Self-Assessment in Cancer Patients Referred to Palliative Care
A Study of Feasibility and Symptom Epidemiology

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BACKGROUND. Research in palliative care is considered difficult due to the poor health of patients. However, patient-provided data are essential for a thorough description of patient symptomatology and for the evaluation of care.

METHODS. The authors examined the feasibility of a questionnaire-based study using the European Organization for Research and Treatment of Cancer quality-of-life instrument EORTC QLQ-C30, the Edmonton Symptom Assessment System (ESAS), and the Hospital Anxiety and Depression Scale (HADS) in cancer patients who were receiving palliative care. This report describes the symptomatology of participating patients and examines differences in symptomatology between patients in three palliative care functions: inpatient, outpatient, and palliative home care.

RESULTS. Of 267 eligible patients who were referred to a department of palliative medicine, initial self-assessment questionnaires were obtained from 176 patients (65.9%). The 91 nonparticipants were older and had lower Karnofsky Performance status (KPS) values than the participants. Almost all participating patients suffered from impaired role function and physical function and had high levels of pain, fatigue, and other symptoms. According to the HADS, 47% of patients suffered from depression. Outpatients had better scores than inpatients and patients in palliative home care for physical function, role function, cognitive function, depression, and inactivity.

CONCLUSIONS. It is possible to carry out a questionnaire-based study of symptomatology in consecutive cancer patients in palliative care, achieving rather complete data from the participants. The symptomatology in these patients was very pronounced. The questionnaires were able to detect clinically important differences between places of service.


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KEYWORDS: palliative care, advanced cancer, feasibility, symptomatology, self-assessment questionnaire, quality of life.

Research in palliative care is influenced by the poor condition of the patients. The feasibility of studies in palliative care may be hampered by poor patient recruitment. Attrition due to deterioration or death—potentially leading to bias—is likely in palliative care studies.1–3 Evaluation of palliative care is difficult due to these and other methodologic difficulties.4 It is unclear to what extent it is possible to evaluate the routine delivery of palliative care outside clinical trials: Which patients in palliative care are willing and able to participate in research, and to what extent is questionnaire-based research feasible? There is little information on this in the literature.

Patients with advanced cancer are most often polysymptom-
atic. Detection and treatment of symptoms are major targets of palliative care. Therefore, a thorough mapping of symptoms and problems in patients is essential to acquire knowledge of symptom variety and severity. A range of self-assessment questionnaires evaluating physical symptoms and psychosocial and cognitive functions is available. The results of questionnaire-based studies can be used to describe the characteristics of patients in palliative care and to evaluate the effect of palliative care. The results may be used to assess and compare the symptomatology and treatment effects within a department and between institutions. Finally, self-assessment questionnaires also may be used clinically for diagnostic purposes.

In our Department of Palliative Medicine, a prospective research project is under way aimed at all patients referred to the department to evaluate palliative care and to develop and validate methods for this purpose. Consecutive patients admitted to the department during the first 2 years of the project are described in this article.

The objectives of the current study were 1) to examine the feasibility from three perspectives: the extent to which consecutive patients in palliative care were willing and able to participate in a questionnaire-based study, the completeness of data from participating patients, and the practicability of self-assessment and the comprehensibility and acceptability of the questions. Furthermore, we wanted 2) to describe and compare the demographic and clinical data from participating and nonparticipating patients to assess the impact of nonparticipation, 3) to describe the symptomatology of participants, and 4) to investigate whether results on feasibility and symptomatology differed between places of service (inpatient, outpatient, and palliative home care).

MATERIALS AND METHODS

Patients

From June 1998 to June 2000, 278 patients were referred to the Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark. In the first part of the period, only inpatient and outpatient services were available; however, in April 1999, a palliative home care service was established. All patients referred to the three services had advanced cancer for which no curative or life-prolonging treatment could be offered. According to the criteria for referral to the department, all patients had pronounced palliative needs. The department has 12 beds and serves a population of 590,000 persons. This implied that, among referred patients with advanced cancer, those with the most pronounced symptoms or problems were selected for admittance. Inclusion criteria for the current study were admission to the department, Danish speaking, age ≥ 18 years, and informed consent. If the staff judged the patient too ill to participate, then the patient was not informed about the study. The Ethics Committee approved the study.

