

**Original Article**

# Symptoms and Functional Status of Patients With Disseminated Cancer Visiting Outpatient Departments

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**Abstract**

Considerable research has focused on pain and other symptoms in terminal cancer patients referred to hospices and palliative care services. These patients differ from Dutch cancer patients in the palliative stage of their disease because the latter are cared for by general practitioners at home and medical specialists in outpatient departments. To clarify the experience of these Dutch patients, a study was started to investigate the prevalence and severity of pain and other symptoms as well as the functional status of consecutive patients visiting oncology outpatient departments for follow-up. After randomization, one group (I) of patients was interviewed at home by a general practitioner using structured questionnaires. The other group (II) received the questionnaires by mail, and scored the symptoms independently. The results of the symptom assessment show that patients in groups I and II suffered 2.4 (SD = 1.7) and 2.8 (SD = 2.0) symptoms, respectively. Between 30% and 40% of all patients reported constipation, nausea, loss of appetite, coughing, and dyspnea. These percentages were 50% lower when only moderate, severe, or extremely distressing symptoms were included. Sixty percent of all patients had pain, and 20% indicated a daytime pain score of 5 or greater on a scale of 0 to 10. Functional status was measured by the COOP-WONCA charts; the mean score for the charts "physical fitness" and "daily activities" was 1.5 points lower for cancer patients than a random sample from the community of the same age and gender. The findings of this study should motivate doctors to put more energy in symptom assessment and interventions in palliative care. *J Pain Symptom Manage* 1998;16:290–297. © U.S. Cancer Pain Relief Committee, 1998.

**Key Words**

*Cancer pain, symptoms, functional status, general practice, palliative medicine*

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**Introduction**

Palliative care for cancer patients is defined as the active total care of patients at a time when their disease is no longer responsive to

curative treatment.<sup>1</sup> It is known from several studies that, in the palliative stage, cancer patients suffer from pain and other symptoms that decrease the quality of life.<sup>2-5</sup> The majority of these studies describe the symptoms of a selected group of patients who were referred because of their symptoms to a tertiary institution such as a hospice<sup>6</sup> or a special palliative care service.<sup>7</sup> This group does not represent the patients with disseminated cancer who are cared for by general practitioners and medical specialists in the Netherlands. The latter patients often are not considered terminal and therefore still visit outpatient departments for follow-up.

The purpose of this cross-sectional study was to investigate the prevalence and severity of symptoms and functional status among outpatients with disseminated cancer in the region of the Comprehensive Cancer Center North Netherlands. In addition, we investigated whether patients score differently when they are interviewed in their home by a general practitioner or when they respond to mailed questionnaires. The same questionnaires also were sent to a control group of noncancer patients randomly selected from the community. This procedure allowed us to compare the scores for cancer patients with those for a comparable community-based population.

## Methods

### Study Subjects

Cancer patients participating in this study had to fulfill the following eligibility criteria: histologically proven malignancy, curative therapy no longer feasible, life expectancy of more than 1 month, not admitted to a hospital or a nursing home, signed informed consent, and age of 18 years or more.

Consecutive patients were asked by their medical specialists to enter the study when they visited the outpatient departments for follow-up. The outpatient departments of radiotherapy, medical oncology, gastroenterology, and urology participated, and it was stressed that consecutive patients had to enter the study and that the presence or absence of a complaint or symptom was neither an inclusion nor an exclusion criterion.

After the patients consented, they were randomly divided into two groups: Group I pa-

tients were assessed by means of a questionnaire at home by a general practitioner researcher and Group II patients received self-administered questionnaires via the mail. The interview and the mailing took place at least 2 weeks after the outpatient follow-up visit.

Group III consisted of a sample of noncancer patients of the same age randomly selected from an urban and a rural family practice in the same region. This sample is representative for the community because, in the Netherlands, practically all inhabitants are registered in general practices. Assuming a 50% response, 140 controls received by mail the same self-administered questionnaires as patients of Group II.

### Methods of Assessment

The symptoms of the cancer patients in both groups and the control patients were assessed using the Symptom Distress Scale<sup>8</sup> and a numerical pain rating scale.<sup>9</sup> In addition, functional status was scored with the help of the COOP-WONCA charts. For scoring the questionnaires, the frame of reference was always "the last 2 weeks."

