6)	<0.001	19
30-44	103	(16.0)	26	(10.4)		
45-59	206	(32.1)	60	(24.0)		
60-75	210	(32.7)	95	(38.0)		
75-95	91	(14.2)	60	(24.0)		
Inpatient	344	(57.8)	151	(69.6)	0.002	99
Outpatient	251	(42.4)	66	(30.4)		
Performance status						
ECOG 0	275	(44.2)	70	(30.0)	<0.001	57
ECOG 1	190	(30.6)	80	(34.4)		
ECOG 2	86	(13.9)	46	(19.7)		
ECOG 3	59	(9.5)	23	(9.9)		
ECOG 4	11	(1.8)	14	(6.0)		

procedure in the SAS [7]. It was explained to the patients that all information offered would be treated confidentially, and that refusal to participate in the study would not in any way jeopardise the care and treatment they would receive in the hospital. The study was authorised by The Board of Ethics of Health Region V. Permission was granted by the Norwegian Data Inspectorate to store personal information concerning each patient.

RESULTS

The diagnoses of the patients in the study population compared to the prevalence of diagnoses in the overall national cancer population is shown in Table 2. Breast, lung and testicular cancer and malignant lymphomas were more prevalent in the study population. Malignant melanomas, kidney and bladder cancers, prostatic cancer and gynaecological cancer were less prevalent. This discrepancy is explained by the fact that the study population consisted of patients offered radiotherapy or medical oncological treatment.

126 of the 630 (20%) participating cancer patients used one or more types of NPTs (95% CI: 16.8-23.1%). (Table 3). There were no significant differences between users and non-users in relation to diagnoses, gender or level of education. However, there was an increasing number of NPT users with increasing education (test for trend: $P = 0.02$). This effect was not apparent when patients aged 75 years or above were excluded (test for trend: $P = 0.17$). Users of NPTs were more frequently middle-aged and had known about their disease for more than 3 months. Among the users of NPTs, more patients had distant metastases, and most users of NPTs were receiving palliative treatment. In the group of patients with relapse of disease, most users had experienced their relapse within the last year. Non-users were more often older people.

Of the users, 47.6% used more than one method (Table 4). The preferred NPTs among cancer patients, when used as single therapy, were healing by hand (18.2%) and faith healing (22.7%).

120 patients (19.0%) had used NPTs for non-malignant diseases prior to the diagnosis of cancer. The most used forms of NPTs were homeopathy (32.8%), zone therapy (10.9%) and

Table 2. Diagnoses in the study group compared with prevalence of cancer diseases in Norway

Malignancy	Multicentre population		Prevalence of cancer*	
	n	%	n	%
Breast cancer	172	26.8	20480	18.5
Malignant lymphomas	77	12.0	4161	3.8
Gastrointestinal cancer	65	10.1	15004	13.6
Gynaecological cancer	53	8.3	15885	14.4
Lung cancer	42	6.5	2326	2.1
Testicular cancer	38	5.9	2580	2.3
Brain tumours	33	5.1	1353	1.2
Prostatic cancer	33	5.1	9209	8.3
Urological cancer	28	4.4	9312	8.4
Malignant melanoma	17	2.6	8511	7.7
Unknown diagnosis	0	0.0	576	0.5
Smaller diagnostic groups	84	13.1	21237	19.2
Sum	642	100.0	110634	100.0

*Prevalence figures referring to the number of patients with a diagnosis of cancer from 1953 to 1992 alive on 1 January 1992 were provided by the Cancer Registry of Norway.

Table 3. Characteristics of 126 users and 504 non-users of NPTs

	Users of NPTs		Non-users of NPTs		P-value	Missing values
	n	%	n	%		
Sex						
Female	73	(57.9)	295	(58.5)	0.90	0
Male	53	(42.1)	209	(41.5)		
Age in years						
15-29	6	(4.8)	25	(5.0)	0.002	0
30-44	27	(21.4)	76	(15.1)		
45-59	48	(38.1)	157	(31.2)		
60-74	41	(32.5)	162	(32.1)		
75-91	4	(3.2)	84	(16.7)		
Education						
Primary school	64	(52.9)	318	(64.1)	0.4	13
Secondary school	27	(22.3)	88	(17.7)		
University degree	30	(24.8)	90	(18.2)		
Stage of disease						
No disease	19	(15.7)	98	(20.1)	0.03	22
Localised/regional	44	(36.4)	221	(45.4)		
Distant metastases	58	(47.9)	168	(34.5)		
Month since diagnosis						
0-3	17	(14.2)	160	(32.1)	0.007	12
3-6	17	(14.2)	48	(9.6)		
6-12	17	(14.2)	56	(11.2)		
>12	69	(57.4)	234	(47.0)		
If relapsed, how many months						
0-3	20	(35.1)	94	(44.1)	0.02	14
3-12	25	(43.8)	63	(29.6)		
>12	12	(21.1)	56	(26.3)		
Intention of treatment						
Cure	36	(33.0)	210	(46.2)	0.008	66
Palliation	73	(67.0)	245	(53.8)		

Table 4. Non-proven therapies used by Norwegian cancer patients

	One type only (n = 66)	In combination with other NPTs (n = 60)
Healing by hand	12	24
Homeopathy	7	21
Zone therapy	0	8
Herbs/vitamins	6	15
Diets	9	14
Nitter therapy*	6	11
Isador	8	21
Others	3	16
Healing by prayers (faith)	15	23

*Nitter treatment consists of vitamin B12, gammaglobulins, tranexamic acid, multivitamins and nutritional supplement.

herbs and diets (7.6%). As many as 24.4% had used combinations of two or more methods in which homeopathy also was the most common treatment modality.

The various types of NPTs used by the patients before diagnosis of cancer in relation to their use of NPTs as cancer

patients are shown in Table 5. The users of NPTs could be divided into two groups: those who used religious forms (faith healing) of NPTs and those who did not. Cancer patients who used non-religious forms of NPTs had very seldom used religious forms of therapy before the diagnosis of cancer. By contrast, patients who used faith healing alone or in combination with other therapies as cancer patients, had often used the same modality earlier for non-malignant diseases.

Patients who had used NPTs before their diagnosis of cancer were more frequent users of NPTs after the cancer diagnosis (age-adjusted relative risk: 2.81). Patients from the northern part of Norway (Health Region V) used relatively more NPTs than patients from the rest of the country. Gender, living conditions and education did not relate significantly to use of NPTs (Table 6). Patients with poor performance status, metastatic disease, and those who had their cancer diagnosed more than 3 months previously used NPTs more frequently (Table 7). In a logistic regression analysis, including all demographic and disease-related factors, no major changes were found in estimates of odds ratio (OR) compared to the age-adjusted RR in Tables 6 and 7. The only exception was for former use of NPTs where the estimate of OR increased to 8.0, (95% CI: 4.6-14.0). This was mostly due to the effect of calculating OR instead of RR in a situation where the prevalence of NPT was high (20%).

144 cancer patients (32.1%) not at present using NPTs reported that they might consider using NPTs, whereas 164 (36.5%) rejected the idea (figures not shown). Patients over 75 years of age were less likely to report that they would consider using NPTs. When asked to state what kind of NPT they might use, most patients preferred homeopathy, zone therapy, herbs and diets.

DISCUSSION

One in five Norwegian cancer patients in our sample used NPTs. The study population was likely to be representative of the cancer patient population seen in Norwegian cancer clinics since all the major Norwegian treatment centres were represented in the study. A response rate to the questionnaire of 70% was deemed acceptable since the study population was unselected, including very sick and old patients. The non-participants in the study were older than the participants. This could have introduced a selection bias giving prevalence figures higher than the actual one since elderly patients were more rarely users of NPTs. Alternatively, participating users may have under-reported their use to us in a non-anonymous study, leading to a lower estimate of users.

We chose to run the major analysis by the use of relative risk as an estimate of the probability of using NPTs, instead of OR, mainly as a consequence of the fact that with high prevalence, OR is no longer an unbiased estimate of the relative number of users [8].

In the U.S.A., three major surveys have been carried out in the last 10 years. Cassileth and associates reported that 13% of cancer centre patients had been or were users of NPTs [9]. Harris and colleagues indicated 15% users of NPTs in a survey including 207 cancer patients [10]. Shapiro and associates, commissioned by the American Cancer Society (ACS), 2 years later conducted a survey including more than 5000 patients [11]. The study was conducted by telephone interviews and indicated that 9% of the cancer patients were users. In a Canadian study from 1984, Eiding and associates only found 7% users of NPTs among 190 interviewed cancer patients [12]. In studies from

Table 5. Relationship between the use of NPTs prior to and after the diagnosis of cancer*

NPTs used prior to diagnoses of cancer	NPTs after diagnoses of cancer					
	No use (n=497)		Use of non-religious NPTs (n=88)		Use of religious variants of NPTs† (n=37)	
	n	%	n	%	n	%
Healing by hand	2	0.4	3	3.4	6	16.2
Healing by prayers‡	1	0.2	0	0.0	7	18.9
Homeopathy	30	6.0	9	10.2	0	0.0
Zone therapy	9	1.8	2	2.3	2	5.4
Herbs/diets	3	0.6	6	6.8	0	0.0
Others	7	1.4	3	3.4	0	0.0
Combinations	17	3.4	10	11.4	2	5.4
Sum	69	13.8	33	37.5	17	45.9

*20 patients did not answer the question of former use as non-cancer patients or use of NPTs as cancer patients. One user of NPTs as a non-cancer patient did not give information as to whether as a cancer patient he was a user of NPTs; †Healing by prayers as only NPTs, or together with other methods of NPTs, are defined in this paper as religious variants of NPTs.

Table 6. The influence of demographic factors on the use of NPTs among Norwegian cancer patients given as relative risk (RR) with 95% confidence interval (95% CI)

Variable	RR*	95% CI
Sex		
Female	1.00	Reference
Male	1.02	0.74-1.41
Living condition		
Living alone	1.00	Reference
Living with others	1.20	0.80-1.81
Education		
Elementary education	1.00	Reference
Higher education	1.30	0.94-1.80
Use of NPTs for non-malignant diseases		
Never used NPTs	1.00	Reference
Former use of NPTs	2.81	2.08-3.80
Health regions		
I	1.00	Reference
II	1.25	0.80-1.96
III	1.51	0.90-2.53
IV	0.77	0.47-1.25
V	1.67	1.06-2.63

*Relative risk adjusted for age.

Germany and Switzerland, as many as 40-50% of the participating cancer patients had been or were users [13, 14]. In a recent Dutch report, 15.2% of the interviewed cancer patients had some experience with NPTs [15]. Scandinavian studies are few. A Finnish survey from 1980 reported 45.0% users [16].

In 1976, a study from the northernmost county of Norway of the general population showed that 34% of the respondents had used NPTs [17]. A national study that was undertaken in 1977 showed that 19% of a general population of 808 had used one or more of the four studied forms of NPT [18]. Studies from Sweden and Denmark [19-21] have indicated use of NPTs among the general population of the same magnitude. A recent study from the U.S.A. in a non-selected group consisting of 1539 subjects, found that 34% of the respondents had used at

Table 7. Disease-related factors in relation to the use of NPTs given as relative risk (RR) and 95% confidence interval (95% CI)

Variable	RR*	95% CI
Stage of disease		
No disease, local disease	1.00	Reference
Locoregional disease/metastatic disease	1.64	1.17-2.28
Performance status		
ECOG=1	1.00	Reference
ECOG=1 and 2	1.73	1.20-2.52
ECOG=3 and 4	1.45	0.80-2.65
Months since diagnosis		
0-3	1.00	Reference
>3	2.34	1.50-3.64

*Relative risk adjusted for age.

least one unconventional therapy during the previous year [3]. The study showed that the prevalence and frequency of use of unconventional methods differed with 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 also users of unconventional therapy. In our study, we found that 19.0% of the patients used NPTs prior to the diagnosis of cancer. This is in accordance with earlier reports. The preferred types of alternative medicine among patients with non-malignant diseases in Norway are homeopathy, zone therapy and acupuncture. This contrasts with the preferred methods of the cancer patients who use healing by hand, faith healing, Nitter therapy, Iscador, herbs, vitamins and diets.

Healing by prayer is a well defined concept in Norway. The probability that patients do not discriminate between "ordinary" prayer and healing by prayer is, therefore, small.

A strong association was found between cancer patients' use of NPTs and their use of NPTs before they developed cancer. Such an association has not been described in earlier studies, but

this finding seems to be the most important predictor for later use in our study.

Some studies conclude that hospitalised users of NPTs are often better educated than non-users [4, 15, 16]. However, we could not find such a relationship. Our findings are in accordance with the findings reported by Cassileth and her group in 1984, and some recently published European studies [7, 11].

When disease progresses, more patients use NPTs. This has also been reported by others [15]. There is, however, a clear decrease in the frequency of use of NPTs when performance status equals ECOG 3 and 4. Older patients' infrequent use of NPT has also been reported in other studies [15].

Eidinger and associates [12] reported that 70% of patients would like to use NPTs but only 7% were in fact using them. In the Norwegian national study from 1977, 66.6% of patients were willing to try NPTs in a hypothetical situation if they had a fatal disease. In our study, one in three non-users would consider trying NPTs, one-third rejected the idea, while one in three was undecided. In their hypothetical choice of method, these patients seem to react more like non-cancer patients preferring homeopathy, zone therapy, diets and vitamins.

Time since diagnosis, symptoms of disease, age and former use are the most important factors related to the use of NPTs. A typical user in our study is a man or a woman between 30 and 60 years of age, with more than 3 months since diagnosis and who has used NPTs for other diseases prior to the diagnosis of cancer. The patient has mild to moderate cancer-related symptoms. The disease is incurable and the patient is offered palliative treatment. The methods preferred by cancer patients differ from the most popular non-proven methods among patients with non-malignant disease.

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APPENDIX

Participating institutions

The Norwegian Radium Hospital	Stener Kvinsland/Claes Tropic
Ullevål Hospital	Steinar Hagen
University Hospital of Bergen	Olav Dahl
University Hospital of Trondheim	Olbjørn Klepp
University Hospital of Tromsø	Erik Wist

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Paper V



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Original Paper

Spiritual Healing Among Norwegian Hospitalised Cancer Patients and Patients' Religious Needs and Preferences of Pastoral Services

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In a national questionnaire-based multicentre study, the use of 'alternative medicine', here called non-proven therapy (NPT), was examined. Five questions about the patients' religious beliefs and their preferences concerning pastoral services in the hospitals were included. Among the 911 invited patients, 642 (70.5%) were included in the analysis. Spiritual healing, defined as faith healing and healing by hand, was the most frequently used NPT among Norwegian cancer patients. Almost 50% of cancer patients using spiritual healing had used NPTs, mainly spiritual healing, prior to the diagnosis of cancer. Women, elderly people and patients using faith healing described themselves more often as religious. 139 (23%) of the responding patients reported a strengthening of their religious belief after the diagnosis of cancer. Patients less than 45 years of age and better educated patients expressed more frequently that all patients should be offered pastoral services during the hospital stay. Older patients, in spite of being more religious, expressed that the patients themselves had to request such services.

Key words: Norway, alternative medicine, spiritual healing, cancer patients, religious belief, pastoral service

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INTRODUCTION

FOR THE majority of cancer patients, the diagnosis of cancer is a shocking experience caused by the unpredictability of the disease and the lack of good treatment results seen in many cancer forms. Patients' 'coping strategies' in this situation might differ. In addition to the traditional psychological coping strategies, many patients use 'alternative medicine' [1] or seek help from God, through 'normal prayers' or spiritual healing [2]. The official religion in Norway is Lutheran Protestantism. Approximately 88% (last official count 1980) of the population are registered as such.

The place of pastoral service in Norwegian hospitals and how the patients should be offered this service during hospital stay have been debated, but to our knowledge never evaluated. The use of spiritual healing among the Norwegian general public was described by Bruusgard and associates [3] in 1978. They reported spiritual healing to be common especially in

the northern part of Norway. Faith healing and healing by hand (spiritual healing) are well-defined entities in Norway, both clearly separated in peoples mind from well wishing and normal religious prayers. These phenomena have not previously been studied among Norwegian cancer patients.

In a national multicentre study, cancer patients' use of 'alternative medicine' including spiritual healing, here called non-proven therapy (NPT), was studied. The patients were also questioned about their religious needs while staying in hospital.

