Original Article

Does the Medical Record Cover the Symptoms Experienced by Cancer Patients Receiving Palliative Care? A Comparison of the Record and Patient Self-Rating

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Abstract

The aim of this study was to investigate the extent to which the symptoms experienced by advanced cancer patients were covered by the medical records. Fifty-eight patients participated in the study. On the day of first encounter with our palliative care department, a medical history was taken, and on this or the following day, the patients completed the EORTC Quality of Life Questionnaire (EORTC QLQ-C30), Edmonton Symptom Assessment System (ESAS), and Hospital Anxiety and Depression Scale (HADS). The symptomatology reported in the patient-completed questionnaires was compared with the symptomatology mentioned by the physician in the medical record. The analysis revealed good concordance concerning pain, but most other symptoms or problems were reported much more often by patients than by their doctors. Reasons for these discrepancies are discussed. It is suggested that the doctor’s knowledge of the patient’s symptomatology might gain from more systematic screening and transfer of information from patient self-assessment questionnaires to the medical records.


Key Words

Palliative care, advanced cancer, symptomatology, self-assessment questionnaire, quality of life

Introduction

Palliative care aims to alleviate as many of the patient’s symptoms as possible, thus providing “the best quality of life for patients and their families.”1 In order to achieve this goal, the doctor must have precise knowledge of the patient’s condition and needs. The medical record serves as an important instrument for the treatment of the patient. Ideally, the record contains every symptom and problem the patient might have: if a symptom is not mentioned, it is unlikely that it will be treated. However, there is reason to suspect that the doctor does not always detect all aspects of the patient’s symptomatology. In a literature review, Sprangers and Aaronson2 found low to moderate levels of concordance between sym-
symptoms assessed by the patient versus symptoms assessed by physician or nurse. Cull et al.\(^3\) reported that for 46\% of cancer patients referred to a psychology service, the oncologist most directly involved with the treatment of the patient did not know whether or not the patient had cognitive disturbances, and for 28\% of patients whether or not the patient was psychologically distressed at the time of referral.

A four-year prospective research project is being conducted in our department of palliative medicine. This includes all patients referred to the department and is designed to develop and validate methods for evaluating the effect of palliative care. The patients fill in questionnaires assessing their physical and psychological symptomatology. The doctors have no access to the completed questionnaires. This is to protect confidentiality and to avoid potential bias arising because the patient wishes to communicate certain messages through his responses to the questionnaire, e.g., that symptoms improve more than they actually do (social desirability bias). In the instruction printed in the patient questionnaire, it is pointed out that the completed questionnaire will not be seen by the physician. It is added that if the patient wants to discuss any issues from the questionnaire with the staff, then he or she should contact the staff.

If it is true that palliative care physicians do not fully know their patients’ symptomatology, one could argue that the information contained in patient-completed questionnaires should be made available to physicians. The usefulness of this has previously been suggested\(^4\)\textendash\(^6\) but has not been formally evaluated in palliative care. The present study elucidated aspects of this question: The aim of the study was to examine the extent to which the initial symptomatology reported by patients in self-assessment questionnaires was covered by the medical records.

**Methods**

**Patients**

From June 3, 1998 to May 26, 1999, 102 patients were admitted to the Department of Palliative Medicine at Bispebjerg Hospital in Copenhagen, Denmark. Patients admitted to the department must have advanced cancer for which no curative or life-prolonging treatment can be offered, and have pronounced palliative needs. The latter criterion implies that among referred patients with advanced cancer, those having the most pronounced symptoms or problems are selected (the department has 12 beds and serves a population of 550,000).

Inclusion criteria for the above-mentioned prospective study were referral to the department, Danish speaking, age ≥18 years, and informed consent. The study was approved by the local Ethics Committee. In the present paper, we use the data from the first 58 eligible patients consenting to participate in the study. Of the 102 patients, one patient was less than 18 years old and three patients were excluded due to insufficient knowledge of the Danish language. The remaining 40 patients declined participation or were not asked due to poor health status.

**Measures**

**Patient self-assessment.** On the day of first encounter with the department or the next day, the patients were given a questionnaire booklet including the Edmonton Symptom Assessment System (ESAS),\(^6\) the EORTC Quality of Life Questionnaire (QLQ-C30),\(^7\) and the Hospital Anxiety and Depression Scale (HADS).\(^8\) The ESAS and the EORTC QLQ-C30 are designed to cover several aspects of the patient’s health-related quality of life (physical as well as psychosocial aspects). The 30-item EORTC QLQ-C30 deals with health and well-being during the last week. These questions are transformed into six functional scales and three symptom scales, and six single items comprising more specific symptoms: pain, fatigue, dyspnea, etc.\(^9\) The ESAS consists of nine visual analogue scales (VAS) on which the patient marks the degree to which he is experiencing pain, inactivity, nausea, etc. 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,\(^8\) 0–7 points on a subscale represents a “non-case”, 8–10 points a “doubtful” or possible case, and 11–21 points a “definite case” of anxiety or depression.

The patients could choose whether they wished to complete all of the questionnaires or only a subset of items, in order to make it possible for patients to participate even if they...
were able or willing to fill in relatively few items only.