The symptom distress scale was originally developed and internationally tested by McCorkle et al.<sup>10-12</sup> We have excluded the psychosocial dimensions of the scale and added the symptoms pruritis, dyspnea, urinary incontinence, and hiccups to the original symptoms of loss of appetite, nausea, vomiting, constipation, coughing. Each symptom is measured by means of a 5-point scale: not at all = 1, a little = 2, moderate = 3, severe = 4, and extremely distressing = 5.

The pain questionnaire is based on numerical rating scales from 0 to 10. Patients have to choose the number which most closely represents the severity of their pain: 0 is absence of pain and 10 is pain as severe as can be imagined. Pain at the moment of the interview, mean pain during the day, and mean pain at night were scored separately. Because pain can also be noncancer-related, patients were asked if they related their pain to cancer or to another disease.

Measurement of functional status by the COOP-WONCA charts is propagated by the World Organization of General Practitioners.<sup>13,14</sup> The instrument consists of seven charts to assess physical fitness, feelings, daily

activities, social activities, change in health, overall health, and pain. Each chart consists of a title, an illustration, and an ordinal 5-point response scale ranging from none to maximum limitation. For the 'change in health' question the scale ranges from improvement to deterioration. In the manual describing the COOP-WONCA charts,<sup>15</sup> a change of one point is considered a moderate and 2 points a considerable change.

### Analysis

The statistical calculations were performed using the SPSS-system. The mean pain scores ( $\pm$ SD) were tabulated for the three groups. The mean values include the score 0. In addition, the percentage of patients with daytime pain and their corresponding scores were separately tabulated.

The difference among Groups I, II and III in percentages of patients suffering symptoms of grade 2 and more, the mean pain scores and the mean COOP-WONCA scores were tested by one-way analysis of variance (ANOVA), with post-hoc comparisons of Group I versus group II and Group I and II versus Group III as appropriate.

For Groups I and II, the Pearson correlation coefficients among the scores of the symptom distress scale, the pain scores, and the scores of the COOP-WONCA charts also were calculated. Correlations were considered significant at a *P* value less than 0.05.

### Results

The recruitment of patients took place during a period of 21 months. The written informed consent procedure was a barrier for about 20% of the patients who otherwise fulfilled the inclusion criteria. A total of 187 patients consented to participate in the study and were randomized to group I (*N* = 91) and group II (*N* = 96). In group I, 11 patients refused after initial consent, and four died. In group II, five patients refused after initial consent, four died, and 12 patients did not return their questionnaire for unknown reasons. This resulted in a total of 151 evaluable cancer patients. In group III, 77 of 140 controls (55%) who received a questionnaire by mail responded. Patients' characteristics, which were

Table 1  
Patient Characteristics

	Group I ( <i>N</i> = 76)	Group II ( <i>N</i> = 75)	Group III ( <i>N</i> = 77)
Male/female	38/38	38/37	32/45
Mean age ( $\pm$ SD)	61 $\pm$ 11	60 $\pm$ 14	50 $\pm$ 10
Cancer site			
Breast	25	28	
Prostate	10	14	
Lung	13	17	
Gastro-intest.	11	8	
Gynecological	3	5	
Others	18	14	
Metastases			
Skeletal	40	45	
Liver	14	13	
Lymph nodes	15	10	
Lung	10	7	
Soft Tissue	3	2	
Brain	2	3	
Previous anti-cancer treatment			
Surgery	47	44	
Radiotherapy	58	54	
Chemotherapy	22	22	

well balanced between group I and II, are described in Table 1.

Figure 1 shows that the cancer patients suffered multiple symptoms, apart from pain. In group I, 10.5% and in group II, 16% of the patients did not suffer any of the nine symptoms of the symptom distress scale, and in group III, 40% of the controls were free of symptoms. The majority of the cancer patients experienced between one and five symptoms. Table 2, which shows the mean number of symptoms per person in all three groups, indicates a significant difference between the cancer patients (groups I and II) and the controls (group III). Moreover, Table 2 describes the percentage of patients suffering a specific symptom, as well as the differences among the groups based on the severity of these symptoms.