The aim of this analysis was to examine the extent of use of spiritual healing (healing by hand or faith healing), and the factors that influence it among Norwegian cancer patients. At the same time, we wanted to explore the relationship between healing and religious belief and to clarify to what extent the diagnosis of cancer influences patients' religious beliefs.

PATIENTS AND METHODS

A nationwide questionnaire-based study was performed in December 1992 to evaluate the use of NPTs among cancer

patients in Norway. The study was undertaken at all five Norwegian regional cancer centres, one in each health region, to obtain a cross-sectional national sample. Health regions I and II are situated in the south and south-west of Norway, including the capital Oslo; health region III in the western part; and health region IV in the central part of Norway. The most northern parts of the country are defined as health region V.

At four of the five regional centres, all in- and outpatients attending the centres during 1 week were invited to take part in the study. In the fifth centre, The Norwegian Radium Hospital (NRH) (health region I), all inpatients seen in the departments of general oncology (combined medical oncology and radiotherapy) and department of gynaecology on one specific day in the same period were included. The study was restricted to 1 day at this centre due to a much larger sample size. The age distribution at this centre was similar to the other centres. Sixty-three per cent (125/200) of the NRH population were women. At the other centres, the percentage of female patients ranged from 53 to 61%. These differences were not statistically significant ($P = 0.5$). 44 of the 49 patients with gynaecological cancer were included at NRH. There were, however, no significant differences between the group of patients with gynaecological cancer and the rest of the participants from NRH with respect to their answers to the questionnaire. The patients with gynaecological cancer could therefore be included in the final analysis. The participating physicians at each centre reported the medical characteristics for all patients attending their institutions.

An expanded version of a questionnaire developed at the University of Tromsø, Norway, was used [4]. The questionnaire was designed by a consensus of experts and its feasibility tested in a pilot study among outpatients at the Department of Oncology. A validating study including 31 patients using a structured interview, with the questionnaire as an interview guide was performed. The questionnaire was completed by the patients within the outpatient clinics during their scheduled visits, while inpatients completed the questionnaires in their hospital rooms. The patients were asked to answer questions about their religious beliefs and their use of NPTs. Forty-eight of the 50 questions in the questionnaire were in a closed form. In two questions, the patients were invited to add open comments. Five questions concentrated on patients religious needs, shown in the Appendix.

Patients able to read and understand the written information and the questionnaire were eligible for the study. 911 patients were invited to participate. 101 patients declined to participate and 128 patients did not return the questionnaire to the investigator. A total of 682 patients (75%) answered the questionnaire. 33 patients answered the questionnaire, but did not sign the written informed consent form and were excluded from the study. 7 patients were excluded because of missing information on age and diagnosis. The final analysis was based on a patient population of 642 (71%). A total of 374 women and 268 men with a mean age of 58.5 years, ranging from 17 to 91 years, were included in the study. Non-participants were older, had worse performance status and were more often inpatients than participants [5]. Sex and diagnoses were evenly distributed. 12 patients did not answer whether they were users of NPTs or not and were excluded from the analysis concerning differences between the users and non-users. The number of participants differed in different questions owing to missing data.

The statistical analyses were conducted using the statistical package SAS with tests for differences between categorical variables with chi-square as given in the Proc Freq procedure [6]. Logistic regression analysis was used to analyse simultaneously factors influencing religious belief, change in religious belief during time of disease and factors influencing use of spiritual healing [7]. The patients were told that all information offered would be treated confidentially and that refusal to participate in the study would not in any way jeopardise their care and treatment in the hospitals. The study was authorised by The Board of Ethics of Health Region V. Permission to store personal information concerning each patient was granted by the Norwegian Data Inspectorate.

RESULTS

Forty-one per cent (246/600) of the participating patients considered themselves to be religious, 39% (236/600) to be non-believers, while 20% (118/600) were in doubt (Table 1).

A total of 24% of the patients (145/594) reported a change in their religious belief after the diagnosis of cancer (Table 2). 139 patients (96%) reported a strengthening of their belief, whereas 6 patients (4%) reported a weakening (data not shown). Patients with advanced disease and patients diagnosed more than 3 months prior to the study reported more frequently a change in their religious belief. Similarly, patients using faith healing and patients who defined themselves religious also reported a change in religiousness after contracting cancer.

In a multivariate analysis of religious faith and change in belief during cancer disease, women, patients older than 60 years and patients using NPTs were found to a larger extent to consider themselves religious. There were no significant differences between believers and non-believers with respect to educational level, stage of disease, time since diagnosis, performance status or treatment intention. Users of NPTs who considered themselves to be believers and with metastatic disease, more often experienced a change in the depth of religious belief during disease compared to other patients. In the multivariate analysis, time since diagnosis was no longer found to be a significant risk factor of change of beliefs (Table 3).

79 of 243 patients (33%) who defined themselves as believers, reported a change in the depth of their belief, 2 of whom reported a decline. Among the non-believers, 31/227 (14%) reported a shift in their religious belief. 31 of 110 patients (29%) who were in doubt about their religiousness reported a change after the diagnosis of cancer. Four of these patients reported a decline in faith during their disease.

Women, patients with performance status ECOG 2-4, patients treated for relapsed disease and patients from the Oslo area and the western part of Norway, were less satisfied with the availability of pastoral services (Table 4). Young patients and those with higher educational level more often stated that patients should be offered contact with a priest (data not shown). Of patients less than 45 years of age, 75/131 (57%) had this opinion compared to 176/465 (38%) of patients above 45 years of age ($P = 0.001$). Among patients using faith healing, 80% wanted pastoral services to be offered to all patients. Very few patients felt that all patients should be encouraged to meet a priest while staying at the department (1%).

A total of 126 (20%) of the 630 participating patients used NPTs in one form or another. When summing all patients

Table 1. Religious beliefs according to sex and age

	Religious <i>n</i> = 246 (41%) <i>n</i> (%)	In doubt <i>n</i> = 118 (20%) <i>n</i> (%)	Non-religious <i>n</i> = 236 (39%) <i>n</i> (%)
Sex			
Female (<i>n</i> = 344)	173 (70)	74 (63)	97 (41)
Male (<i>n</i> = 256)	73 (30)	44 (37)	139 (59)
	$\chi^2 = 43.79$	d.f. = 2	<i>P</i> = <0.001
Age in years			
15-29 (<i>n</i> = 31)	10 (32)	6 (19)	15 (48)
30-44 (<i>n</i> = 99)	31 (31)	16 (16)	52 (53)
45-59 (<i>n</i> = 196)	73 (37)	42 (21)	81 (41)
60-74 (<i>n</i> = 194)	83 (43)	45 (23)	66 (34)
75-91 (<i>n</i> = 80)	49 (61)	9 (11)	22 (28)
	$\chi^2 = 26.17$	d.f. = 8	<i>P</i> = 0.001

42 (6.5%) patients did not answer the question.

Table 2. Changes in religious belief after contracting cancer

	No change <i>n</i> (%)	Slightly changed <i>n</i> (%)	Changed to a great extent <i>n</i> (%)
Sex			
Female (<i>n</i> = 340)	250 (74)	63 (19)	27 (8)
Male (<i>n</i> = 254)	199 (78)	37 (15)	18 (7)
	$\chi^2 = 1.94$	d.f. = 2	<i>P</i> = 0.34
Age in years			
15-29 (<i>n</i> = 30)	25 (83)	2 (7)	3 (10)
30-44 (<i>n</i> = 96)	71 (74)	18 (19)	7 (7)
45-59 (<i>n</i> = 194)	140 (72)	44 (23)	10 (5)
60-74 (<i>n</i> = 190)	143 (75)	27 (14)	20 (11)
75-91 (<i>n</i> = 84)	70 (83)	9 (11)	5 (6)
	$\chi^2 = 14.10$	d.f. = 8	<i>P</i> = 0.08
Stage of disease			
No disease/local (<i>n</i> = 263)	214 (18)	36 (14)	13 (5)
Regional/metastatic (<i>n</i> = 312)	222 (71)	60 (19)	30 (10)
	$\chi^2 = 8.76$	d.f. = 2	<i>P</i> = 0.01
Users of NPTs			
Non-users of NPTs (<i>n</i> = 461)	365 (72)	72 (16)	24 (5)
Users, non-religious (<i>n</i> = 86)	59 (69)	18 (21)	9 (11)
Users, religious forms (<i>n</i> = 36)	16 (44)	10 (28)	10 (28)
	$\chi^2 = 34.0$	d.f. = 4	<i>P</i> < 0.001
Are you a religious person?			
Yes, I am religious (<i>n</i> = 243)	164 (68)	44 (18)	35 (14)
I do not know (<i>n</i> = 110)	79 (72)	25 (23)	6 (6)
No, I am not religious (<i>n</i> = 227)	196 (86)	29 (13)	2 (1)
	$\chi^2 = 40.14$	d.f. = 4	<i>P</i> < 0.001
Months after diagnosis			
0-3 months (<i>n</i> = 162)	133 (82)	24 (15)	5 (3)
More than 3 months (<i>n</i> = 420)	306 (73)	74 (18)	40 (10)
	$\chi^2 = 8.14$	d.f. = 2	<i>P</i> = 0.02

Characteristics such as education, number of relapses, inpatient/outpatient, intention of treatment or performance status (ECOG), did not separate the groups.

Table 3. Factors influencing patients' religious beliefs and changes of such during cancer disease

Variable	Religious beliefs among cancer patients		Change of religiousness during cancer disease	
	OR*	95% C.I.	OR*	95% C.I.
Sex				
Male	1.00	Reference	1.00	Reference
Female	3.61	2.32-5.59	0.99	NS
Age in years				
15-29	1.00	Reference	1.00	Reference
30-44	0.82	NS	1.72	NS
45-59	1.06	NS	1.64	NS
60-74	2.16	NS	1.19	NS
75-91	4.01	1.28-12.60	1.00	NS
Use of NPTs				
No use of NPTs	1.00	Reference	1.00	Reference
Use of NPTs (religious forms inclusive)	2.61	1.52-4.50	1.79	1.12-2.86
Stage of disease				
Local disease	1.00	Reference	1.00	Reference
Metastatic disease	1.27	NS	1.62	1.05-2.49
Religiousness				
Not believing in God	----	----	1.00	Reference
Uncertain	----	----	2.04	1.13-3.68
Believing in God	----	----	2.67	1.64-4.37

*Adjusted for the variables included in the table, in addition to non-important factors in these analysis, education, family life, time since diagnosis, purpose of treatment and function status (ECOG).

using spiritual forms of NPTs alone or in combination with non-spiritual forms, we found that 63 patients used spiritual and 63 used non-spiritual forms of NPTs. In the northern and western part of Norway, we found that 71% of the users of NPTs (30/42) had used spiritual healing. Patients from the eastern and southern parts of Norway including Oslo used more non-religious forms of NPTs. Only 36% (23/64) used spiritual healing, while 64% (41/64) used non-religious forms of NPTs. In central Norway 50% of the users of NPTs (10/20) used healing by hand or faith healing (Table 5).

When patients using healing by hand alone or in combination with others NPTs were defined as users of healing, we found that healing by hand was more frequently used by women (8%, 29/368) than men (3%, 8/262), a difference of 4.8% (C.I.: 1.29-8.31) and more often by younger (10%, 14/134) than older patients (6%, 23/408), a difference of 4.8% (C.I.: 1.04-8.56). Among patients under 30 years of age, all users (6/31) used spiritual healing (data not shown). Non-spiritual forms of NPTs seemed to be more frequently used by men (13%, 33/262) than women (8%, 30/368) but the difference failed to reach significance (Table 6). In a multivariate analysis, spiritual healing was more often used by patients reporting to be religious (odds ratio (OR) = 5.13, 95% C.I.: 2.46-10.68) and by patients being in doubt of their own belief (OR = 3.39, 95% C.I.: 1.43-8.00) compared to patients who were non-believers. Significantly more patients

knowing their diagnosis of cancer for more than 3 months used spiritual healing than patients more recently diagnosed (OR = 3.15, 95% C.I.: 1.40-7.04) while stage of disease had no significant impact on patients decision to use spiritual healing or not (mutually adjusted).

Patients were classified according to their religious belief. Religious patients used non-spiritual NPTs as much as the non-religious patients, but used more spiritual forms of NPT (Table 7). Of 13 patients that used faith healing only, 2 expressed doubt whether they were religious or not and 11 defined themselves as believers. Patients employing healing by hand did not consider themselves as more religious than non-users of NPTs. Non-religious patients never used faith healing and only seldom healing by hand. In the group of patients uncertain about their religious beliefs, healing by hand was employed, while few used faith healing.

17 of 36 (47%) employing faith healing had been prior users of NPTs (faith healing, 8/17, healing by hands, 6/17, and other types of alternative medicine, 3/17). In contrast, users of non-religious forms of NPTs had in no instance used faith healing as treatment for other diseases before contracting cancer. Of 84 patients that used non-religious NPTs as cancer patients, 33 (39%) had employed NPTs as treatment for an earlier non-malignant disease. 4 of these 33 patients (12.1%) had used healing by hand alone or in combination with other NPTs (data not shown).

Table 4. Satisfaction with spiritual care and pastoral services in the hospital

	No <i>n</i> (%)	Yes <i>n</i> (%)		
Sex				
Female (<i>n</i> = 198)	87 (44)	111 (56)		
Male (<i>n</i> = 157)	51 (33)	106 (68)		
	$\chi^2 = 4.84$	d.f. = 1	$P = 0.03$	
Age in years				
15-29 (<i>n</i> = 23)	9 (39)	14 (61)		
30-44 (<i>n</i> = 70)	26 (37)	44 (63)		
45-59 (<i>n</i> = 112)	39 (35)	73 (65)		
60-74 (<i>n</i> = 108)	42 (39)	66 (61)		
75-91 (<i>n</i> = 42)	22 (52)	20 (48)		
	$\chi^2 = 4.01$	d.f. = 4	$P = 0.39$	
Treatment				
Primary treatment (<i>n</i> = 151)	59 (39)	92 (61)		
First relapse (<i>n</i> = 76)	29 (38)	47 (62)		
Second relapse (<i>n</i> = 65)	34 (52)	31 (48)		
Outpatient control (<i>n</i> = 57)	14 (25)	43 (75)		
	$\chi^2 = 9.86$	d.f. = 3	$P = 0.02$	
ECOG				
0 (<i>n</i> = 155)	53 (34)	102 (66)		
1 (<i>n</i> = 98)	36 (37)	62 (63)		
2-4 (<i>n</i> = 92)	47 (51)	45 (49)		
	$\chi^2 = 7.31$	d.f. = 2	$P = 0.03$	
Health regions*				
Central south/east area (I) (<i>n</i> = 113)	48 (43)	65 (58)		
Oslo area (II) (<i>n</i> = 59)	30 (51)	29 (49)		
Western areas (III) (<i>n</i> = 33)	19 (58)	14 (42)		
Central areas (IV) (<i>n</i> = 91)	23 (25)	68 (75)		
Northern areas (V) (<i>n</i> = 59)	18 (31)	41 (70)		
	$\chi^2 = 17.86$	d.f. = 4	$P = 0.001$	
Religious belief				
Not believing in God (<i>n</i> = 156)	75 (48)	81 (52)		
In doubt (<i>n</i> = 66)	17 (26)	49 (74)		
Believing in God (<i>n</i> = 130)	45 (35)	85 (65)		
	$\chi^2 = 11.33$	d.f. = 2	$P = 0.003$	

*Health regions: I (Norwegian Radium Hospital), II (Ullevål), III (Haukeland), IV (Trondheim), V (Tromsø).

Characteristics such as education, number of relapses, inpatients/outpatients, intention of treatment or performance status (ECOG), did not separate the groups.

Table 5. Nature of non-proven therapies used by the cancer patients according to health regions (*n* = 630)*

Health region	(I) Central south/east areas (<i>n</i> = 200)	(II) Oslo area (<i>n</i> = 134)	(III) Western areas (<i>n</i> = 62)	(IV) Central areas (<i>n</i> = 153)	(V) Northern areas (<i>n</i> = 81)
Non-users of NPTs (<i>n</i> = 504)	165 (83%)	105 (78%)	45 (73%)	133 (87%)	56 (69%)
Healing by hand/healing by prayers (<i>n</i> = 63)	13	10	12	10	18
Other NPTs (<i>n</i> = 63)	22	19	5	10	7
Sum users (<i>n</i> = 126)	35 (18%)	29 (22%)	17 (27%)	20 (13%)	25 (31%)
	$\chi^2 = 30.17$	d.f. = 8	$P < 0.001$		

*Missing 12 patients.