Assessments

From all patients, information on gender, age, and survival from first contact with the department was obtained, and the physician assessed the patient’s Karnofsky Performance status (KPS). On the day of first contact with the department, the patients were asked if they would participate in the study. Consent ing patients were given the following self-assessment questionnaires: the Edmonton Symptom Assessment System (ESAS), the European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire (EORTC QLQ-C30, version 3.0), the Hospital Anxiety and Depression Scale (HADS), and the Multidimensional Fatigue Inventory (MFI-20). The results from the MFI-20 are being reported in another article. On the last page of the questionnaire booklet containing the three latter questionnaires, the patients could state whether they had completed the questionnaires themselves or whether another person had assisted in writing down the responses. Furthermore, the patients were asked to identify any questions that they found difficult to understand as well as questions that they considered objectionable. Completion of the questionnaires was to take place on the first or second day of contact with the department.

On admittance, the physician gave inpatients the ESAS to complete immediately. This division of inpatient self-assessment into two parts was chosen because we believed that the combination of two different data collection strategies would enhance the probability of obtaining at least a partial description of each patient’s symptomatology. The outpatients and patients in palliative home care, however, received the ESAS as a part of a questionnaire booklet that also contained the three other self-assessment questionnaires. This data-collection strategy made subsequent weekly self-assessments possible, even if the patient did not see the physician on the same day of the week. Regardless of the place of service, cognitive functioning was evaluated by the physician by means of the Mini-Mental State Examination (MMSE). To make it possible for patients to participate even if they were willing or able to fill in relatively few items, the patients could choose whether they wished to complete all of the questionnaires or only a subset of items. In this article, a participant is defined as a consenting patient who managed to complete some
part of the three self-assessment questionnaires (EORTC QLQ-C30, ESAS, and/or HADS).

The ESAS and the EORTC QLQ-C30 were designed to cover several aspects of the patient’s health-related quality of life (physical as well as psychosocial aspects). For the ESAS, the version published in 1991 was used. The ESAS consists of nine visual analogue scales, each comprised of a symptom or a problem and ranging from 0 to 100, where 100 corresponds to maximal symptomatology.

The questions in the EORTC QLQ-C30 are transformed into six function scales and three symptom scales. Six single items comprise specific symptoms. According to the scoring manual, the responses were converted to 0–100 scales. For single items, 0 indicates not at all (symptom), 33.3 indicates a little, 66.7 indicates quite a bit, and 100 indicates very much. In the function scales, a high score reflects a good functioning, whereas a high score on a symptom scale reflects a high level of the symptom.

The 14-item HADS measures anxiety and depression. Respondents can score 0–21 points on each of the subscales on anxiety and depression. According to Zigmond and Snaith, 0–7 points on a subscale represent a noncase, 8–10 points represent a doubtful or possible case, and 11–21 points represent a definite case of anxiety or depression.

The MMSE includes 21 items on orientation, memory, attention, and ability to name, to follow verbal and written instructions, to write a sentence spontaneously, and to copy a figure. The patient can score 0–30, and scores ≥ 24 generally are considered normal, although thresholds determined by age and education also have been proposed. In the current study, the threshold of 23–24 was used.

Suggested cut-off values exist for the HADS and the MMSE for the distinction between cases and noncases of anxiety/depression and cognitive impairment, as mentioned above. For the ESAS and the EORTC QLQ-C30, there are no defined cut-off values to indicate whether a given patient’s score on a function or symptom should be interpreted as a case. We chose a cut-off value of ≥ 34 as the threshold for symptom for the ESAS and EORTC QLQ-C30 symptom scales. This corresponds to more than a little (33.3) in the EORTC QLQ-C30. For the EORTC QLQ-C30 function scales, the threshold for impairment was ≤ 66, corresponding to scores of more than a little on the items forming these scales. Prevalence rates for each symptom were estimated using these cut-off values.

The mean number of EORTC QLQ-C30 symptoms (function scores ≥ 66 or symptom scores ≥ 34) also were estimated. Overall quality of life was not considered to be a single symptom; thus, symptom scores were not estimated. Due to considerable overlap between the EORTC QLQ-C30 and the ESAS, we estimated the number of symptoms for the EORTC QLQ-C30 only. Thus, the highest possible number of symptoms was 14.

For comparison with the general population, we used the EORTC QLQ-C30 scores of 553 persons age 60–69 years (corresponding to the mean age in our patient material) from a random sample of the Swedish general population. Danish general population data are available for version 1 of the questionnaire and for women only. Swedish data are available for version 3 and for men and women. We compared the published Danish and Swedish data for women in this age group. There was a tendency toward better scores in the Swedish general population. However, because version 3 data are most relevant, Swedish data for both genders are available, and the differences were relatively modest, we decided to use the Swedish data for comparison.