With respect to pain, a total of 44 patients (58%) of group I and 53 patients (71%) of group II reported pain at one of the three intervals assessed. When these 97 patients were asked about the cause of their pain, 59 (60%) assumed direct tumor involvement and the remaining patients reported a variety of causes, including muscle pain, joint pain, previous chemotherapy, surgery, or radiation therapy, and ischialgia. When patients in group III were asked about the cause of their pain 65% (*N* = 25) mentioned joint and muscle pain; 25% (*N* =

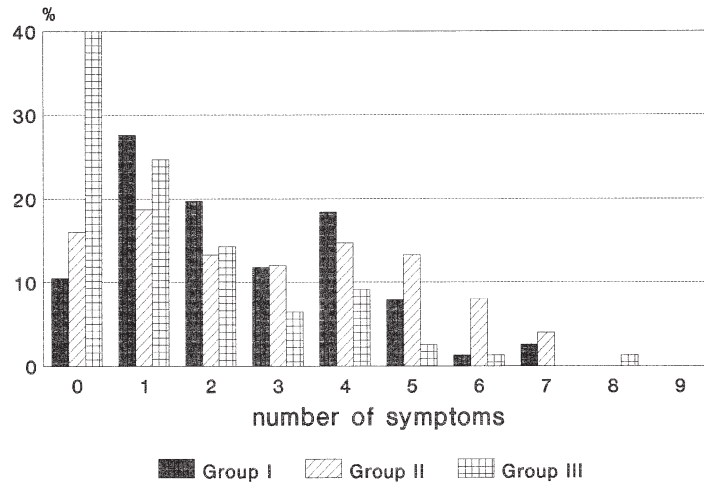


Fig 1. Percentage patients with the corresponding number of symptoms determined by means of the symptom distress scale.

10) could not indicate the cause of their pain. A total of 40 patients (51%) from group III also reported pain according to the rating scale at one of the three relevant times.

Table 3 describes the mean pain scores. Because these mean pain scores also include patients without pain, the percentages for all patients and controls, and their corresponding values for daytime pain, are presented in Figure 2. This figure shows that 20% of the cancer patients and 18% of the controls scored pain as 5 or higher during the day.

Functional status, measured as the mean score per COOP-WONCA chart among cancer

patients compared to the control group, differed in some charts and almost none in others. Differences between the two groups of cancer patients could not be found. The scores are described in Table 4.

*Correlations*

For patients in both group I and II, the results of some COOP-WONCA charts correlated significantly with some symptom scores, indicating that the impairment of the patient's functional status was associated with symptom distress (Table 5). Some of these significant cor-

*Table 2*  
**Mean Number of Symptoms per Patient and Percentage Patients of Groups I, II or III Suffering a Symptom with Severity Grade 2 and Grade 3 or More Measured by Means of the Symptom Distress Scale**

	Group I (N = 76)		Group II (N = 75)		Group III (N = 77)	
Mean number of symptoms per patient (± SD)	2.4 ± 1.7		2.8 ± 2.0		1.4* ± 1.6	
Symptoms	≥ grade 2	≥ grade 3	≥ grade 2	≥ grade 3	≥ grade 2	≥ grade 3
Constipation	39.5%	23.7%	41.3%	20.0%	18.2%*	3.9%
Nausea	38.2%	13.2%	45.3%	16.0%	16.9%*	2.6%
Loss of appetite	32.9%	17.1%	44.0%	22.7%	11.7%*	1.3%
Cough	32.9%	18.4%	34.7%	17.3%	22.1%*	9.1%
Vomiting	15.8%	2.6%	24.0%	1.3%	5.2%*	0.0%
Pruritis	27.6%	11.8%	26.7%	17.3%	18.2%	7.8%
Dyspnea	27.6%	15.8%	30.7%	13.3%	24.7%	6.5%
Urinary incontinence	15.8%	6.6%	28.0%	4.0%	14.3%	2.6%
Hiccups	11.8%	1.3%	8.0%	5.3%	9.1%	0.0%

No significant differences for contrast group I versus group II by one way ANOVA -test for symptoms ≥ grade 2.  
 \*P < 0.05 for contrast groups I + II versus group III by one way ANOVA test for symptoms ≥ grade 2.  
 ANOVA, analysis of variance.