Table 6. Nature of non-proven therapies used by the cancer patients according to sex and age groups (n = 630)

Number	Sex		P†	Age in years			P†
	Female (368)	Male (262)		15-45 (134)	45-75 (408)	>75 (88)	
	%	%		%	%	%	
No NPTs	80	80	0.98	75	78	96	0.004
Non-spiritual NPT	8	13	0.09	9	12	2	0.02
Healing by hand alone or combined*	8	3	0.02	10	6	0	0.005
Faith healing alone or combined	4	5	0.08	5	4	2	0.6

*7 patients used healing by prayers and faith healing. 4 patients used multiple therapy forms also including healing by hand and faith healing. These 11 patients are included in the group called healing by hand. † χ^2 test.

Table 7. Nature of non-proven therapies used by the cancer patients according to their religious beliefs (n = 589)

	Religious n = 240 (40.8%)	In doubt n = 115 (19.5%)	Non-religious n = 234 (39.7%)
	n (%)	n (%)	n (%)
No NPTs	177 (74)	93 (81)	199 (85)
Non-spiritual NPT	25 (10)	8 (7)	27 (12)
Healing by hand alone or combined*	17 (7)	11 (10)	8 (3)
Faith healing alone or combined	21 (9)	3 (3)	0 (0)
	$\chi^2 = 31.94$	d.f. = 6	$P < 0.001$

*7 patients used healing by prayers and faith healing. 4 patients used multiple therapy forms also including healing by hand and faith healing. These 11 patients are included in the group called healing by hand.

For 41 patients, answers concerning faith or use of NPTs were missing.

The cost of faith healing is very low. All patients had used less than NOK 500 (approximately £50). No patients considered this sum to represent an economical burden.

10 of 126 patients that used NPTs believed that this treatment might cure their disease. Among these patients, 7 used faith healing and 3 patients non-religious forms of NPTs. A total of 20% of patients using faith healing believed in the possibility of cure. Three patients believed they had been cured by alternative treatment. All of them used faith healing. One patient had seminomatous testicular cancer stage I, one patient had breast cancer stage 1 and one patient had metastatic colon cancer. The last patient died later of progressive disease.

DISCUSSION

This study suggests that spiritual healing (faith healing and healing by hand) is used by 10% (63/630) of Norwegian cancer patients. The use of spiritual healing is therefore as commonly used as non-religious forms of NPTs. Spiritual healing is often used in combination with other forms of NPTs. We have previously documented that spiritual healing is the preferred method when only one method of NPT is used [5].

The study population is likely to be representative for the

patient population seen in Norwegian oncological centres since all the major Norwegian treatment centres took part in the study. A response rate to the questionnaire of 70% is acceptable as the study population was unselected including very sick and old patients. The non-participants in the study were older than the participants. This might have introduced a selection bias giving prevalence figures higher than the actual one since older patients use NPTs less often. However, the participants may under report their use in such a non-anonymous study leading to a lower estimate of users of NPTs.

The inclusion of faith healing in the group of NPTs might have confused some patients since they may not define faith healing as a form of NPT. If so, this would result in a too low estimate of the number of patients using faith healing. In a validating study performed at the University Hospital of Tromsø, 31 patients answered an identical questionnaire. Fourteen days later the patients participated in a structured interview where the questionnaire was used as an interview guide. This study suggested an under reporting of faith healing of 30%, but this figure is uncertain due to the small sample population (only 12 patients were users of NPTs in the study). The use of other forms of NPTs were not under reported [8].

The finding that spiritual forms of healing are more common in the western and northern part of Norway is supported

by a study of 808 participants in the general population from 1978 [3]. Between 50 and 60% of the respondents from the northern part of Norway did believe in or had actually used faith healing while only 15–25% of the study sample from rural areas in the southern and eastern parts believed in faith healing. In a study in 1977, among 150 individuals of the general population of northern Norway 51 (34%) used NPTs. More than half of the participants believed in faith healing or healing by hand [9]. In a report from two hospitals situated in the southern part of Norway in 1980, next of kin of recently deceased patients were asked whether the patients did believe in faith healing or not. Only 15% found reason to believe that the patients had had such a belief [10]. It could be argued that availability of spiritual healing affects use. The more extensive use of spiritual healing in northern and western Norway could also be a reflection of non-spiritual NPTs not being available to the same degree in these regions. Similarly, spiritual healing could be less available in southern Norway. We have, however, no reason to believe this is so.

From other studies, it has been known that spiritual healing is common in many countries. In an American study from 1984, Cassileth reported an 18.8% use of spiritual healing among users of NPTs. It was reported to be the fifth most common used NPT [11]. In a report from Switzerland, healing by hand was frequently employed among users of NPTs (16.9%), while faith healing was seldom reported (3.6%) [12].

The finding that patients using spiritual healing had often employed this technique previously in the treatment of non-malignant disease, corresponds to our findings of patients' use of non-religious NPTs [5]. These strong associations with both type and frequency of earlier use are not reported in other studies, but seem to be strong predictors for use of NPTs when becoming a cancer patient.

4 of 10 in the study population defined themselves as religious. The same number of participants described themselves as non-religious while 2 out of 10 expressed doubt in own beliefs. This corresponds well with the numbers found in the general Norwegian population [13].

The finding that 1 of 4 patients experience a change in religious intensity after the diagnosis of cancer has been supported by others. Newelles and associates [14] comparing patients from the U.K. and the U.S.A. found that 36% of the U.K. patients and 67% of the patients from the U.S.A. described themselves as religious before the diagnosis of cancer. Among the believers, 56% of U.K. patients reported a stronger belief after contracting cancer compared to 35% of the American patients. No patients with a firm religious belief before cancer reported a reduction in intensity of their beliefs when contracting cancer. In the group of patients being in doubt whether they were believers or not, 6 and 7% in the two groups reported reduction in faith intensity. A German survey by Berger reported that patients using non-religious NPTs had a stronger belief than patients not using NPTs (67 versus 33%) during cancer disease [15, 16].

As seen in Table 3, advanced cancer, use of NPTs and religiousness were factors predicting a higher frequency of change towards stronger belief among cancer patients during their disease. These results correspond to the findings by Ringdal from 1994. She found that cancer patients with a serious prognosis more often defined themselves as believers [17].

Patients' description of their belief and their use of faith healing strongly predict changes in religious belief. The find-

ing in our study that many users of faith healing have applied religious forms of NPTs in an attempt to cure non-malignant disease, support the importance of prior religious experiences with respect to use of religious forms of NPTs in later sickness.

6 patients reported a decline of their faith after the diagnosis of cancer. 2 of these patients described themselves as religious prior to diagnosis. This may indicate that in time of danger and despair patients with a Christian background might turn to God for more support. A reaction of turning away from God and losing faith seems to occur very seldom among Norwegian cancer patients.

The common policy in Norwegian hospitals with respect to pastoral service has been to await patients signalling a wish of contact with the priest. This policy has been grounded on the view that faith is a private matter. It has been argued that offering contact with a priest could be interpreted as a way of conveying information of bad prognosis to the patient. Others have argued for a selective offer of pastoral service to patients where the staff have the impression that this is the wish of the patients. Studies among nurses have indicated that they inaccurately assessed their patients spiritual needs [18, 19]. The difficulties in such assessments are also demonstrated in our study. The finding that older patients were less satisfied with the offer of pastoral service in the hospitals is contradicted by the finding that they felt that pastoral services should be given only on demand from the patient. Younger patients seemed to be more open-minded and stated more often that all patients should be offered these services.

The knowledge about the use of spiritual healing among Norwegian cancer patients is very scarce. It is the most widely used NPT in our study, but we have little information about the form of faith healing applied. Many patients see faith healing as a very powerful remedy. Some cancer patients believe that spiritual healing might cure even advanced disease.

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APPENDIX

Five questions asked concerning religious belief and patients needs of pastoral services within hospital wards

- (1) Do you see yourself as a religious/believing person? *Yes, No, I do not know.*
- (2) Would you say that your faith has changed in strength during your cancer disease? *No, Yes, but only to a slight degree, Yes, very much so.*
- (3) If your religious faith has changed during your cancer disease. Are you then: *A stronger believer in God, Less believing in God.*
- (4) Did you find the offering of pastoral service/spiritual comfort satisfying within the hospital? *No, Yes.*
- (5) Do you feel that an offer of pastoral service/spiritual comfort should be given to the patients within hospitals? *Never, Only if demanded by the patient, All patients should be offered such service, All patients should be encouraged to seek contact with a priest.*

Participating Institutions

The Norwegian Radium
Hospital
Ullevål Hospital
University Hospital of Bergen
University Hospital of Trondheim
University Hospital of Tromsø

Stener Kvinsland/Claes
Trope
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Paper VI



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Original Paper

Why are Cancer Patients Using Non-proven Complementary Therapies? A Cross-sectional Multicentre Study in Norway

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This study addressed the use of alternative medicine, here called non-proven therapies (NPTs), among hospitalised Norwegian cancer patients. A total of 126 (20%) of the assessable 630 patients were users of NPTs. Approximately 43% of all patients and more than 60% of the users of NPTs stated that they would like NPTs to be an option in hospitals belonging to the National Health Service. Most users of NPTs (82%) consulted traditional medicine first, while 15% started treatment with NPTs simultaneously. Users of NPTs reported to have received less hope of a cure (30%) from their physicians than non-users (50%). Users mostly learned about NPTs from friends and relatives. Most users believed that NPTs might give them strength and relieve their symptoms. Very few patients believed in a cure (10%). Nearly 40% were uncertain of any effect of the NPTs or felt there had been no effect. 4 patients reported adverse effects. 15 patients had been treated abroad, most of them in Denmark. Expenses incurred through use of NPTs were mostly moderate, but some patients used large sums of money. Patients' opinions on whether or not the treatment had been expensive were closely linked to their anticipation of the effect of the treatment. © 1997 Elsevier Science Ltd. All rights reserved.

Key words: Norway, multicentre study, cancer patients, alternative medicine, complementary therapies, non-proven

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INTRODUCTION

ALTERNATIVE MEDICINE, here called non-proven therapies (NPTs), refers to a multitude of heterogeneous treatment modalities used in a wide variety of diseases.

The number of users of NPTs among Norwegian cancer patients is uncertain. Two studies from the late 1970s report the number of users as ranging from 20% to more than 50% [1, 2]. Studies from other Scandinavian countries are few. A Finnish survey from 1980 reported 45% users among the participating cancer patients [3]. A similar number of users were found in a recent large Danish study [4]. In studies from Germany and Switzerland as many as 40-50% of the participating cancer patients had been or were currently users [5, 6], while only 15% of patients in a recent

Dutch study, and 16% in a British study from 1994, reported experience with NPTs [7, 8]. In the U.S.A., studies report use of NPTs among cancer patients from 9% to 15% [9-11].

The answers to why Norwegian cancer patients are using NPTs, what type of NPTs they prefer, and their opinion on which role NPTs should play within the official Norwegian healthcare system are largely unknown. This lack of knowledge is contrasted by the intense public discussions concerning NPTs and their usefulness in the treatment of cancer as well as other diseases.

In order to assess the use of NPTs among cancer patients seen in Norwegian hospitals a multicentre questionnaire-based study was undertaken in December 1992. All major cancer centres in Norway participated in the study. In two earlier publications, using data from this study, we reported that 20% of hospitalised cancer patients used NPTs,

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ranging from 15% to 31% in different parts of the country [12, 13].

The aim of the analysis described in this paper is to examine the patients' experiences and their confidence in NPTs. Patients' beliefs in practitioners of NPTs and their attitudes towards having NPTs as an option in hospitals are also presented.

MATERIALS AND METHODS

A nationwide survey designed to evaluate the use of NPTs among cancer patients in Norway was initiated in December 1992. All five regional cancer centres participated to obtain a good cross-sectional national sample. Health regions I and II are situated in the South and Southwest of Norway, including the capital, Oslo. Health region III covers the western part, and Health region IV, the central part of Norway. The most Northern parts of the country are defined as Health region V. At four of the centres, all in- and outpatients attending the centres during one particular week were invited to take part in the study. In the fifth centre, The Norwegian Radium Hospital, all in-patients seen in the Department of Medical Oncology and Gynaecology on one specific day were included. The study was restricted to one day at this centre because of the much larger sample size due to a wider patient recruitment area.

The study was designed to answer a broad spectrum of questions about cancer patients and their use of NPTs. An expanded version of a questionnaire developed at the University of Tromsø was used [14]. The questionnaire was designed by consensus of experts and its feasibility tested in a pilot study in Tromsø among outpatients at the Department of Oncology. A validating study was done including 31 patients, using a structured interview with the questionnaire as the interview guide [15]. Most of the 50 questions in the questionnaire were put in a multiple-choice form. Patients were also invited to offer open comments.

911 patients were invited to participate in the national survey. 101 patients declined to participate and 128 patients did not return the questionnaire to the investigator. A total of 682 patients (75%) answered the questionnaire. 33 patients answered the questionnaire but did not sign the written consent and were, therefore, excluded. 7 patients were excluded because of missing information on age and diagnosis. The final analysis is based on a patient population of 642 (71%). A total of 374 women and 268 men with a mean age of 58.5 years (range 17–91 years) were included in the study. 12 of the 642 patients did not answer whether they were users of NPTs or not and were excluded from the analysis concerning differences between users and

non-users. A detailed description of patient characteristics are described in two recently published papers [12, 13].

The number of participants varied in various questions due to missing data.

The statistical package SAS was used for statistical analysis. To test for differences between categorical variables, the chi-square test as given in the Proc Freq procedure was used [16]. After dichotomising the answer categories, logistic regression analysis was used to analyse simultaneously factors influencing patients' perception of hope connected to the given treatment at first contact with their physician [17]. The answers "No hope of improvement" or "only very little hope of improvement", connected to the treatment given, were analysed as "little hope". Patients reporting that their physician had promised them "much improvement", "very much improvement" or "to cure their disease" were analysed as given "much hope".

The study was authorised by The Board of Ethics of Health Region V. Permission was granted by the Norwegian Data Inspectorate to store personal information concerning patients.

RESULTS

As previously published [12, 13], 20% of the participating cancer patients used, or had been users, of one or more types of NPTs. At the time of the survey, 73% of the reported users were still using NPTs while 27% had ended their use. The patients had used NPTs for less than one month up to more than 2 years (mean 44 weeks, range 2–144 weeks).

The concept of NPT was defined as the use of faith healing or healing by hand, homeopathy, zone therapy, herbs, vitamins or diet treatments, or injection therapies such as Iscadore (a mistletoe preparation) and "Nitter" therapy. Nitter therapy consists of vitamin B12, gammaglobulins, tranexamic acid, multivitamins and nutritional supplements. Patients could also add any other types of therapy as a response to an open question. Fifty per cent of the users of NPT used faith healing or healing by hand (spiritual types of NPT) alone, or in combination with non-spiritual forms of NPT. Spiritual types of NPT were commonly used in the Western and Northern parts of Norway.

Place and importance of NPTs in cancer treatment

Sixty-seven per cent (82/123 patients) of the users of NPTs and 34% (168/490) of the non-users believed that practitioners of NPTs possess useful knowledge in the treatment of cancer. Sixty-three per cent (76/121) among users and 38% (185/487) of the non-users of NPTs reported a positive attitude with respect to NPTs being offered in

Table 1. Patient trust in practitioners' of NPTs and their opinion about the place of NPTs within our public hospitals

Questions asked	Users of non-proven therapy (%)			Non-users of non-proven therapy (%)			P
	No	Yes	Do not know	No	Yes	Do not know	
Might practitioners of NPTs have useful knowledge in the fight against cancer?*	4	66	30	24	34	42	>0.001
Should NPTs be an option within our hospitals?*	8	63	29	24	38	38	>0.001
Number of participants in the two questions	Users of NPT			Non-users of NPT			
	*	123		490			
	**	121		487.			

Table 2. Patient trust in the promises of a practitioner of NPTs compared to their trust in that of a physician

Questions asked	Users of non-proven therapy (n = 118) (%)			Non-users of non-proven therapy (n = 466) (%)			P
	Cure	Maybe cure/ almost cure	Not to be cured	Cure	Maybe cure/ almost cure	Not to be cured	
If a practitioner of NPTs promises you that his treatment will cure you, what would your expectations be?	23	66	11	23	48	29	0.001
If a physician promises you that his treatment will cure you, what would your expectations be?	60	39	1	71	27	2	0.06

Norwegian hospitals (Table 1). Patients between 30 and 60 years of age believed more often (52%, 156/300 patients) than other patients (30%, 97/325) that practitioners of NPTs possess important knowledge concerning the treatment of cancer ($P < 0.001$). This age group of patients also felt more often (51%, 151/297) than younger and older patients (35%, 110/311) ($P = 0.001$) that NPTs should be an option within our hospitals. Sex, education, disease-related characteristics, such as stage of disease, time since diagnosis and type of planned treatment, had no impact on the patients' answers to these questions.

