

0959-8049(95)00328-2

Original Paper

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

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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 Eur J Cancer, Vol. 31A, No. 11, pp. 1785–1789, 1995

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, socioeconomical, 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 Gynaccology on one specific day were included. The study was restricted to 1

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Revised 30 Jan. 1995; accepted 8 Jun. 1995.

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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

	Parti	Non- Participants participants				Number of patients with	
	n	%	n	%	P-value	missing data	
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)			
6075	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 middleaged 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

		icentre Ilation	Prevalence of cancer*		
Malignancy	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

		ers of PTs		isers of PTs		
	n	%	n	%	P-value	Missing values
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)		. ,	•••	
University degree	30	(24.8)		(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 r	nonth	ıs				
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)		(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
Iscador	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, Eidinger 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 after	diagnoses of ca	ncer	
	No use (n=497)			eligious NPTs =88)	•	variants of NPTs†
NPTs used prior to diagnoses of cancer	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 d	liseases	
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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Acknowledgements—This study was initiated by the Norwegian Board of Health and supported by a grant from the Norwegian Cancer Society and by The Research Council of Norway. We also would like to thank Haakon Melsom at the Norwegian Board of Health for his support.

APPENDIX

Participating institutions

The Norwegian Radium Hospital
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