*Table 3*  
**Mean Pain Scores  $\pm$  SD According to the Three Numerical Rating Scales (0–10) for Groups I, II, and III**

	Group I (N = 76)	Group II (N = 75)	Group III (N = 77)
Pain at the interview	1.3 $\pm$ 2.1	2.2* $\pm$ 2.4	1.5 $\pm$ 2.4
Daytime pain	2.1 $\pm$ 2.4	2.6 $\pm$ 2.4	1.8 $\pm$ 2.5
Pain at night	0.8 $\pm$ 1.9	1.6 $\pm$ 2.3	1.2 $\pm$ 2.2

\* $P < 0.05$  for contrast group I versus group II by the one-way ANOVA test.

relations were between some COOP-WONCA charts and the pain scales.

## Discussion

This cross-sectional study shows that patients with incurable cancer still visiting outpatient departments suffer multiple symptoms, which in most cases are mild. More than 60% reported pain as their main symptom. For daytime pain, 20% indicated the experience of severe pain with a score of 5 and more on the numerical rating scale. It is remarkable that in the control group of patients without cancer, 18% reported pain of the same severity. The correlation coefficients between the symptom distress scale, pain scales and COOP-WONCA charts showed that symptom distress and pain can contribute to a decrease in the functional status of cancer patients.

In the Netherlands, patients who do not longer respond to anti-cancer treatment are pri-

marily cared for by their general practitioners<sup>16</sup> and will consult these practitioners in the case of pain or other symptoms. These cancer patients also visit the oncology outpatient departments for psychological and follow-up reasons. When the general practitioner is not able to manage the pain and symptoms, the oncologist who originally administered the anticancer treatment is available for consultation. In addition, patients can be referred by their general practitioner to university pain centers and anesthesiologists in regional hospitals.

The comparison of the results of this study with those of other studies has its limitations because different populations of cancer patients and different kinds and numbers of symptoms were investigated. Moreover, in our study, the patients were assessed only once. The percentage patients suffering one or more specific symptoms in our study is similar to the findings of Grond et al.<sup>17</sup> However, pain was an inclusion criterion in the latter study, while in our study a random sample of incurable cancer patients with or without complaints was investigated. In addition, Grond et al. did not consider the severity of symptoms, while we found a rather mild severity. This is what one would expect for a group of patients who are not necessarily terminal. Donnelly and Walsh<sup>18</sup> studied the symptoms of 1000 patients with advanced cancer referred to a Palliative Care Service. They found much higher percentages for loss of appetite and dyspnea than our patient group, most probably because then patients were in a more advanced stage of disease.

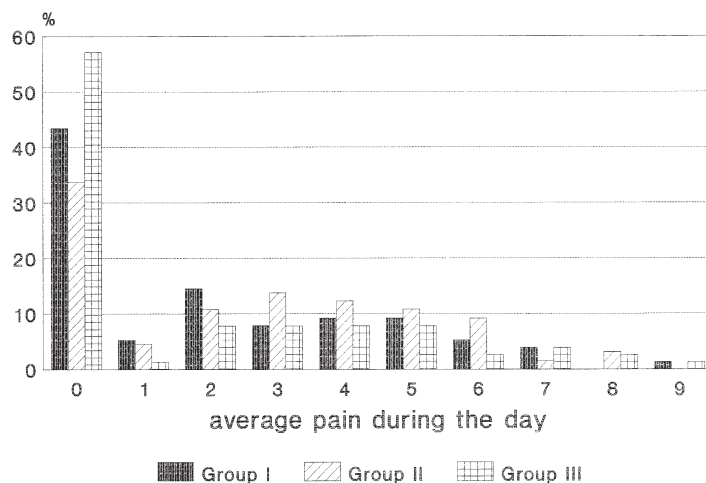


Fig 2. Percentage patients of group I, group II and group III with a given average daytime pain as assessed by means of the pain questionnaire.

Table 4  
Mean Score  $\pm$  SD per COOP-WONCA Chart (1-5)

COOP-WONCA charts	Group I (N = 76)	Group II (N = 75)	Group III (N = 77)
Physical fitness	3.8 $\pm$ 0.7	3.4 $\pm$ 1.7	2.2* $\pm$ 1.0
Feelings	1.9 $\pm$ 1.0	1.9 $\pm$ 1.0	1.9 $\pm$ 1.1
Daily activities	2.9 $\pm$ 1.4	2.8 $\pm$ 1.4	1.8* $\pm$ 1.0
Social activities	1.9 $\pm$ 1.1	2.1 $\pm$ 1.5	1.5* $\pm$ 0.8
Overall health	3.1 $\pm$ 0.9	3.3 $\pm$ 1.5	2.5* $\pm$ 1.0
Change in health	2.8 $\pm$ 0.9	2.6 $\pm$ 1.0	2.8 $\pm$ 0.5
Pain	2.2 $\pm$ 1.2	2.4 $\pm$ 1.1	2.0* $\pm$ 1.0

\* $P < 0.05$  for contrast groups I + II versus group III by one-way ANOVA test.