**Statistics**

Nonparametric analyses were used to compare distribution in groups, because scores were distributed. Most data were analyzed using the SAS statistical package (version 6.12; SAS, Inc., Cary, NC). Wilcoxon tests were used for the comparisons of clinical data (gender, age, and KPS) and symptom and function scores. Log-rank tests were used for comparison of survival data. Pearson chi-square tests were used to compare the distribution of place of service as well as the distribution of primary tumors between participants and nonparticipants. The chi-square tests were evaluated with exact P values estimated with 1000 Monte Carlo simulations using the software program DIGRAM (University of Copenhagen, Copenhagen, Denmark).

**RESULTS**

**Feasibility**

**Participation**

Of the 278 consecutive patients who were referred to the department, 267 patients were eligible. Reasons for exclusion were age < 18 years (1 patient) and not Danish speaking (10 patients). Sixty-six eligible patients declined participation or were not approached about the study because the staff considered them too ill. Thus, 201 patients consented to participate in the study (Fig. 1). Of these, there were 121 inpatients, 40 outpatients, and 40 patients who received palliative home care. Twenty-three consenting patients did not complete any part of the self-assessment questionnaires. Two consenting patients did not complete the questionnaires within the time limit (the day of ad-
mission or the next day). Thus, among the consenting patients, initial self-assessment questionnaires were obtained from 176 patients (65.9% of eligible patients referred during the 2-year period).

Completeness
The completeness of data is depicted in Figure 1 (bottom). The inpatients, although they had the highest rate of participation, delivered less complete EORTC QLQ-C30 and HADS data compared with the outpatients and the patients in palliative home care. This is addressed further below (see Discussion).

TABLE 1
Practicability and Acceptability Data for 176 Participants

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who filled in the questionnaire?</td>
<td></td>
</tr>
<tr>
<td>The patient</td>
<td>76</td>
</tr>
<tr>
<td>The patient with help</td>
<td>56 (nurse, 29; relative, 25; unspecified, 2)</td>
</tr>
<tr>
<td>Total</td>
<td>132</td>
</tr>
<tr>
<td>Did you find any questions difficult to understand?</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>70</td>
</tr>
<tr>
<td>Yes</td>
<td>38</td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
</tr>
<tr>
<td>Did you find any questions objectionable?</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>109</td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>115</td>
</tr>
</tbody>
</table>

Demographic and Clinical Data
Table 2 shows the demographic and clinical data and the KPS of participating and nonparticipating patients. More women (59%) than men were admitted to the department, but there was no significant gender difference between participants and nonparticipants. The participation ratio was considerably lower for patients in palliative home care than for inpatients and outpatients. Participants were younger and had higher KPS and longer survival from first contact with the department compared with nonparticipants. Among those with primary malignant disease, there was a significant difference between participants and nonparticipants ($P = 0.023$). The main difference was that there were 12 nonparticipants and 5 participants with unknown primary tumors.

Symptomatology
Table 3 shows the mean scores for the EORTC QLQ-C30, the ESAS, the HADS, and the MMSE for all participating patients and for patients subdivided by place of service. The first column shows the EORTC QLQ-C30 mean scores from the Swedish general population sample.21 Compared with this general population, the symptomatology in our patients was ex-
tremely pronounced. For example, the mean score for pain was 70.1 compared with 19.3 in the general population sample; for fatigue, scores were 76.7 and 19.8, respectively; and, for reduced appetite, the scores were 68.8 and 3.2, respectively.

The prevalence of symptoms or problems also is shown in Table 3 with the chosen cut-off values. Almost all patients suffered from fatigue and pain as well as impaired overall health and quality of life. Almost 70% of patients suffered from reduced appetite; and, for reduced emotional, social, or cognitive function. The mean number of EORTC QLQ-C30 symptoms was 7.7 (median, 8 symptoms; range, 0–14 symptoms). The possible maximum using our estimation system was 14 symptoms.

**Place of Service**

KPS, gender, age, and survival of the participating patients are subdivided by place of service in Table 4. With regard to age and gender, no statistically significant difference between services was found. Outpatients had the longest mean survival and the highest KPS. Inpatients had the shortest mean survival and the lowest KPS. With regard to symptomatology (Table 3), the most noticeable difference was that outpatients scored significantly better in physical, cognitive (self-