Forty-nine per cent (300/611) of the patients believed that a closer co-operation between oncologists and practitioners of NPTs with regard to treatment of cancer would be important, while 28% (173/611) believed that such co-operation would be of little or no value.

Twenty-three per cent of both users and non-users of NPTs believed they would be cured from cancer in the hypothetical situation where a practitioner of NPT promised that the therapy would cure them. Seventy-one per cent of patients using only conventional treatment believed conventional treatment would cure them, if promised so, compared to 60% among users of NPT. Only 1% of users and 2% of non-users found promises of a cure given by a physician to be of no value. Twenty-nine per cent of non-users and 11% of users of NPTs believed such promises given by practitioners of NPTs to be of limited value (Table 2).

The influence of the disease-related and demographic factors on the amount of hope given to the patients by their physician, as perceived by the patients, is shown in Table 3. Patients with widespread disease and patients who had known their diagnosis for more than 24 months felt that they had been given less hope of cure. Users of NPTs (30%) felt they had been given less hope of cure than non-users (50%). Thirty-seven per cent of the users of NPTs felt that they had been left no hope or only very little hope by their physician. Among non-users, 19% reported being left little or no hope. Patients from the Western part of the country reported to have received a higher degree of hope from their physicians than patients treated in other parts of the country. Gender, family situation and education did not influence perception of hope given by the physician.

When and why did the patients start use of NPTs

104 patients (83% of users of NPTs) responded to the question about when they started their use of NPTs in relation to when they started medical treatment. Eighty-two per cent (85/104) reported that they were treated initially with conventional methods followed by NPTs. 4 patients (4%) started NPTs prior to medical treatment, while 13

patients (13%) started scientific medical treatment and NPTs simultaneously. 2 patients reported that they did not receive any conventional treatment.

Expectations and reported effects of NPTs, recommendations to other patients. Patients were given a multiple-choice list of different reasons to start using NPTs. The most common reason to start NPTs was believing in the methods

Table 3. The amount of perceived hope given to the patients by their physicians

Variable	OR	95% CI
Stage of disease		
No disease, local disease	1.00	Reference
Locoregional disease/metastatic disease	0.29	0.15-0.56
Use of NPTs		
No use of NPTs	1.00	Reference
User of NPTs	0.42	0.23-0.77
Months since diagnosis		
0-3 months	1.00	Reference
4-6 months	0.71	0.24-2.12
7-12 months	1.07	0.37-2.06
13-24 months	0.77	0.31-1.93
More than 24 months	0.34	0.15-0.76
Health region**		
V	1.00	Reference
IV	1.01	0.42-2.45
I	1.76	0.71-4.36
II	1.16	0.46-2.91
III	3.83	1.14-12.84
Age in years		
15-29	1.00	Reference
30-44	0.30	0.06-1.59
45-59	0.31	0.06-1.58
60-74	0.16	0.03-0.83
75-91	0.36	0.06-2.32

*The logistic regression analysis is adjusted for the variables included in the table, in addition to sex, education, family life and performance status (ECOG).

Question asked:

How much hope did the doctor at home or at the hospital give you before start of the treatment he prescribed for you?

No improvement (categorised as little hope)
Some improvement

Much improvement

Very much improvement (categorised as much hope)

Cure of disease

**Health regions I and II are situated in the South and Southwest of Norway, including the capital, Oslo. Health region III covers the Western part and Health region IV covers central Norway. The most Northern parts of the country are defined as Health region V.

Table 4. Reported, compared to anticipated effects of NPTs among users of NPTs

Effect	Patients' reports of possible effect of NPTs (n = 104) (%)	Patients' reports of actual effect of NPTs (n = 104) (%)
1. Prevent relapse	0	0
2. Give a partial remission	3	3
3. Cure the disease	10	3
4. Prevent growth of disease	4	4
5. Prevent metastatic disease	2	1
6. Improve general condition	7	36
7. Do not know	12	32
8. Improvement in physical resistance	16	No option*
9. No effect	No option*	7
Combinations		
6, 8	16	No option*
Multiple	21	3
Other combinations	9	11
Total	100.0	100.0

*Not an option in the multiple-choice answers.

undertaken or being advised by others 33% (35/106). Thirteen per cent (14/106) used the treatment in an attempt to strengthen their immunological defence. 8 patients (8%) gave other reasons than those offered in the multiple-choice list. The rest of the patients stated multiple reasons to start NPTs. No patients reported that lack of trust in traditional medicine, or that no offer of treatment was given, to be the main reason for using NPTs. The physicians' direct influence on the use of NPTs was low. Ninety per cent (94/104) of the users stated that their doctor had neither advised for nor against the use of NPTs. In 6% (6/104) of the patients, the physician had advised them to use NPTs.

Patients' opinion on a potential effect of NPTs compared to patients' reported effects of the treatments used are shown in Table 4. Patients using NPTs were first asked to report on the actual effect they had experienced with their chosen NPT, and in a second question to state the theoretical optimal effects of the treatment. 41 patients (39%) believed that the use of NPTs might improve physical resist-

ance and/or their general condition. 10 patients (10%) believed NPTs could cure their cancer. Most patients expressing this view were users of spiritual NPTs. Only 3 patients (3%) believed they had been cured by the NPTs. 7 patients (7%) believed that the treatment had had no effect. Thirty-eight per cent (39/104) felt that the treatment had improved their general condition, whereas 32% (33/104) were uncertain with respect to whether the used non-proven treatment had any effect at all.

59 patients (53%) using NPTs would recommend NPTs to other cancer patients, while 31 patients (41%) would recommend the use of NPTs with some reservations. Six per cent would advise other patients not to try NPTs. In the group of 90 patients that would recommend other patients to try NPTs to a greater or lesser extent, their recommendations were mostly in accordance with their own choice of NPTs.

Treatment abroad, side-effects and cost of treatment

Costs. Fifty-five per cent (52/94) of the responding patients had used less than £200 on NPTs, 15% (14/94) had used between £200 and £400 and 30% (28/94) more than £400. Users of non-religious variants of NPTs usually paid more for their treatments. Only 9% (9/103) of the users had received any form of economical support in relation to the use. A total of 42% (44/105) of the users of NPTs felt that the treatment had been expensive. Among patients receiving palliative treatment, 56% reported the NPTs to be expensive as did 19% of patients being treated with curative intent. Patients who had experienced relapse of disease after the initial treatment also found the treatment to be expensive (Table 5).

15 patients (14%), mostly in the age group of 45-59 years, had been treated by practitioners of NPTs abroad. Most of these patients were treated in The Norwegian Radium Hospital (7 patients) and at Haukeland Hospital, Bergen (4 patients). From the other centres, very few patients (4/66) had been treated abroad. 11 out of 15 patients had been treated in Denmark. 7 patients had visited clinics abroad once, while 8 patients had been treated from 2-5 times. Diets, herbs and Iscador were the most used methods offered abroad. 5 patients had paid between £100

Table 5. Patients view on the costs of NPTs

	Treatment not expensive		Treatment was expensive		P value	Missing information
	n	(%)	n	(%)		
Stage of treatment						
Primary treatment (n = 33)	26	(79)	7	(21)	0.003	24
First or second relapse (n = 33)	33	(48)	36	(52)		
Intention of treatment						
Cure (n = 33)	25	(81)	6	(19)	0.002	36
Palliation (n = 59)	26	(44)	33	(56)		
Treatment modalities						
Non-religious forms (n = 75)	37	(49)	38	(51)	0.004	21
Mixture of treatment forms with some sort of faith healing (n = 19)	13	(68)	6	(32)		
Faith healing alone (n = 11)	11	(100)	0	(0)		
Costs of treatment						
Less than £200 (n = 41)	37	(90)	4	(10)	<0.001	36
More than £200 (n = 51)	15	(29)	36	(71)		

and £1000 for the treatment abroad, 7 patients had paid between £1000 and £4000 and 2 patients more than £4000.

Side-effects. 25 patients of the 40 patients that had stopped using NPTs reported their reason for doing so. 8 patients (32%) stated that they had completed their treatment. The remaining patients had stopped their treatment because of loss of confidence in the methods, for economical reasons, or because of side-effects. 4 patients specified side-effects as the reason for stopping their treatment. 3 of these patients had used injections with Iscador. One patient had suffered an anaphylactic reaction causing hospitalisation. 2 patients had localised allergic reactions at the site of the injection. One patient receiving homeopathic treatment reported a generalised allergic reaction.

Information of NPTs, patients' experience of outside pressure and criticism

The users of NPTs were informed about NPTs by their relatives and friends in 64% (66/103) of the cases. No patient had received their main information about NPTs by radio or television, while 5% (5/103) of the patients stated magazines to be their main source of information about NPTs.

A total of 85% (497/587) of all patients, both users and non-users of NPTs, had felt no pressure from their relatives and friends to use NPTs for their cancer disease. 83 patients (14%) had felt some pressure. Among patients aged 30-45 years, 25% (25/100) had felt some pressure. This difference between age groups is highly significant ($P=0.001$). Fourteen per cent (15/110) of the users of NPTs felt they had been criticised for their use of NPTs, while 84% (92/110) stated that they had felt no criticism from anyone because of their use of NPTs.

DISCUSSION

This study shows that approximately 41% of the cancer patients seen in specialised cancer centres believed that practitioners of non-proven therapy might have some knowledge that would be useful against cancer. Even more patients wanted non-proven methods to be an option within our hospitals. However, the questions given to the patients concerning their opinion on the importance of NPT in the treatment of cancer, and whether or not NPT should be optional in hospitals, were general, and not restricted to methods favoured by the patients. The answer given by the patients might, therefore, be biased since it is possible that many patients believe that their preferred methods should be an option in our hospitals, but that other methods should be excluded. The results are, however, consistent with the findings of a Norwegian study [18] performed in 1976 where 67% of the participating non-cancer patients were prepared to try NPTs in a hypothetical situation of having contracted a potentially life-threatening disease. Studies among cancer patients from other countries also support our findings. In a Canadian report from 1984 [19], only 7% were users of NPTs, but as many as 70% would consider using it. In a recent large Dutch study, 50% of the patients were interested in NPTs as treatment for their cancer disease [7].

It has been argued that one of the main reasons why cancer patients start using NPTs might be that they feel neg-

lected by their own physicians [20]. This study did not confirm this hypothesis. Only a very small fraction of our patient population stated that their physician had had any impact on their decision to start treatment with NPTs. However, we found a great difference between the non-users and the users of NPTs in the way they perceived that their physician had given them a hope of cure. Nearly four out of ten users felt that they had been given no hope or only very little hope of a cure from their physicians, compared to two out of ten non-users. The primary contact with the physician might, therefore, be of importance with respect to patients' later choice of therapy. Whether or not this difference in perceived hope reflects a true difference in hope given, or simply reflects a difference in understanding between the two groups is unknown. In a study by Downer and associates [8], similar conclusions were made: users of NPTs were less satisfied with conventional treatment, largely because of side-effects and lack of hope of a cure.

The patients' were asked about their reasons for starting NPT and their expectations from it. The answers might be biased by the multiple-choice design of our study, even though the respondents had other options than those offered by us. However, the main reasons given, that of believing in the methods and being advised by others, are supported by other results in our study. As earlier reported [12], more than 4 out of 10 cancer patients had previously used NPTs as a treatment of non-malignant disease. It, therefore, seems likely that the use of NPTs for many patients is a known way of dealing with a health problem. The observation that information and advice given to the patients about NPTs are mostly given by family and close friends is also supported by others [5, 7]. In a study among Norwegian non-cancer patients [21], 41% reported family and friends to be their main informants of NPTs in comparison to 64% in our patient population. It is possible that cancer patients in a difficult situation receive advice from close friends and family, and listen to it, to a higher degree than patients with less threatening diseases. It is possible that this process represents a way of coping both for the patient and the family. Patients' modest expectation of possible effects of the treatment are also found in other studies [5-7]. Most patients seem to use NPTs as supportive treatment, with hopes for improved physical resistance and improvement of their general condition. Only few patients use the NPTs with a curative intent. It is interesting that patients trust the promises from a physician, but do not believe in promises of a cure given by practitioners of NPTs. It supports the low expectations of effect reported by the patients and supports patients' strong beliefs in scientific medicine. In the often heated debates between supporters of NPTs and supporters of scientific medicine, patients' modest expectations of NPTs are mostly forgotten. Instead, possible cure, side-effects of treatments or absolute absence of such are the topics.

In the same way that many patients have modest expectations of the treatment effect of their chosen NPTs, most Norwegian users of NPTs also use only small amounts of money on the treatment. This is also reported in foreign studies [4-7]. The finding that the patients' opinion on whether the treatment is expensive or not is related to their health situation is interesting. It supports the finding that the patients' use of NPTs are linked to their expectations of

benefit and that how they consider the costs is related to their opinion as to a possible effect of the treatment.

Why should we then bother with patients' use of NPTs and the practitioners supporting their treatment? One of the main concerns among physicians are the possible side-effects of NPTs. Side-effects may be mild but may also be life-threatening [22]. The aspect of delay might also be of importance [23]. Patients with a possibly curable disease could choose NPTs and postpone medical treatment. In such situations, physicians have a moral obligation to inform the patients that no valid documentation exists proving that NPTs can improve their chances of survival nor relieve their symptoms. Among the group of young patients in our study, as many as 25% had felt strong pressure from relatives and friends to use NPTs. This might add to the already heavy burden for this vulnerable patient group.

It is important that traditional medicine secures the best possible treatment for patients. However, we have to respect the patients' choice of using NPTs. The treatment of cancer patients is not only related to diagnosis and the correct use of chemo- and radiotherapy. Optimal patient information and communication will improve patients' ability to cope with a difficult situation and help them adjust to the situation. Improvement in this part of the doctors' skill may reduce the need for use of NPTs.

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APPENDIX

Participating institutions:

The Norwegian Radium Hospital, Stener Kvinnsland/Claes Tropé
 Ullevål Hospital, Steinar Hagen
 University Hospital of Bergen, Olav Dahl
 University Hospital of Trondheim, Olbjørn Klepp
 University Hospital of Tromsø, Erik Wist

Paper VII

Cancer Patients Use of Nonproven Therapy: A 5-Year Follow-Up Study

By T. Risberg, E. Lund, E. Wist, S. Kaasa, and T. Wilsgaard

Purpose: To investigate the prospective pattern of use of alternative medicine, here called nonproven therapy (NPT), among oncologic patients during a 5-year period, and the relationship between this use and survival, a questionnaire-based follow-up study was performed at the Department of Oncology, University of Tromsø, from 1990 to 1996.

Patients and Methods: Two-hundred fifty-two patients answered the first questionnaire during the period July 1990 to July 1991. Eligible patients were mailed follow-up questionnaires after 4, 12, 24 and 60 months. A telephone interview performed after the last follow-up questionnaire showed little disagreement with the prospective collected information as regards the number of patients reported as users of NPT (κ , 0.92).

Results: The number of patients who reported ever using NPT in each cross-sectional part of the study varied between 17.4% and 27.3%. However, the estimated cumulative risk of being a user of NPT during the

follow-up period was 45%. Seventy-four percent of NPT users in this north Norwegian study population used faith healing or healing by hand (spiritual NPT) alone or in combination with other forms of NPT. The proportion of patients who used spiritual versus nonspiritual forms of NPT was consistent throughout the follow-up period. Women were more often users than men (50% v 31%, $P = .002$). Patients older than 75 years of age seldomly used NPT. The 5-year observed survival rate was not influenced by the use of NPT. Adjusted for sex, age, and diagnosis, patients with a high educational level had a borderline higher 5-year survival rate than patients with less education ($P = .06$).

Conclusion: Our results demonstrate that cross-sectionally designed studies will underestimate the number of ever-users of NPT in a cancer patient population. The use of NPT does not influence observed survival among cancer patients seen in north Norway.

