

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.

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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
Some improvement (categorised as little hope)

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 Kvinsland/Claes Tropé
 Ullevål Hospital, Steinar Hagen
 University Hospital of Bergen, Olav Dahl
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