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**TABLE 2**

Demographic and Clinical Data for 267 Eligible Patients Referred to the Department: Results of Significance Tests for Comparison of Participants and Nonparticipants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participation (%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of patients</td>
<td>176 (65.9)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>99 (62.7)</td>
<td>0.177a</td>
</tr>
<tr>
<td>Male</td>
<td>77 (70.6)</td>
<td></td>
</tr>
<tr>
<td>Age (yrs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>62.9</td>
<td>0.020a</td>
</tr>
<tr>
<td>Median</td>
<td>63</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>37–91</td>
<td></td>
</tr>
<tr>
<td>Function</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatients</td>
<td>116 (73.9)</td>
<td></td>
</tr>
<tr>
<td>Outpatients</td>
<td>34 (70.8)</td>
<td>0.001b</td>
</tr>
<tr>
<td>Palliative home care</td>
<td>26 (42.6)</td>
<td></td>
</tr>
<tr>
<td>Survival from first contact with department (days)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>81.2</td>
<td>0.042c</td>
</tr>
<tr>
<td>Median</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0–908</td>
<td></td>
</tr>
<tr>
<td>KPS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>46.5</td>
<td>0.010a</td>
</tr>
<tr>
<td>Median</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>20–80</td>
<td></td>
</tr>
<tr>
<td>Primary tumor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain</td>
<td>0 (0%)</td>
<td></td>
</tr>
<tr>
<td>Head and neck</td>
<td>8 (4.5%)</td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal tract</td>
<td>36 (20.5%)</td>
<td></td>
</tr>
<tr>
<td>Respiratory system</td>
<td>46 (26.1%)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>30 (17.0%)</td>
<td></td>
</tr>
<tr>
<td>Genitourinary system</td>
<td>29 (16.5%)</td>
<td></td>
</tr>
<tr>
<td>Gynecologic</td>
<td>13 (7.4%)</td>
<td></td>
</tr>
<tr>
<td>Sarcoma</td>
<td>2 (1.1%)</td>
<td></td>
</tr>
<tr>
<td>Melanoma/skin</td>
<td>5 (2.8%)</td>
<td></td>
</tr>
<tr>
<td>Hematologic</td>
<td>2 (1.1%)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>5 (2.8%)</td>
<td></td>
</tr>
</tbody>
</table>

KPS: Karnofsky performance status.

\* Wilcoxon test.

\( ^{b} \) Pearson chi-square test.

\( ^{c} \) Log-rank test (including six patients who were still alive; censored February 22, 2001).
assessed as well as measured by MMSE), and role function (EORTC QLQ-C30) and had significantly lower scores for depression (HADS) compared with inpatients and patients in palliative home care. Outpatients had a mean of 7.1 symptoms (median, 7 symptoms; range, 0–12 symptoms), patients in palliative home care had a mean of 7.6 symptoms (median, 7 symptoms; range, 3–14 symptoms), and inpatients had of mean of 7.9 symptoms (median, 8 symptoms; range, 1–13 symptoms). We found no significant difference in the number of symptoms between places of service.

### DISCUSSION

#### Feasibility

The 91 nonparticipating patients were significantly older and had lower KPS than participants (Table 2). This suggests that their symptomatology, if disclosed, would be even more pronounced. Thus, there may be some systematic underestimation of the level of symp-
toms if the scoring of the poorest performing patients is unattainable. This phenomenon represents a general problem with patient self-assessment in palliative care and should be taken into account when interpreting the data.

The rather high rate of participation (65.9%) indicates that research in palliative patients is feasible. Due to the natural course of the patients’ disease, one must anticipate that the completeness of data will decrease over time; however, initial data seem to be obtainable. In comparison, Jenkins et al.24 obtained primary ESAS from 61.8% of patients who were admitted to a palliative care unit, but these were filled in by the patient or by a surrogate evaluator.

Only 42.6% of patients in palliative home care participated compared with 73.4% participation of inpatients and 69.4% participation of outpatients (Table 2). In contrast, as shown in Figure 1 and Table 3, inpatients seemed to provide less complete data, especially in the patient-administered EORTC QLQ-C30 and HADS. This apparent difference in data completeness probably was caused by the way we defined a participant, namely, that he or she should have managed to fill in at least a part of one of the three self-assessment questionnaires. For inpatients, the physician distributed the ESAS to the patient during the first contact, thus, probably facilitating the completion of this questionnaire. Inpatient data from the physician-administered evaluation instruments were almost complete: Of 121 consenting inpatients, 113 patients (93.4%) completed the ESAS, and 108 patients (89.3%) completed the MMSE, whereas only 85 patients (70.2%) and 77 patients (63.6%) managed to fill in the EORTC QLQ-C30 and the HADS, respectively. In comparison, all participating patients in palliative home care filled in these two questionnaires. Thus, according to the a priori definitions, inpatients had a high participation rate and low data completeness, whereas patients in palliative home care had a low participation rate and high data completeness. Outpatients were willing to participate and delivered quite complete data, probably due to their relatively better performance.