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THE NUMBER OF CANCER patients who use alternative medicine or nonproven therapies (NPTs) varies from 5% to 60% in reported studies.¹⁻⁴ This large difference might be due to geographic, socioeconomic, religious, cultural, demographic, or disease-related factors. Another reason for the reported large variation in the number of users could be the different ways the information is collected (different interview techniques and questionnaires).⁵ Furthermore, until now, all of the surveys performed have been designed cross-sectionally, often with nonrepresentative samples of patients. The heterogeneity of the reported patient populations could therefore be of major concern. The differences in study design might thus explain some of the differences found with regard to the influence of demographic and disease-related factors on cancer patients' use of NPT.

The relationship between the use of NPT and survival has

rarely been studied. In a population of patients with breast cancer who attended the Bristol cancer help center in the late 1980s, survival was analyzed.⁶ No differences were found between users and nonusers of various alternative treatments. The same conclusion was reported by Cassileth et al⁷ in 1991 in a study that compared survival rates between patients who received the so-called Livingston-Wheeler therapy⁸ versus patients treated with conventional methods.

In an attempt to study how the pattern of NPT use changes throughout the life of cancer patients, we started a prospective study in 1990 with a 5-year follow-up period. This also gave us the opportunity to study survival with regard to patients' use of NPT.

PATIENTS AND METHODS

Questionnaires

A longitudinal questionnaire-based study was performed at the Department of Oncology, University Hospital of Tromsø, during the period July 1990 to June 1996. Questionnaires were based on multiple-choice questions. Patients were additionally invited to give open comments. The questionnaires were designed by a consensus of experts and their feasibility tested in a pilot study in Tromsø among outpatients at the Department of Oncology. A validating study was performed of the last three questionnaires, which were mailed to 31 patients after 12, 24, and 60 months and used a structured interview with the questionnaire as an interview guide.⁹

The first questionnaire, presented to cancer patients on arrival at the oncology unit in the period July 1990 to June 1991, was designed to assess patients' attitudes and their use of NPT. The questionnaire also

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Table 1. Longitudinal Study of Nonproven Medicine: Five-Year Follow-Up

Questionnaire No.	Invited Participants (n)	Dead Since Last Questionnaire (n)	Nonresponders (n)	Responders (n)	Cumulative Risk of Being Dead (%)	Patients Answering All Possible Questionnaires: Percentage Compliance (%)
1 (start of study)	263	—	11	252	—	96
2 (4 months)	210	42	29	181	16.7	86
3 (12 months)	162	48	30	132	35.7	82
4 (24 months)	135	27	37	98	46.4	73
5 (60 months)	110	25	17	93	56.3	85
Total						69*

*A total of 173 of 252 participating patients answered all questionnaires possible, for an overall compliance rate of 69%.

addressed topics like patients' opinions on causes of cancer, need of information, and psychologic distress connected to delay before admittance to our department. Results from these parts of the study are reported elsewhere.¹⁰⁻¹²

Four months after answering the first questionnaire, patients received a follow-up questionnaire by mail. This questionnaire focused on possible changes in their use of NPT and their opinions of perceived information and communication during their stay in the Department of Oncology. The next three questionnaires were mailed to the patients after 12, 24, and 60 months after arrival at the oncology unit and focused in more detail on different aspects of patients' use of NPT.

In addition, a quality-of-life study was included in the survey. To estimate patients' mental distress, a validated combination of five questions¹³ from the General Health Questionnaire (GHQ) 20 was submitted to the patients in the first and the second questionnaire. In questionnaires 3 to 5, eligible patients answered the complete GHQ 20 and the European Organization for Research and Treatment of Cancer (EORTC) 30 questionnaire. This information was not used in the present analysis. Patients who did not respond to the questionnaire were sent one reminder.

Patients

All cancer patients referred to the Department of Oncology, University Hospital of Tromsø for the first time were eligible for the study. To be included, patients had to be able to read and understand the questionnaire. Patients with a poor performance status (Eastern Cooperative Oncology Group [ECOG] = 4) were considered ineligible. Patients were promised confidentiality, but not anonymity, because of the longitudinal design of the study.

At inclusion in the study, a physician responsible for the patient completed a questionnaire that concerned patient diagnosis, time since diagnosis, stage of disease, performance status (ECOG), and aim of treatment (palliative/curative). Patients filled in a questionnaire, stored by a clerk in the department, which gave information on demographic data, including level of education, occupation, marital status, and living conditions. Oncology providers were not given any information about the patients' use of NPT.

Of 263 eligible patients, 252 (95.8%) filled out the first questionnaire. The mean age was 58 years (range, 17 to 89); 52% of the study population were men. Most patients (75%) had only an elementary school education. Eighteen percent lived alone, while the rest of the patients lived with family or close relatives.

Sixty-nine percent of patients had been informed of the malignant diagnosis less than 3 months before study inclusion. Fifty-eight percent of patients had localized/regional disease, while the rest had locally advanced or metastatic disease. Fifty percent of patients were classified as ECOG 0 and 39% as ECOG 1. Treatment was given with a curative

intention in 45% of cases. Details concerning patients' disease-related and demographic factors at the start of the study have been reported previously.¹⁴

A total of 142 patients (56%) died during the study period (Table 1). Response rates to the mailed questionnaires after 4, 12, 24, and 60 months were 86%, 82%, 73%, and 85%, respectively. A total of 173 patients returned all possible questionnaires, for an overall compliance rate of 69% (173 of 252; adjusted for time of death).

Use of NPT

The concept of NPT was defined as the use of faith healing or healing by hand, homeopathy, zone therapy, herbs, vitamins, or diet treatments and injection therapies such as Iscadore and Nitter therapy. Nitter therapy consists of vitamin B₁₂, gammaglobulins, tranexamic acid, multivitamins, and nutritional supplements. Patients could also add any other types of therapy as a response to an open question. Faith healing or healing by hand are referred to here as spiritual NPT, and other types of NPT as nonspiritual NPT. If patients had used combinations of spiritual healing and nonspiritual healing, they were registered as users of spiritual healing. The concept of ever-user of NPT is defined as a patient who used one or more methods of NPT one or more times during the follow-up period.

Telephone Interview (validation)

To validate patients' status as users or nonusers of NPT, all patients reported to be alive after 5 years were invited to participate in a short semistructured telephone interview in November 1996. Ninety-six patients were eligible. Twenty-one percent (20 of 96) of patients declined participation. The reasons for nonparticipation in the interview are unknown to us (the ethical committee did not give permission to make such inquiries). Among the remaining 76 patients, 96% (73 of 76) were interviewed (one patient was excluded because of deafness and two patients could not be contacted). Participants in the interview were somewhat younger than nonparticipants (mean age, 50.2 years v 57.0 years; $P = .02$). Otherwise, there was no significant difference between participants and nonparticipants in the interview as to sex, education, or use of NPT as measured in the questionnaire-based study. The interview focused among other things on patients' knowledge of different types of NPT and whether they had used one or more types of NPT as treatment for cancer. Patients' perceptions of different forms of spiritual healing were explored. The proportion of agreement between the questionnaire-based follow-up study and the telephone interview with regard to the status of patients as ever-users or never-users of NPT was 0.96 (95% confidence interval, 0.91 to 1.00) or kappa = 0.92.¹⁵ Twenty-nine patients were registered as users in the questionnaire-based study and in the interview. Three patients registered as users only in the interview; all

Table 2. Patients Alive at Start of Study and After 4, 12, 24, and 60 Months

Malignancy	Start		Population Alive at (months)			
	No.	%	4 (%)	12 (%)	24 (%)	60 (%)
Breast cancer	52	100	96	79	69	42
Lung cancer	40	100	65	25	13	13
Urogenital cancer	40	100	85	70	58	58
Malignant lymphomas	30	100	100	97	90	83
Gastrointestinal cancer	30	100	63	37	27	13
Head and neck cancer	15	100	100	93	67	60
Gynecological cancer	13	100	100	69	62	46
Smaller diagnostic groups	32	100	72	63	56	50
Total						
%		100	83	64	54	44
No.	252	210	162	135	110	

reported that their next of kin had contacted a faith healer one time and that this contact were made without their knowledge. These three patients are registered as nonusers in the previous calculation. Among the three patients reported as users in the questionnaire and not in the interview, one patient had used zone therapy, one patient used "other" methods, and one patient used spiritual healing. Forty-one patients in both groups were registered as nonusers. However, comparing the different methods of NPT used among patients who participated in the interview and in the follow-up study, a somewhat larger discrepancy emerged. In 77% (56 of 73) of patients, the questionnaire-based study and the interview rendered equal results, while in 11% and 12% (eight of 73 and nine of 73), there was no or only partial agreement between the two studies. In 10 cases, additional types of NPT were reported in the questionnaire-based study compared with information given in the interview. All of these patients reported use of nonspiritual types of NPT. In the interview, three patients reported the use of spiritual NPT and three patients described the use of herbs that were not reported during the follow-up period in the prospective study. One patient reported the use of homeopathy in the first questionnaire and only the use of faith healing in the interview.

Statistics and Ethics

Statistical analyses were performed by the statistical computer program SAS.¹⁶ Cox's proportional hazards regression was used to assess the impact on survival adjusted for the use of NPT and important demographic factors such as sex, age, level of education, living conditions, and disease-related factors (diagnosis, time since diagnosis, stage of disease, performance status [ECOG], and aim of treatment palliative/curative). The same statistical method was used to assess the

importance of the independent variables on the risk of being a user of NPT during the study. The cumulative risk of being a user of NPT was calculated using the Kaplan-Meier method and presented in a life-table analysis.

The study was authorized by the Board of Ethics of Health Region V.

RESULTS

Longitudinal Questionnaire-Based Study

The distribution of diagnoses among participating patients at the start of the study and the percentage of patients alive in each diagnostic group during the follow-up study are listed in Table 2. As reported earlier, no significant difference was found with regard to diagnosis between participants compared with all patients seen in the Department of Oncology during the study period.¹⁴

Table 3 lists the use of NPT in the study population during the 5-year follow-up period. Users of NPT in each cross-sectional part of the study were defined as ever-users (used NPT one or more times during the follow-up period) and as new users of NPT (started use since last follow-up evaluation). The percentage of patients who used NPT varied from 17.4% to 27.3% in the different parts of the study. At inclusion in the study, 44 patients were users of NPT. Among these, 41% (18 of 44) had known their malignant diagnoses for more than 3 months. During the entire study period, 40% (101 of 252) of patients had used NPT on one or more occasions. The number of participants who reported new use of NPT who used faith healing and healing by hand only varied in the cross-sectional parts of the study from 50% to 64%. In total, 74% of NPT users in this north Norwegian study population used spiritual forms of NPT (alone or in combination with nonspiritual forms).

The majority of users (26 of 44) started their use less than 3 months after becoming aware of their cancer or during the first 4 months (36 patients) of the study (61%, 62 of 101).

After 5 years of follow-up evaluation, 110 patients were still alive. The material was analyzed with the life-table method adjusted for mortality within the study population. The cumulative risk of becoming a user of NPT during the

Table 3. Longitudinal Study of Nonproven Medicine: Number of Users of NPT During 5 Years of Follow-Up

Questionnaire No.	Ever-Users of NPT*		New Users of NPT Since Last Questionnaire (n)	Type of NPT Among New Users		
	No.	%		Spiritual NPT Only (n)	Spiritual NPT Combined (n)	Nonspiritual (n)
1 (Start of study)† (n = 252)	44	17.4	—	28	2	14
2 (4 months)† (n = 210)	54	25.7	36	25	4	7
3 (12 months)† (n = 162)	38	23.5	10	6	2	2
4 (24 months)† (n = 135)	24	17.8	4	2	2	0
5 (60 months)† (n = 110)	30	27.3	7	2	1	4
Total	—	—	101	63	11	27

*Patients who used NPT ≥ 1 time during the follow-up period.

†Number of patients alive in each cross-sectional part of the study.

5-year follow-up period was 45.0%. The use of NPT was established mainly during the first year of follow-up evaluation. The probability of becoming a user of NPT and the percentage of patients who survived during the follow-up period is shown in Fig 1.

After 5 years of follow-up evaluation, women more often than men had used or were users of NPT (women, 50% [61 of 122]; men, 31% [40 of 130]; $P = .002$). In accordance with this difference in use between sexes, we found different patterns of use in the different diagnostic groups. The rate of use of NPT in women with breast cancer or gynecologic cancer was 54% (35 of 65) during the study period. Among diagnostic groups composed of or dominated by men (cancer of the testis, cancer of the prostate, and cancer of the lung), 28% (22 of 80) were users of NPT. Seventeen percent (four of 21) of patients older than 75 years became users during the study. In the intermediate age group (30 to 59 years), 50% became users.

The risk of being a user of NPT was analyzed using the

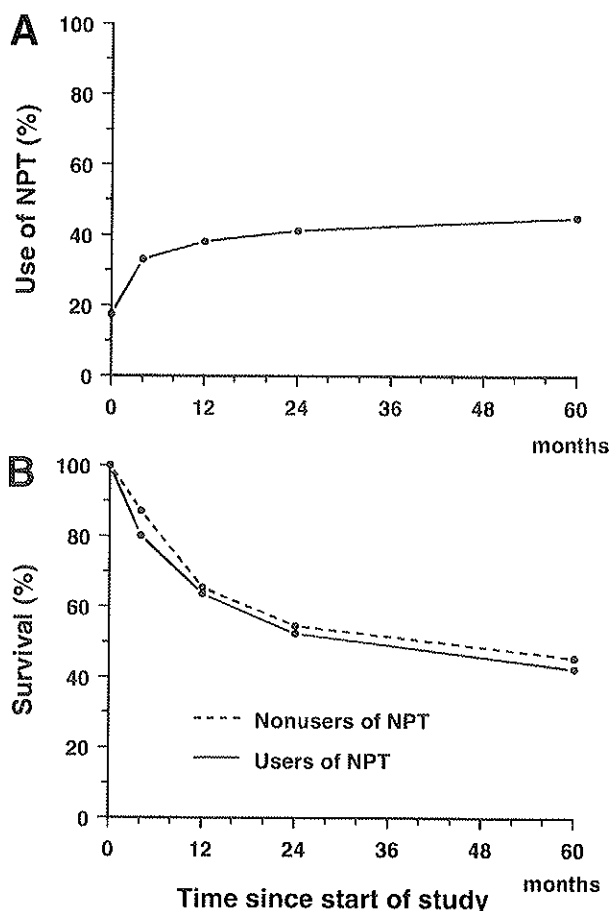


Fig 1. (A) Probability of becoming a user of NPT; and (B) percentage of patients surviving during the follow-up period.

Table 4. RR and 95% CI of Dying During Study Period Related to Disease and Demographic Factors

Variable	RR	95% CI
Sex (male/female)	1.1	0.72-1.71
Age, years		
45-59	1.0	Reference
15-29	0.5	0.06-3.42
30-44	0.8	0.43-1.66
60-74	0.9	0.59-1.42
75-90	1.4	0.74-2.68
Education (higher/elementary)	0.6	0.36-1.02
Treatment intention (palliation/cure)	2.1	1.26-3.28
Performance status (ECOG 1-3/0)	1.9	1.22-2.81
Use of NPT (nonuse/use)	0.9	0.63-1.32

NOTE. Values mutually adjusted for all variables in the table and all diagnostic groups as shown in Table 2. Cox regression analysis (proportional hazards model).

Cox's proportional hazards method censoring patients at death or the end of the follow-up period. The following variables measured at the start of the study were included in the model: sex, age, educational level, treatment intention, performance status and time since diagnosis. Women used NPT more (relative risk [RR], 1.73; 95% CI, 1.14 to 2.62), while patients more than 59 years of age used NPT less (RR, 0.53, 95% CI, 0.32 to 0.89). In our study, educational level did not have a significant influence on patients' use of NPT. Disease-related factors measured at start of the study, like stage of disease, performance status, treatment intention, and time since diagnosis, did not have a significant impact on patients' later use of NPT (data not shown).

The effect of different disease and demographic factors on survival was assessed in a similar Cox's proportional hazard model (which also included diagnostic groups) as described earlier (Table 4). The use of NPT did not influence mortality. Patients offered palliative therapy and patients with reduced physical function (ECOG performance status 1 to 3) had an increased mortality rate. Patients with a high educational level had a higher 5-year survival rate than patients with less education ($P = .06$).

Telephone Interview

The telephone interview confirmed the impression that faith healing is mostly seen as something other than normal religious praying. However, a group of patients, 35% (43% of nonusers and 21% of users of NPT) did express doubt whether such a difference existed. Only 7% (five of 73) thought normal religious prayers and faith healing were the same. No patients who reported use of faith healing expressed the opinion that faith healing was the same as normal religious praying.