Pain was prevalent in 68% of our patients and thus a greater cause of concern than the other symptoms. The finding that 61% of patients assume direct tumor involvement as the cause of their pain is similar to the findings of Foley,<sup>3</sup> who noted that 62% of pain problems in an outpatient population were attributed to direct tumor involvement. Ventafridda et al.<sup>19</sup> described pain in 59% of 115 patients, Donnelly and Walsh<sup>18</sup> reported pain in 62% of 1000 patients, and Curtis et al.<sup>20</sup> noted pain in 89% of 500 patients referred to a palliative care service. The inclusion criteria for all of these studies differed from ours; specifically, patients in these studies were referred because of symptoms.

In our study, 20% of patients reported a pain score of five or more during the day. In the course of personal contacts, we had the impression that such a score represents substantial pain, having a negative impact on daily life. This corresponds with the opinion of Cleeland et al.<sup>21</sup> who believed outpatients with metastatic cancer suffered substantial pain when they scored pain as 5 or higher.

It is remarkable that the pain scores for the cancer patients did not differ from the pain scores of the control group, suggesting that pain is a common symptom in this age group and is frequently caused by noncancerous disorders. Meyboom de Jong<sup>22</sup> described morbidity patterns of elderly patients in 12 Dutch general practices and concluded that pain, and especially pain of the musculoskeletal system, was the most frequent reason for encounter in general practice. In this context, Twycross stated that it is important to realize when dealing with cancer patients that "when pain is wrongly assumed to be cancerous in origin, it tends to be invested with all of the negative implications of cancer pain, which makes the pain worse."<sup>23</sup>

The observed decline in functional status compared to the response of a control group indicated by the COOP-WONCA charts 'physical fitness' and 'daily activities' is understandable in view of the illness of our patients. In fact, it is surprising that the chart "feelings" does not yield a difference in response, be-

Table 5  
Spearman Correlation Coefficients Between the Symptom Distress Scales, Pain Rating Scales and COOP-WONCA Charts

Group I + II N = 151	Physical fitness	Feelings	Daily activities	Social activities	General health	Change in health	Pain
Appetite	0.19	0.15	0.34	0.38	0.27	—	0.30
Nausea	—	—	0.35	0.25	0.34	—	0.34
Vomit	—	—	0.28	—	—	—	0.30
Constipation	—	0.25	0.26	0.37	0.25	—	0.32
Cough	—	—	—	—	0.19	—	—
Urinary incontinence	—	0.23	—	—	0.23	—	—
Dyspnea	—	—	0.20	—	0.27	—	—
Pain at the interview	—	0.21	0.33	0.24	0.36	—	0.65
Daytime pain	0.16	0.31	0.37	0.36	0.40	0.23	0.78
Pain at night	—	0.32	0.23	0.31	0.29	0.22	0.57

All correlation coefficients are significant at  $P < 0.05$ .

cause one would expect more emotional problems in patients with disseminated cancer. This lack of difference might be explained by our personal impression that the patients were somehow inhibited in expressing negative feelings to protect their partners who were usually present during the completion of the questionnaires. The score for the charts 'overall health' and 'change in health' was often scored a 3 (=good), indicating that denial of illness and symptoms can occur. The treating doctor should be aware of this.

No significant difference in outcome could be found for the Symptom Distress Scale, the pain scale, and the COOP-WONCA charts between group I and group II. Only the mean score for pain at the interview differed between these groups. This indicates that our questionnaires can be completed by cancer patients independently and that the presence of an interviewer does not influence the answers.

Finally, the results of this study suggest that better symptom recognition can be achieved if symptoms are assessed actively by the attending doctors, because patients frequently do not report symptoms spontaneously.<sup>24</sup> One of the most important reasons for not reporting symptoms is the fear of opioids, including the fear of addiction and side effects. Thus, doctors play an important role in patient education on the treatment of pain and symptoms.<sup>25</sup> This education must start early in the course of the cancer because pain can already exist in an early phase, as illustrated by this study.

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