Symptomatology
The prevalence data are in line with other studies of symptom prevalence rates5–7,9,25 showing that fatigue, inactivity, pain, loss of appetite, and reduced role function and quality of life are issues of major concern for patients in palliative care. According to the EORTC QLQ-C30, the participating patients reported that they were affected very much by fatigue, pain, poor physical functioning, appetite reduction, and reduced overall health and quality of life. Similarly, the ESAS showed high scores for inactivity, appetite reduction, reduced well-being, and pain. Compared with the fatigue score found in the current study (76.7), Pater et al.26 looked at the levels of fatigue in 10 clinical trials in cancer patients (not in the palliative phase) and found much lower EORTC QLQ-C30 fatigue scores ranging from 20 to 50.

Jenkins et al.8 found somewhat lower ESAS mean scores than those presented here. This may be because their study took place in a palliative care unit within the continuing care hospital system, where one would expect patients to be comparatively less symptomatic than the inpatients and the patients in palliative home care in our study.

Looking at the HADS scores in our study, 26.5% of patients had definite cases of anxiety, and 47.0% scored had definite cases of depression. For cancer patients overall, the reported prevalences of depression range from 4% to 40%.27–31 In palliative care settings, prevalences of depression range from 26% to
Hence, the depression prevalence of 47% in our study seems very high. For inpatients and for patients in palliative home care, the prevalence was 55.8% and 50.0%, respectively. For outpatients, the depression prevalence was considerably lower at 24.2%.

The mean overall MMSE score was 25.9 (range, 16–30). According to the literature, a score ≥ 24 is considered normal. Despite their very high symptom scores, only 41 of 163 patients (25.1%) scored < 24 points. In comparison, Pereira et al. found a mean MMSE score of 23.1 in 321 patients with terminal cancer. An element of selection bias is probable here, because we would expect a poorer cognitive status for those patients who were not evaluated with the MMSE. Nineteen patients consented to the study and were evaluated only with the MMSE but did not complete self-rating questionnaires. Therefore, these patients were not counted as participants: Their mean MMSE score was 23.2, which was not significantly lower (P = 0.090).

**Symptomatology by Place of Service**

Patient status on referral—inpatient, outpatient, or palliative home care—probably was influenced by several factors: The performance status was much lower in inpatients (mean, 41.0) compared with outpatients (mean, 62.4), and no outpatient had a KPS < 50. This makes sense clinically, because one would expect that the best performing patients would prefer outpatient status. Furthermore, by definition, a KPS < 50 implies that the patient requires an equivalent of institutional or hospital care. Similarly, the outpatients lived more than twice as long as the inpatients from the day of first contact with the department (outpatients: mean, 130 days; median, 92 days; inpatients: mean, 63 days; median, 24 days). In general, the symptomatology was somewhat milder in outpatients compared with inpatients and with patients in palliative home care. Outpatients reported significantly higher levels of functioning on the EORTC QLQ-C30 physical function scale, the role function scale, and the cognitive function scale, the ESAS item *reduced activity*, and depression in the HADS. The MMSE, as mentioned above, showed a slightly higher cognitive functioning in outpatients compared with inpatients and with patients in palliative home care. We expected that patients in palliative home care would be the poorest performing and most symptomatic of the three service groups. However, this assumption could not be supported by the data.

This study demonstrates that it is feasible to perform a questionnaire-based study on consecutive patients in palliative care, because almost 66% of eligible patients participated. The completeness of data probably was influenced by the condition of the participating patients, because outpatients delivered very complete data. The difference in inpatient data completeness for different questionnaires (and, thus, for different approaches for administering the questionnaires) strongly indicates that the use of a short questionnaire presented to the patient by the physician enhances the probability of obtaining information from the patient. Most patients managed to complete the self-assessment questionnaires without assistance. About 33% of patients found one or more questions difficult to understand, but only a few patients found any of the questions objectionable. The patients exhibited a very pronounced symptomatology: Almost all patients suffered from severe fatigue, impaired role function and physical function, poor quality of life, and pain. Many patients also suffered from reduced appetite, and almost 50% of patients scored a diagnosis of depression. Outpatients seemed to be less symptomatic compared with inpatients and with patients in palliative home care. The results confirmed that patients who were referred to this specialist palliative care service were certainly in need of care.

Data collection most probably would gain in completeness and acceptability if patients were presented with fewer questions. However, we have used the questionnaires in parallel to evaluate and compare their contents and practical usefulness, because it is still not evident which questionnaires are optimal for patients receiving palliative care.

**REFERENCES**