As found in the questionnaire, most patients (21 of 28) started their use of NPT shortly after being informed of their

cancer. The main reasons given for starting treatment among users were feelings of despair and confusion. Nonusers reported to have received positive information from their doctors and that they expected to be cured by traditional medicine. Most nonusers did not feel that NPT was an interesting option.

DISCUSSION

In this prospective study, we found that during the 5-year follow-up period, 45% of all cancer patients used NPT one or more times. Spiritual healing was commonly used. Whether patients survived their disease in the follow-up period was not associated with the use of NPT.

The number of cancer patients who use NPT varies in reported studies from less than 10% to greater than 60%.^{17,18} The reasons for these conflicting results are several. Local and cultural differences are reported to be important factors.¹⁹ In some countries, like Switzerland, Germany, and England, alternative methods thought to be supportive and adjunctive to mainstream treatment are more accepted within official medicine and are reportedly widely used.^{20,21} Some studies demonstrate that the use of NPT as treatment for cancer differs within the same country.^{1,2,4,22}

As described by McGinnis,² one of the major reasons for discrepancy in the prevalence of NPT use in reported studies may be explained by the differences in data collection. In the United States, four major studies among cancer patients were conducted in the 1980s. Lerner and Kennedy²² reported that 9% of participants were users and Harris et al.²³ indicated that 15% were users, while Shapiro et al.,²⁴ in the American Cancer Society (ACS) study, reported that 7% of respondents were users. In contrast to these three investigations, conducted by telephone interview, Cassileth et al.,²⁵ who reported use of NPT among 54% of participants, performed by personal interview. However, in that study, the patient population was composed of two very different samples of cancer patients. Approximately 50% of patients were recruited from institutions that practiced NPT and the rest from a general hospital that practiced scientific medicine. Among patients treated within the hospital, Cassileth et al. found that 13% were users of NPT. It seems evident that the mixing of two heterogeneous patient populations explains the difference found between the reported studies to a much larger degree than differences in interview techniques.

Representativity of the study population might be the most important factor to ensure whether a study provides valid information. Clinical and demographic characteristics in the studied sample must be known, as well as whether the study cohort is representative of the cancer patient population in question. All recruited participants in our study were

from northern Norway. The patient population was enrolled during 1 year and included all patients seen for the first time in the Department of Oncology. Our hospital has the only cancer department in this area of the country. We therefore believe our patient population to be representative of patients seen in northern Norway. However, as reported earlier,⁴ there are major differences in the prevalence and type of NPT used which is preferred by patients from the north and west of Norway compared with the rest of the country. The high number of patients who used spiritual forms of NPT seems to be connected to greater religious activity and belief in supranatural phenomena found in these areas of the country. On the other hand, the inclusion of faith healing in the group of NPTs might have confused some patients, since they may not define faith healing as a form of NPT. The data reported here are therefore unlikely to be representative for the total Norwegian cancer patient population. However, the methodologic questions addressed in the study seem to be important and relevant, and not restricted to our part of the country.

Until now, all studies on patients' use of NPT have been cross-sectional in design. To our knowledge, no prospective follow-up study has been performed with the purpose to investigate the changing pattern of use of NPT over time. A possible bias in follow-up studies is the lack of anonymity. Some cancer patients may consider the hospital staff to have negative attitudes to NPT and therefore underreport their use of NPT. However, in an earlier study¹⁴ that described patients who answered the first questionnaire compared with 305 noncancer patients who answered the same questionnaire on use of NPT, we found that more patients in the anonymous arm of the study did not answer questions that addressed their use of NPT. It is also known that the response rates in many anonymous studies are low,^{20,21} and therefore might give biased results.

The excellent agreement between the questionnaire-based study and the interview performed after a follow-up time of 6 years with regard to the number of users of NPT strengthens the evidence which suggests that the results found in the study are correct. However, the discrepancy between the follow-up study and the interview may indicate that patients tend to forget use of nonspiritual methods of NPT over such a long period. Another explanation might be that patients tend to rate the importance of the different methods, as perceived by themselves, and not report methods they believe have less potential for cure than others. This might explain why patients report more use of spiritual healing than nonspiritual forms of NPT in a situation in which they have lived with their cancer for 5 to 6 years and in which most of them are cured of their disease.

Most studies have not shown any correlation between patients' use of NPT and time since diagnosis.^{5,23} However, the time aspect was an important predictor in our study. The study reported by Hauser¹⁹ supports our findings. It seems important that at least 6 months should pass before the number of users of NPT in a population is estimated. Our patients started their use of NPT in the period shortly after being informed of their cancer and during the subsequent 4 months. This time represents the most difficult period for most cancer patients. It is characterized by difficult and sometimes painful diagnostic procedures, uncertainties, and for most patients, hard treatments. The disease is new to the patient and expectations for the future are uncertain.

In studies in which patients are recruited shortly after learning their diagnosis, the number of users could be underestimated. In further cross-sectionally designed research on patients' use of NPT, the aspect of time since diagnosis must therefore be optimal.

Most studies in the literature have not found differences in the use of NPT as treatment for cancer among sexes.^{5,23} However, in a Norwegian study²⁶ and a Finnish study from 1980,²⁷ women used NPT more than men. Typical for these studies were the high number of users (45% to 55%) and that most patients used birch ash, which was popular in Norway and Finland at that time. At inclusion time in our study, more women used NPT than men. This difference grew during the study to highly significant levels. This result may have been caused by the large number of patients who used spiritual NPT. In a previously reported national cross-sectional study conducted in 1993, we found no difference in the overall use of NPT among men and women. Men seemed to use more nonspiritual forms of NPT than women, whereas women more often used spiritual forms.²⁸

The age distribution within a studied population seems to be important. Patients in the age group from 30 to 59 were the most prevalent users of NPT in our study, as reported by others.^{5,19} A correlation between better education and more frequent use of NPT is found in most studies.^{5,21,23} However, in the present study, if patients older than 75 years of age are excluded, the correlation is not statistically significant. The low level of education found among patients who participated in this north Norwegian study (75% of patients had only an elementary school education) might explain why higher educational level did not influence the use of NPT. However, the same results were found in the national study,⁴ even when patients situated in the west or northern part of the country were excluded.

A problem in our study, as in most reported studies, is that patient characteristics are only noted at the start of the study. The correlation between factors such as stage of disease,

ECOG performance status, and intention of treatment to patients' ever-use of NPT are thus estimated based on the baseline measurements of these factors.

In our study, the use of NPT had no impact on survival. Similar results were reported by Cassileth et al⁷ in 1991 and by Bagenal et al⁶ in 1990, who used conventionally treated cancer patients as control groups in a matched design. As in the study reported by Ringdal et al,²⁹ the prognosis measured by treatment objectives and the physical functioning of the patients were the most important prognostic factors related to survival adjusted for different diagnostic groups. The finding that better-educated patients seemed to have a better survival after adjusting for age and diagnostic groups is interesting. This observation should be explored in more detail, especially since income has no impact on the treatment offered cancer patients in Norway. Possibly, patient and doctor delay related to social class may explain the findings.

It is possible that the use of outcome measurements other than the length of survival could be more appropriate for measuring the benefits of NPT use among cancer patients. Measurements of quality of life were included in our study. However, the question of possible gain in quality of life among patients who use NPT is difficult to analyze. A major shortcoming in our data is that demographic and disease-related characteristics are only noted at the start of the study. As reported by Stoll,³⁰ any belief that increases hope of cure or benefit will improve quality of life in cancer patients and may override other components of quality-of-life measurements. A retrospectively designed study has therefore been undertaken on all patient files to add information about important events that might have happened to the patient during the follow-up period. This will be published elsewhere.

This study shows that cross-sectionally designed studies will underestimate the number of ever-users of NPT in a cancer patient population. However, the number of users found in each part of the study, as long as the diagnosis of cancer has been known for more than 6 months, was much the same. We also found that the percentage of patients who used spiritual versus nonspiritual forms of NPT was more or less unaltered among the different cross-sections of the study. If our findings are also relevant in other populations, cross-sectional studies seem to give valid information on the number of users and the types of NPT in use, as long as the probable underestimation is kept in mind and corrections are made for it.

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Appendix I

Questionnaire; 1-5



ALTERNATIVE MEDICINE AND CANCER PATIENTS

National Study

Serial number

Patient's name

Address (and postal code)

Patient's date of birth

Is the patient willing to fill out the questionnaire?

Yes

No

Diagnosis

- | | | | |
|--------------------------------|--------------------------|-----------------------|--------------------------|
| <i>Breast cancer</i> | <input type="checkbox"/> | <i>Head and Neck</i> | <input type="checkbox"/> |
| <i>Prostatic cancer</i> | <input type="checkbox"/> | <i>Kindey cancer</i> | <input type="checkbox"/> |
| <i>Gastrointestinal cancer</i> | <input type="checkbox"/> | <i>Bladder cancer</i> | <input type="checkbox"/> |
| <i>Lung cancer</i> | <input type="checkbox"/> | <i>Sarcoma</i> | <input type="checkbox"/> |
| <i>Malignant melanoma</i> | <input type="checkbox"/> | <i>Brain cancer</i> | <input type="checkbox"/> |
| <i>Malignant lymphoma</i> | <input type="checkbox"/> | <i>Cervix cancer</i> | <input type="checkbox"/> |
| <i>Myelomatose</i> | <input type="checkbox"/> | <i>Uterine cancer</i> | <input type="checkbox"/> |
| <i>Testicular cancer</i> | <input type="checkbox"/> | <i>Ovarian cancer</i> | <input type="checkbox"/> |

Treatment

- | | |
|--------------------------|--------------------------|
| <i>Primary treatment</i> | <input type="checkbox"/> |
| <i>1. relapse</i> | <input type="checkbox"/> |
| <i>2. later relapse</i> | <input type="checkbox"/> |
| <i>control</i> | <input type="checkbox"/> |

Modality

- | | |
|----------------------------|--------------------------|
| <i>Chemotherapy</i> | <input type="checkbox"/> |
| <i>Hormonal therapy</i> | <input type="checkbox"/> |
| <i>Radiation</i> | <input type="checkbox"/> |
| <i>Surgery</i> | <input type="checkbox"/> |
| <i>Surgery + Radiation</i> | <input type="checkbox"/> |
| <i>Surgery + chemo</i> | <input type="checkbox"/> |
| <i>Chemo + radiation</i> | <input type="checkbox"/> |
| <i>OtherSpecify</i> | <input type="checkbox"/> |

Medical data at the start of the study

Histology

Stage

T N M

ECOG 0 1 2 3 4

Number of months since diagnosis

- 0-1 months
- 1-3 months
- 3-6 months
- 6-12 months
- more than 2 years

If treated earlier, how long is it since the initial diagnosis

- 0-1 months
- 1-3 months
- 3-6 months
- 6-12 months
- more than 2 years

Goals of the treatment

- Curative
- Palliative symptom preventative treatment
- Palliative symptom relief treatment

QUESTIONNAIRE 1990-91, Follow-up Study

RST

INITIAL FORM FOR THE 1990-91 RST QUESTIONNAIRE

Medical information:

Patient's name.....

Address.....

Patient's Personal number

Is the patient willing to fill out the questionnaire?

Yes

No

If no, why not?

SOCIAL STATUS

Sex:

Female

Male

Marital status:

Single, never married

Married

Divorced, separated

Widow, widower

The patient lives:

alone

with a spouse

with children

with other relatives

in an institution

The patient's level of education is comparable to:

- 7 years primary school
- 9 years secondary school
- High school diploma
- College degree
- Graduate school degree

The patient is for the present

- Working
- Please specify profession
- Unemployed
- Unable to work/senior citizen

Medical data at the start of the study

- Diagnosis
- Histology
- Stage
- ECOG

The patient is an inpatient at the Cancer centre Yes

No

If no, Referred as an out-patient

Referred by another Cancer centre

INITIAL FORM FOR THE QUESTIONNAIRE (1992-93)

Dear patient,

As a supplement to the questionnaire you are asked to participate in it is very important that you answer the following questions.

The information will be kept confidential.

Are you a man or a woman?

- Woman
- Man

Marital status

- Single, never married
- Married
- Divorced, separated
- Widow, widower

What kind of education do you have?

- 7 years primary school
- 9 years secondary school
- High school diploma
- College degree
- Graduate school degree

Are you living:

- alone
- with a spouse
- with children
- with other relatives
- in an institution

What is your present occupation?

- Working
- Please specify profession
- Unemployed
- Housewife
- Student
- Unable to work/senior citizen

QUESTIONNAIRE Part 1

Please mark an X in the box next to the answer that best fits your situation.

All information will be strictly confidential.

A) A few questions about the waiting period

1) *How long did you experience symptoms before contacting your doctor?*

- Less than a week
- 1-4 weeks
- 1-3 months
- More than 3 months
- Not sure

2) *How long did it take to get an appointment with your doctor?*

- Less than a week
- 1-4 weeks
- 1-3 months
- More than 3 months
- Not sure

3) *How much time passed from the time you first contacted your doctor until he referred you to an outpatient clinic, specialist or local hospital?*

- Less than a week
- 1-4 weeks
- 1-3 months
- More than 3 months
- Not sure

4) *How long did it take before you were admitted to the local hospital after being referred?*

- Less than a week
- 1-4 weeks
- 1-3 months
- More than 3 months
- Not sure

5) *How long did it take before you were admitted to the Cancer centre after your doctor, a specialist, or the local hospital referred you?*

- Less than a week
- 1-4 weeks
- 1-3 months
- More than 3 months
- Not sure

B) The Cancer centre's roll

Now that there is a Cancer centre in Northern Norway, please rate the following according to what is important for you. Please mark an X on the line next to each statement. If you mark off at the left it means that this is not important, whereas if you mark off at the right it means that you think this is very important.

6) Short distance to travel for treatment 0 _____ 10

7) Being closer to friends and relatives 0 _____ 10

8) Easier to obtain leave of absence 0 _____ 10

9) Easier to travel to check ups 0 _____ 10

10) How does the treatment available at the Cancer centre here in Tromsø compare to the treatment available at another Cancer centre in Norway?

- Not as good in Tromsø
- Just as good in Tromsø
- Better in Tromsø
- Not sure

C) Information

11) Which of the following statements do you agree with most? Please mark one of the following.

- It is very important to me to know everything there is to know about my disease.
- It is important for me to have a general understanding of my disease without needing to know all the details. The doctors are doing their best anyhow.
- It is not important for me to know about my disease.
- It is not wise to know too much.

12) *How well informed were you before being admitted to the Cancer centre?*

Well informed

Somewhat informed

Not well informed

Had no information

13) *Do you feel that your primary doctor held back any information about your disease?*

The doctor gave me all the information

The doctor held back some information

The doctor gave me very little information

14) *Do you feel that your primary hospital held back any information about your disease?*

The primary hospital gave me all the information

The primary hospital held back some information

The primary hospital gave me very little information

D) Causes of cancer

15) *Do you believe that the environment surrounding us is important as a cause of cancer?*

- Not at all
- Yes, but only to a slight degree
- Yes, very much so
- I do not know

16) *If you believe the environment to be important as a cause of cancer, which environmental factors do you believe are the most important. Please rank the factors given in the list so that the most important factor is given the number 7 and the least important factor is given the number 1. If you believe other environmental factors to be more important, please state so with the name of the factor.*

- 1. Air pollution
- 2. Radiation from the ground
- 3. Radiation from high voltage electricity
- 4. Radiation from computers
- 5. Sun exposure
- 6. Chemical substances
- 7. Virus
- 8. Other environmental factors

17) *Do you believe that anything vi eat or drink might cause cancer?*

- Not at all
- Yes, but only to a slight degree
- Yes, very much so
- I do not know

18) *Do you believe that stimulants (like tobacco and alcohol) might cause cancer?*

- Not at all
- Yes, but only to a slight degree
- Yes, very much so
- I do not know

19) *Do you believe cancer to be a heritable disease?*

- Not at all
- Yes, but only to a slight degree
- Yes, very much so
- I do not know

20) *Do you believe cancer might be a contagious disease?*

- Not at all
- Yes, but only to a slight degree
- Yes, very much so
- I do not know

21) *Do you believe that (a cancer-patient) by changing your (his/her) way of living, in a positive way, would improve on the outcome of your (his/her) disease?*

- Not at all
- Yes, but only to a slight degree
- Yes, very much so
- I do not know

22) *What would be the most important change in life-style for most people to prevent cancer?*

- Stop smoking
- Avoid alcohol
- More (daily) exercise
- Healthier diet
- Do not know
- Other changes. Please mark them here

E) Psychosocial relationship

- 23) *Do you think that your friends and family will act differently towards you now that you have cancer?*
- No
- Somewhat
- Yes, very much so
- Not sure

In connection with your illness you have experienced waiting periods. Can you rate the following questions by marking on the line. 1 means that this hasn't bothered you whereas 10 means that this has been very difficult for you.

- 24) *Waiting period before your first doctors appointment* 0 _____ 10
- 25) *Waiting period before admittance to the local hospital* 0 _____ 10
- 26) *Waiting period before admittance to the Cancer centre* 0 _____ 10

F) Alternative Medicine

27) *Do you think that others than medical doctors (as represented by doctors in hospitals) could have knowledge which may be helpful in the fight against cancer. Examples of such practitioners could be: healers, zone therapists, homeopaths*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

28) *Would you consider consulting someone who practices «other» cancer treatments, besides those which are offered by traditional medical doctors*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

29) *Would you like alternative medicine to be an optional treatment offered within the hospitals?*

- No
- Yes
- I don't know

30) *If you are using or have used alternative medicine please mark which type*

- | | | |
|--------------------------------------|--------------------------|--------------------------|
| | Do not use | <input type="checkbox"/> |
| Healer | <input type="checkbox"/> | |
| Homeopath | <input type="checkbox"/> | |
| Zone therapy | <input type="checkbox"/> | |
| Herb/vegetable cure | <input type="checkbox"/> | |
| “Nitterkur” | <input type="checkbox"/> | |
| Sevenstar treatment | <input type="checkbox"/> | |
| Other types of alternative treatment | _____ | |

31) *If you have used or are using alternative forms of medical treatment, how did you hear about these?*

- Via friends or family
- TV or radio
- Newspaper or magazine
- I do not know
- Other sources _____

32) *Have you ever felt pressure by those around you to try alternative medicine?*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

33) *Been able to concentrate on whatever you're doing?*

- Better than usual
- Same as usual
- Less than usual
- Much less than usual

34) *Felt that you are playing a useful part in things?*

- More than usual
- Same as usual
- Less useful than usual
- Much less useful

35) *Found everything getting on top of you?*

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

36) *Been feeling unhappy and depressed?*

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

37) *Been feeling nervous and stung up all the time?*

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

38) *We have asked you a number of questions. Did any of the questions make you uncomfortable or did you find any to be offensive? If so, please state the number or numbers below.*

- None
- The following questions made me uncomfortable, were offensive

39) *Did you need help to fill out the questionnaire?*

- Yes
- No

Who helped you _____

40) *If you have any comments regarding the questionnaire, please write them in the space provided below*

.....

QUESTIONNAIRE

1990-91, Cancer centre, RST

Part 2

QUESTIONNAIRE

Name

Address

Personal number

Please mark an X in the box next to answer that best fits your situation.

All information will be strictly confidential.

A Infomation

The following questions concern your reaction to the information given to you during your first inpatient visit to the Cancer centre, or at another Cancer centre while you were receiving radiation treatment.

1) *Do you feel that it was easy to ask questions at the time you were admitted?*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

2) *Do you feel that the information you were given at the Cancer centre was easy to understand?*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

3) *Do you feel that any information was held back*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

4) *Were you given any information that you did not want to know?*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

5) *How well informed were you after admittance to the Cancer centre?*

- Well
- Somewhat well informed
- Not well informed
- Had no information

B The Cancer centre's roll

6) *Do you feel that we at the Cancer centre explained why we recommended a particular type of treatment*

- Explained well
- Some explanation
- Too little was explained
- Nothing was explained

7) *Do you feel that you had influence on the choice of treatment that you received?*

- A lot of influence
- Some influence
- Too little influence
- No influence

8) *Do you feel that you have received the best treatment available?*

- No, not at all
- Yes, absolutely
- I do not know

C Psychosocial relationship

9) *Do you feel that your friends or family act differently towards you now that you have cancer?*

- No
- Somewhat
- Yes, very differently
- I don't know

10) *If you feel that your relationship to your friends or family has changed since you became ill, how has it done so? Please mark on the line below. If you cross off on the right it means that your relationship to your family or friends has become more difficult, to the left means that it has become much easier.*

Much easier

Unchanged

Very difficult

X-----X-----X

11) *Been able to concentrate on whatever you're doing?*

- Better than usual
- Same as usual
- Less than usual
- Much less than usual

12) *Felt that you are playing a useful part in things?*

- More than usual
- Same as usual
- Less useful than usual
- Much less useful

13) *Found everything getting on top of you?*

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

14) *Been feeling unhappy and depressed?*

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

15) *Been feeling nervous and stung up all the time?*

- Not at all
- No more than usual
- Rather more than usual
- Much more than usual

D Alternative medicine

16) *Have you been involved with alternative medicine after you were admitted to the Cancer centre?*

No

Yes

17) *If you are using or have used alternative medicine please mark which type*

Healer

Homeopath

Zone therapy

Herb or vegetable cure

"Nitterkur"

Sevenstar treatment

Healing by prayer

Other types of alternative treatment _____

18) *If you have not been in touch with persons practicing «other» (alternative) treatment, would you consider doing so?*

No, not at all

Maybe

Yes, absolutely

Not sure

19) *Have you ever felt pressure from those around you to try alternative medicine?*

No, not at all

Somewhat

Yes, very much so

I don't know

20) *If you are in contact with or are thinking about contacting someone who practices alternative medicine, would you find this difficult to discuss with the doctors at the Cancer centre.*

No, not at all

Somewhat

Yes, very much so

I don't know

QUESTIONNAIRE

1991-92, Cancer centre, RST

Part 3

Alternative medicine (Alternative treatment)

Alternative medicine is a very diverse concept under which many forms of treatment are represented. In question 2 we have listed some of the most common types of treatment. The use of these methods by cancer patients in Norway has not been documented previously, and for those of us who work with cancer disease it is therefore important to know more about this. Please try to answer all of the questions. The fact that you use one or more of these methods will not effect our relationship to you.

1) *Have you used alternative medicine to treat other ailments prior to having cancer?*

- No
- Yes

2) *If so, what type did you use prior to having cancer?*

- Healing
- Homeopathic
- Zone therapy
- Herb or vegetable cure
- "Nitterkur"
- Iscador
- Sevenstar treatment
- Change of diet
- Cure by prayer, anointment
- Other types of alternative (other) treatment _____

3) *Do you think that others than medical doctors (as represented by doctors in hospitals) could have knowledge which maybe helpful in the fight against cancer? Examples of such practitioners could be: healers, zone therapists, homeopaths.*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

4) Do you think that the option of such an alternative treatment should be given to you by the hospitals? No

Yes

I do not know

5) If you are using or have used alternative medicine please mark which type

Do not use

Healing

Homeopathic

Zone therapy

Herb or vegetable cure

"Nitterkur"

Iscador

Sevenstar treatment

Change of diet

Healing by prayer

Other types of alternative (other) treatment _____

6) Do you know if your disease has spread beyond the area where it first started

No it has not spread

Yes it has spread

Not sure

If you have not used alternative medicine in connection with your cancer illness please move on to question 20.

7) Did you know whether the cancer had spread before you began using alternative medicine?

It had not spread

Yes, I knew that it had spread

No, I did not know that it had spread

Not sure

8) When was the first time that you used an alternative treatment after you learned that you had cancer?

After 0-1 month

After 2-3 months

After 6-12 months

After 1-2 years

After more than 2 years

9) *What is your main reason for using another treatment besides the one that the health service has to offer?*

- Was not offered treatment by the health service
- The health service's treatment is not working
- Alternative treatment has been shown to be curative before
- It is curative, contains active substances, and strengthens the immune system
- Have heard from others that it works
- Believe in it
- Not sure
- Other reasons for using alternative medicine _____

10) *What do you think might be the effect of the alternative treatment? You may select several options*

- Prevent recurrence
- Cure the disease
- A partial remission
- Prevent the disease from spreading
- Increase the body's resistance
- Improve general health
- I do not know

11) *What do you feel has been the effect of the treatment?*

- Prevent recurrence
- Cure the disease
- A partial remission
- Prevent the disease from spreading
- Increase the body's resistance
- Improve general health
- I do not know

12) *Have you stopped using the alternative treatment you used?*

- No, I am still using the treatment
- Yes, I stopped

13) *How long have you used (or did you use) the treatment?*

- 0-1 months
- 2-3 months
- 4-6 months
- 6-12 months
- 1-2 years
- more than 2 years

14) *If you stopped using the alternative treatment, why did you stop?*

- The treatment was completed
- The treatment did not work
- I stopped believing in it
- It was recommended that I stopped
- I experienced side effects
- It was too tiring/ difficult to obtain treatment
- For financial reasons
- I do not know

15) *If you stopped because of side effects, what were they. Please describe the side effects in the space provided below.*

16) *Do you think that the alternative treatment has been expensive?*

- No
- Yes

17) *What has been the total cost of the treatment?*

- Kr 0-500
- Kr 500-1000
- Kr 1000-2000
- Kr 2000-4000
- More than Kr 4000

18) *Have you obtained financial aid in order to undergo treatment?*

- Yes
- No

19) *How were you informed of the treatment?*

- Via friends or family
- TV or radio
- Newspaper or magazine
- I do not know

20) *If a practitioner of alternative medicine (for example homeopath, zone therapist, healer) says to you that you will be cured by the treatment, do you expect*

- to be cured
- to be almost cured
- maybe to be cured
- not to be cured

21) *If a traditional doctor (for example your local doctor or a doctor at the hospital) tells you that you will be cured by the treatment he or she gives you, do you expect:*

- to be cured
- to be almost cured
- maybe to be cured
- not to be cured

22) *What kind of hope did the practitioner of alternative medicine give you when you started the treatment? (If you have used alternative medicine)*

- No improvement
- A little improvement
- Much better
- Very much better
- Be cured
- I haven't used alternative medicine

23) *What kind of hope did your doctor give you when you started the treatment? (Hospital doctor or local doctor)*

- No improvement
- A little improvement
- Much better
- Very much better
- Be cured
- I haven't used alternative medicine

24) *Have you ever felt pressure from those around you to try alternative medicine?*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

25) *If you have not been in touch with persons practicing «other» (alternative) treatment, would you consider doing so?*

- No, not at all
- Maybe
- Yes, absolutely
- Not sure

26) *If you have not been in touch with alternative treatment, but would like to try such treatment. In that case, what sort of treatment would you like to try*

- Healer
- Homeopath
- Zone therapy
- Herb or vegetable cure
- "Nitterkur"
- Iscador
- Sevenstar treatment
- Healing by prayer
- Other types of alternative treatment _____

27) *If you are in contact with or are thinking about contacting someone who practices alternative medicine, would you find this difficult to discuss with the doctors at the Cancer centre.*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

28) *Do you consider yourself to be a religious person?*

- Yes
- No
- I do not know

29) *Do you feel that your faith has changed since you got cancer?*

- No
- Yes, somewhat
- Yes, very much so

30) *If your faith has changed after you became ill,*

- have you become more religious
- less religious?

31) *Do you think that the spiritual/clerical services offered to you by the hospital has been satisfactory?*

- Yes
- No

32) *Do you feel that spiritual/clerical services should be made available to patients?*

- Never
- Only when the patient asks for it
- Each patient should obtain clerical services
- Each patient should be encouraged to contact a clergyman

QUESTIONNAIRE

1992-93, Cancer centre, RST

Part 4 and 5

1) *Have you used alternative medicine to treat other ailments prior to having cancer?*

- No
- Yes

2) *If so, what type did you use prior to having cancer?*

- Healing
- Homeopathic
- Zone therapy
- Herb or vegetable cure
- "Nitterkur"
- Iscador
- Sevenstar treatment
- Change of diet
- Healing by prayer
- Other types of alternative (other) treatment _____

3) *Do you think that others than medical doctors (as represented by doctors in hospitals) could have knowledge which maybe helpful in the fight against cancer? Examples of such practitioners could be: healers, zone therapists, homeopaths.*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

4) *Do you think that the option of such an alternative treatment should be given to you by the hospitals?*

- No
- Yes
- I do not know

5) *Some people think that there should be a cooperation between alternative medicine and traditional medicine when it comes to treating patients who have cancer. Do you feel that such a collaboration would be beneficial?*

- Yes
- No
- Somewhat
- I do not know

6) *If you are using or have used alternative medicine please mark which type*

Do not use

- Healing
- Homeopathic
- Zone therapy
- Herb or vegetable cure
- "Nitterkur"
- Iscador
- Sevenstar treatment
- Change of diet
- Healing by prayer
- Other types of alternative (other) treatment _____

7) *Do you know if your disease has spread beyond the area where it first started?*

- No it has not spread
- Yes it has spread
- Not sure

If you have not used alternative medicine in connection with your cancer illness please move on to question 20.

8) *Did you know whether the cancer had spread before you began using alternative medicine?*

- It had not spread
- Yes, I knew that it had spread
- No, I did not know that it had spread
- Not sure

9) *When was the first time that you used an alternative treatment after you learned that you had cancer?*

- After 0-1 month
- After 2-3 months
- After 3-6 months
- After 6-12 months
- After 1-2 years
- After more than 2 years

10) *After you learned that you had cancer did you choose the treatment offered by alternative medicine as the primary form of treatment, or did you choose the treatment that your physician recommended?*

- I was treated initially by practitioners of alternative medicine
- I was initially treated by traditional doctors
- I started with both types of treatments
- I have not been treated by doctors

11) *If you chose to begin with alternative medicine as the first treatment, how long did you use it before you obtained treatment from traditional doctors (doctors at the hospital)?*

- I have not been offered treatment by traditional doctors
- 0-1 months
- 1-3 months
- 3-6 months
- 6-12 months
- More than a year

12) *Have you ever sought treatment abroad in connection with your disease?*

- No, I have never been abroad to obtain treatment
- Yes, I have sought treatment abroad

If you have not sought treatment abroad, go on to question 17.

13) *If you sought alternative treatment abroad, what kind of treatment did you obtain?*

- Do not use
- Healing
- Homeopathic
- Zone therapy
- Herb or vegetable cure
- "Nitterkur"
- Iscador
- Sevenstar treatment
- Change of diet
- Healing by prayer
- Other types of alternative (other) treatment _____

14) *In which country was the treatment administered.*

Please write the name of the country here _____

15) *How many times have you been abroad to obtain treatments for your illness?*

- Once
- Twice
- Three times
- 4-6 times
- 6-10 times
- More than 10 times

16) *What is the total cost of the treatments you received abroad?*

- Kr 1000-10000
- Kr 10000-20000
- Kr 20000-40000
- More than Kr 40000

17) *What is your main reason for using another treatment besides the one that the health service has to offer?*

- Was not offered treatment by the health service
- The health service's treatment is not working
- Alternative treatment has been shown to be curative before
- It is curative, contains active substances, and strengthens the immune system
- Have heard from others that it works
- Believe in it
- Not sure
- Other reasons for using alternative medicine _____

18) *Has your doctor at home or a doctor at the hospital influenced the choice of alternative medicine?*

- The doctor recommended the treatment
- The doctor has neither recommended nor advised against the treatment
- The doctor advised against the treatment

19) *Do you feel that the public health service, your doctor or the hospital staff have shown you consideration and tried to meet your needs, including your daily needs?*

- No, not at all
- Yes, somewhat
- Yes, very much so

20) *Do you feel that the health service's lack of consideration or interest in you was one of the main reasons for choosing the alternative treatment?*

- No, not at all
- Yes, somewhat
- Yes, very much so

21) *What effect might the alternative treatment have on your disease? If you believe the treatment will be effective in several ways, please mark in the box next to the one which is most important.*

- Prevent recurrence
- Cure the disease
- Give a partial remission
- Prevent the disease from spreading
- Increase the body's resistance
- Improve general health
- I do not know

22) *What effect has the alternative treatment had*

- Prevent recurrence
- Cure the disease
- Give a partial remission
- Prevent the disease from spreading
- Increase the body's resistance
- Improve general health
- I do not know

23) *Have you stopped using the alternative treatment?*

- No, I am still using the treatment
- Yes, I stopped

24) *How long have you used (or did you use) the treatment?*

- 0-1 months
- 2-3 months
- 4-6 months
- 6-12 months
- 1-2 years
- more than 2 years

25) *If you stopped using the alternative treatment, why did you stop?*

- The treatment was completed
- The treatment did not work
- I stopped believing in it
- It was recommended that I stopped
- I experienced side effects
- It was too tiring/ difficult to obtain treatment
- For financial reasons
- I do not know

26) *If you stopped because of side effects, what were they. Please describe the side effects in the space provided below.*

27) *Do you think that the alternative treatment has been expensive?*

- No
- Yes

28) *What has been the total cost of the treatment?*

- Kr 0-500
- Kr 500-1000
- Kr 1000-2000
- Kr 2000-4000
- More than Kr 4000

29) *Have you obtained financial aid in order to undergo treatment?*

- Yes
- No

30) *How were you informed of the treatment?*

- Via friends or family
- TV or radio
- Newspaper or magazine
- I do not know

31) *Using your experience with alternative medicine as a basis, would you recommend that other cancer patients should seek alternative treatments?*

- No, not at all
- Yes, somewhat
- Yes, very much so

32) *If you recommend that other cancer patients should use alternative medicine, what type of treatment would you recommend. Mark in the box next to the treatment that you feel is most effective. (choose one answer).*

- Healing
- Homeopathic
- Zone therapy
- Herb or vegetable cure
- "Nitterkur"
- Iscador
- Sevenstar treatment
- Change of diet
- Cure by prayer, anointment
- Other types of alternative (other) treatment _____

33) *If a practitioner of alternative medicine (for example homeopath, zone therapist, healer) says to you that you will be cured by the treatment, do you expect:*

- to be cured
- to be almost cured
- maybe to be cured
- not to be cured

34) *If a traditional doctor (for example your doctor or a doctor at the hospital) tells you that you will be cured by the treatment he or she gives you, do you expect:*

- to be cured
- to be almost cured
- maybe to be cured
- not to be cured

35) *What kind of hope did the practitioner of alternative medicine give you when you started the treatment? (If you have used alternative medicine)*

- No improvement
- A little improvement
- Much better
- Very much better
- Be cured
- I haven't used alternative medicine

36) *What kind of hope did your doctor give you when you started the treatment? (Hospital doctor or local doctor*

- No improvement
- A little improvement
- Much better
- Very much better
- Be cured
- I haven't used alternative medicine

37) *Have you ever felt pressure from those around you to try alternative medicine?*

- No, not at all
- Somewhat
- Yes, very much so
- I don't know

38) *Have you ever been criticized by those around you for using alternative medicine?*

- No, not at all
- Somewhat
- Yes, very much so
- I do not know
- Have not used it

39) *If you have not been in touch with persons practicing «other» (alternative) treatment, would you consider doing so?*

- No, not at all
- Maybe
- Yes, absolutely
- Not sure

40) *If you have not been in touch with alternative treatment, but would like to try such treatment. In that case, what sort of treatment would you like to try*

- Healer
- Homeopath
- Zone therapy
- Herb or vegetable cure
- "Nitterkur"
- Iscador
- Sevenstar treatment
- Healing by prayer
- Other types of alternative treatment _____

41) *If you are in contact with or are thinking about contacting someone who practices alternative medicine, would you find this difficult to discuss with the doctors at the Cancer centre.*

- No, not at all
- Somewhat
- Yes, very much so
- I do not know

42) *Do you consider yourself to be a religious person?*

- Yes
- No
- I do not know

43) *Do you feel that your faith has changed since you got cancer?*

- No
- Yes, somewhat
- Yes, very much so

44) *If your faith has changed after you became ill,*

- have you become more religious
- less religious?

45) *Do you think that the spiritual/clerical service offered to you by the hospital has been satisfactory?*

- Yes
- No

46) *Do you feel that spiritual/clerical services should be made available to patients?*

- Never
- Only when the patient asks for it
- Each patient should obtain clerical services
- Each patient should be encouraged to contact a clergyman

47) *When you think about the way things are going at this time are you satisfied with your situation or are you dissatisfied?*

- Very satisfied
- Quite satisfied
- Somewhat satisfied
- Ok
- Somewhat dissatisfied
- Quite dissatisfied
- Very dissatisfied.

48) *Do you feel fit and strong, or tired and weak?*

- Very fit and strong
- Fit and strong
- Somewhat fit and strong
- Ok
- Somewhat weak and tired
- Weak and tired
- Very weak and tired

EORTC QLQ-C30

Please answer all the questions yourself by circling the number that best applies to you.

	No	Yes
49) Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2
50) Do you have any trouble taking a long walk?	1	2
51) Do you have any trouble taking a short walk outside of the house?	1	2
52) Do you have to stay in a bed or a chair for the most of the day?	1	2
53) Do you need help with eating, dressing washing yourself or using the toilet?	1	2
54) Are you limited in any way in doing either your work or doing household jobs?	1	2
55) Are you completely unable to work at a job or to do household jobs?	1	2

During the past week:

	Not at all	A little	Quite a bit	Very much
56) Were you short of breath?	1	2	3	4
57) Have you had pain?	1	2	3	4
58) Did you need to rest?	1	2	3	4
59) Have you had trouble sleeping?	1	2	3	4
60) Have you felt weak?	1	2	3	4
61) Have you lacked appetite?	1	2	3	4
62) Have you felt nauseated?	1	2	3	4
63) Have you vomited?	1	2	3	4
64) Have you been constipated?	1	2	3	4

GHQ-20

Have you recently:

78) been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
79) lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
80) been managing to keep yourself busy and occupied?	Better than usual	Same as usual	Rather less than usual	Much less than usual
81) been getting out of the house as much as usual?	More than usual	Same as usual	Less than usual	Much less than usual
82) felt on the whole you were doing things well?	Better than usual	About the same	Less well usual	Much less well
83) been satisfied with the way you've carried out your task?	More satisfied	About the same	Less satisfied than usual	Much less satisfied
84) felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
85) felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
86) felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
87) felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
88) been able to enjoy your normal day-to-day activities?	Not at all	No more than usual	Rather more than usual	Much more than usual
89) been taking things hard?	Not at all	No more than usual	Rather more than usual	Much more than usual
90) been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
91) found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
92) been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
93) been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual

94) been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
95) been feeling reasonable happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual
96) been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual
97) found at times you couldn't do anything because your nerves were to bad?	Not at all	No more than usual	Rather more than usual	Much more than usual

98) If you have any comments, please wright here

.....

Appendix II

Questionnaire; telephone interview



Patient Name.....

LPNum.....

Interview

What is the first thing that comes to mind when I ask you what alternative medicine is ?

.....
.....
.....
.....

Did you use NPT as treatment for your cancer disease Yes..... No.....

Which types of alternative medicine do you know about ?

	Know about	Have used (cancer)
1. Healing by prayer
2. Healing by laying on of hands
3. Health food/ diet cure
4. herbal medicine/ vitamin cure
5. Homeopathic medicine
6. foot zone therapy
7. Iscador
8. Nitterkur
9. Acupuncture
10. Other types

Which types.....
.....

We consider now healing by prayer and healing by laying on of hands as forms of alternative medicine.

A) <u>Healing by prayer</u>	Yes	No	Not sure
Is healing by prayer something that is often practised in the region you live in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you used healing by prayer before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is healing by prayer different than the usual «evening prayer»?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Was it you or someone else who got the idea that you should try healing by prayer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you believe that «healing by prayer» can cure cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments

.....
.....

B) <u>Laying on of hands</u>	Yes	No	Not sure
Is healing by laying on of hands something which is commonly practised in the region you live in?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you used healing by laying on of hands before (for another illness)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know about different ways of healing by laying on of hands?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Was it you or someone else who got the idea that you should try healing by laying on of hands?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you believe that healing by laying on of hands can cure cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments

.....
.....

Alternative medicine at the hospital

	Yes	No	Not sure
Would you like alternative medicine to be an optional treatment offered within the hospitals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel that the hospital should offer all forms of alternative treatment or just certain types?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If so, which types?

.....

Non users of Alternative medicine

What is the main reason for not trying an alternative to the treatment offered by the doctors?

Patient's answer:

.....

.....

1. Was cured by the traditional medical treatment
2. Was not offered an alternative
3. Do not believe in alternative medicine
4. Was advised not to try alternative treatments
5. Thought that the alternative treatment was too expensive
6. Other reasons

Use of alternative medicine as a cancer patient

What is the main reason for using another treatment besides the one that the health service has to offer?

- 1. Was not offered treatment by the health service
- 2. The health service's treatment is not working
- 3. Alternative treatment has been shown to be curative before
- 4. It is curative, contains active substances, and strengthens the immune system
- 5. Have heard from others that it works
- 6. Believe in it
- 7. Not sure
- 8. Other reasons for using alternative medicine

How soon after your diagnosis did you start the alternative treatment?

0-1 months 1-3 months 3-6 months 6-12 months 12-24 months >24 months

Was a change in the progression of your illness an important factor in your decision to start the alternative treatment?

Yes No

If so, what was the change?

How many times have you used alternative medicine? 1x 2x 3x 4x

Which treatments have you used?

1x.....

2x.....

3x.....

4x.....

What did you hope would be the effect of the treatment?

1x.....

2x.....

3x.....

In your opinion, what effects has the treatment had on your illness?

1x.....

2x.....

3x.....

Explain in your own words:

What is the most important reason for trying alternative medicine

.....
.....
.....
.....

ISM SKRIFTSERIE - FØR UTGITT:

1. Bidrag til belysning av medisinske og sosiale forhold i Finnmark fylke, med særlig vekt på forholdene blant finskattede i Sør-Varanger kommune.
Av Anders Forsdahl, 1976. (nytt opplag 1990)
2. Sunnhetstilstanden, hygieniske og sosiale forhold i Sør-Varanger kommune 1869-1975 belyst ved medisinalberetningene.
Av Anders Forsdahl, 1977.
3. Hjerte-karundersøkelsen i Finnmark - et eksempel på en populasjonsundersøkelse rettet mot cardiovasculære sykdommer. Beskrivelse og analyse av etterundersøkelsesgruppen.
Av Jan-Ivar Kvamme og Trond Haider, 1979.
4. The Tromsø Heart Study: Population studies of coronary risk factors with special emphasis on high density lipoprotein and the family occurrence of myocardial infarction.
Av Olav Helge Førde og Dag Steinar Thelle, 1979.
5. Reformen i distriktshelsetjenesten III: Hypertensjon i distriktshelsetjenesten.
Av Jan-Ivar Kvamme, 1980.
6. Til professor Knut Westlund på hans 60-års dag, 1983.
- 7.* Blodtrykksovervåkning og blodtrykksmåling.
Av Jan-Ivar Kvamme, Bernt Nesje og Anders Forsdahl, 1983.
- 8.* Merkesteiner i norsk medisin reist av allmennpraktikere - og enkelte utdrag av medisinalberetninger av kulturhistorisk verdi.
Av Anders Forsdahl, 1984.
9. "Balsfjordsystemet." EDB-basert journal, arkiv og statistikkssystem for primærhelsetjenesten.
Av Toralf Hasvold, 1984.
10. Tvunget psykisk helsevern i Norge. Rettsikkerheten ved slikt helsevern med særlig vurdering av kontrollkommisjonsordningen.
Av Georg Høyer, 1986.

11. The use of self-administered questionnaires about food habits. Relationships with risk factors for coronary heart disease and associations between coffee drinking and mortality and cancer incidence.
Av Bjarne Koster Jacobsen, 1988.
- 12.* Helse og ulikhet. Vi trenger et handlingsprogram for Finnmark.
Av Anders Forsdahl, Atle Svendal, Aslak Syse og Dag Thelle, 1989.
13. Health education and self-care in dentistry - surveys and interventions.
Av Anne Johanne Søgaard, 1989.
14. Helsekontroller i praksis. Erfaringer fra prosjektet helsekontroller i Troms 1983-1985.
Av Harald Siem og Arild Johansen, 1989.
15. Til Anders Forsdahls 60-års dag, 1990.
16. Diagnosis of cancer in general practice. A study of delay problems and warning signals of cancer, with implications for public cancer information and for cancer diagnostic strategies in general practice.
Av Knut Holtedahl, 1991.
17. The Tromsø Survey. The family intervention study. Feasibility of using a family approach to intervention on coronary heart disease. The effect of lifestyle intervention of coronary risk factors.
Av Synnøve Fønnebø Knutsen, 1991.
18. Helhetsforståelse og kommunikasjon. Filosofi for klinikere.
Av Åge Wifstad, 1991.
19. Factors affecting self-evaluated general health status - and the use of professional health care services.
Av Knut Fylkesnes, 1991.
20. Serum gamma-glutamyltransferase: Population determinants and diagnostic characteristics in relation to intervention on risk drinkers.
Av Odd Nilssen, 1992.
21. The Healthy Faith. Pregnancy outcome, risk of disease, cancer morbidity and mortality in Norwegian Seventh-Day-Adventists.
Av Vinjar Fønnebø, 1992.

22. Aspects of breast and cervical cancer screening.
Av Inger Torhild Gram, 1992.
23. Population studies on dyspepsia and peptic ulcer disease: Occurrence, aetiology, and diagnosis. From The Tromsø Heart Study and The Sørreisa Gastrointestinal Disorder Studie.
Av Roar Johnsen, 1992.
24. Diagnosis of pneumonia in adults in general practice.
Av Hasse Melbye, 1992.
25. Relationship between hemodynamics and blood lipids in population surveys, and effects of n-3 fatty acids.
Av Kaare Bønaa, 1992.
26. Risk factors for, and 13-year mortality from cardiovascular disease by socioeconomic status. A study of 44690 men and 17540 women, ages 40-49.
Av Hanne Thürmer, 1993.
27. Utdrag av medisinalberetninger fra Sulitjelma 1891-1990.
Av Anders Forsdahl, 1993.
28. Helse, livsstil og levekår i Finnmark. Resultater fra Hjerte-karundersøkelsen i 1987-88. Finnmark III.
Av Knut Westlund og Anne Johanne Søgaard, 1993.
29. Patterns and predictors of drug use. A pharmacoepidemiologic study, linking the analgesic drug prescriptions to a population health survey in Tromsø, Norway.
Av Anne Elise Eggen, 1994.
30. ECG in health and disease. ECG findings in relation to CHD risk factors, constitutional variables and 16-year mortality in 2990 asymptomatic Oslo men aged 40-49 years in 1972.
Av Per G. Lund-Larsen, 1994.
31. Arrhythmia, electrocardiographic signs, and physical activity in relation to coronary heart risk factors and disease. The Tromsø Study.
Av Maja-Lisa Løchen, 1995.
32. The Military service: mental distress and changes in health behaviours among Norwegian army conscript.
Av Edvin Schei, 1995.

33. The Harstad injury prevention study: Hospital-based injury recording and community-based intervention.
Av Børge Ytterstad, 1995.
- 34.* Vilkår for begrepsdannelse og praksis i psykiatri.
En filosofisk undersøkelse.
Av Åge Wifstad, 1996. (utgitt Tano Aschehoug forlag 1997)
35. Dialog og refleksjon. Festskrift til professor Tom Andersen på hans 60-års dag, 1996.
36. Factors affecting doctors' decision making.
Av Ivar Sønbo Kristiansen, 1996.
37. The Sørreisa gastrointestinal disorder study. Dyspepsia, peptic ulcer and endoscopic findings in a population.
Av Bjørn Bernersen, 1996.
38. Headache and neck or shoulder pain. An analysis of musculoskeletal problems in three comprehensive population studies in Northern Norway.
Av Toralf Hasvold, 1996.
39. Senfølger av kjernefysiske prøvespreninger på øygruppen Novaya Semlya i perioden 1955 til 1962. Rapport etter programmet "Liv". Arkangelsk 1994.
Av A.V. Tkatchev, L.K. Dobrodeeva, A.I. Isaev, T.S. Podjakova, 1996.
40. Helse og livskvalitet på 78 grader nord. Rapport fra en befolkningsstudie på Svalbard høsten 1988.
Av Helge Schirmer, Georg Høyer, Odd Nilssen, Tormod Brenn og Siri Steine, 1997.
41. Physical activity and risk of cancer. A population based cohort study including prostate, testicular, colorectal, lung and breast cancer.
Av Inger Thune, 1997.
42. The Norwegian - Russian Health Study 1994/95. A cross-sectional study of pollution and health in the border area.
Av Tone Smith-Sivertsen, Valeri Tchachtchine, Eiliv Lund, Tor Norseth, Vladimir Bykov, 1997.

De som er merket med * har vi dessverre ikke flere eksemplarer av.