Medical records. On the day of first encounter with the department, a medical record was taken, focusing on the patient’s palliative needs. The medical records were available for all 58 patients. Almost all records were written by one of the department’s two consultants or by the senior registrar.

Extraction of data from medical records. From the patient-assessed questionnaires, we constructed a checklist containing the nine scales and six single items of the EORTC QLQ-C30, the nine items of the ESAS, and the anxiety and depression items from the HADS. This checklist was used to review the qualitative content of the medical records: For each symptom in the checklist, it was noted whether or not this symptom was mentioned in the medical records of each patient.

Analysis

Categorization. We wished to estimate “doctor’s symptom recognition percentage” (DSR), i.e., the extent to which symptoms experienced by patients are recognized by their doctors. This requires a definition of which patient responses represent “symptoms.” Once this is defined, the DSR is the number of patients having the symptom mentioned in their medical record, as a percentage of the number of these patients scoring above the threshold in the questionnaires.

Patient responses on the three standard questionnaires were scored according to standard procedures for these instruments. The only instrument having a definition of ‘case- ness’ is the HADS. It would not make much sense to assume that a patient rating pain as ‘2’ on a 0–100 scale (where 100 corresponds to maximal pain) had any important pain. Furthermore, it was of interest to compare the DSR of patients reporting modest symptom intensity against those reporting severe symptoms.

We, therefore, had to define (arbitrary) thresholds for ‘having a symptom’ based on scores on the ESAS and the EORTC QLQ-C30, i.e. define the lower limit for ‘having a symptom’, and to define thresholds between low, moderate, and high levels of symptoms.

The ESAS scores are in principle continuous on a scale from 0–100 mm, and according to the scoring manual, the responses on the EORTC QLQ-C30 are also converted to a 0–100 scale. For EORTC QLQ-C30 single items, “0” corresponds to “not a problem”, “1” to “a little”, “2” to “quite a bit”, and “3” to “very much.” In contrast, there is no simple verbal interpretation of the EORTC QLQ-C30 multi-item scales estimated as the average of 2–5 items or of the ESAS visual analogue scales, both of which have multiple score levels between 0 and 100.

The thresholds we chose in order to define the lower limit for ‘having a symptom,’ and to define thresholds between low, moderate, and high levels of symptoms were inspired by the values assigned to the response categories of the EORTC QLQ-C30 single items (see above) (Figure 1). The lower limit for having a symptom was defined as 17. Thus, EORTC QLQ-C30 and ESAS scores 0-16.9 mm were termed “not a problem,” 17–33.9 mm “a little,” 34–66.9 mm “quite a bit,” and 67–100 mm “very much.” For dichotomous analyses where we wanted to distinguish patients having ‘a significant symptom’ from those not having it, we decided that those scoring 34–100 had a “significant symptom.”

These limits were chosen in order to make clinical sense for single items as well as for scales estimated from two or more items. In the latter case we decided, for example, that the score on a scale composed of two items, where one item was scored “a little” and one was scored “quite a bit,” should be categorized “quite a bit.” This procedure attaches interpretations to the ESAS scores which may be disputed but seem reasonable for the use in the present study.

For this analysis, the six functional (positively phrased) scales of the EORTC QLQ-C30 were reversed so that, corresponding to the symptom scales, a high score indicated a poor performance or an unpleasant sensation.

The HADS scores were analyzed using the three categories described above.

Cross-tabulation. The patient’s scores on the ESAS, the EORTC QLQ-C30, and the HADS (categorized as described above) were cross-tabulated against the dichotomous outcome of
whether or not each symptom was mentioned in the medical records of the same patient.

**Results**

The age, sex, and primary site of malignancy of the 58 patients are shown in Table 1. EORTC QLQ-C30 was completed by 57, ESAS by 55, and HADS by 51 of the patients.

According to the EORTC QLQ-C30, patients reported their physical function to be significantly impaired (reversed score $\geq 34$) in 88%, role function in 91%, emotional function in 58%, cognitive function in 49%, social function in 63%, and general quality of life in 86% of cases. “Significant” pain (score $\geq 34$) was recorded by 91%, fatigue by 96%, nausea/vomiting by 44%, dyspnea by 91%, sleep disturbances by 42%, reduced appetite by 73%, constipation by 43%, diarrhea by 23%, and financial difficulties by 25% of the patients (data not shown in tabular form).

According to the ESAS, “significant” pain was experienced by 80%, inactivity by 91%, nausea/vomiting by 47%, depression by 47%, anxiety by 47%, drowsiness by 76%, reduced appetite by 78%, impaired well-being by 85%, and dyspnea by 55% of the patients.

According to the HADS, “doubtful” or “definite” anxiety and depression were present in 53% and 67% of the patients, respectively.

For the scales or single items of the three questionnaires (down), Table 2 shows the number of patients scoring above the different thresholds, the number of times the symptom was mentioned in the medical records, and the DSR. The rightmost set of columns shows the figures for patients scoring 34 or above, so-called “significant” symptoms. The four middle sections show the results broken down by patient scores ranging from “not a problem” ($\leq 16.9$) to “a lot” ($\geq 67$).

The highest levels of DSR were seen for pain. In almost all cases where the patient had scored pain $\geq 34$, pain was mentioned in the medical record (DSR 96 and 98% in the EORTC QLQ-C30 and the ESAS, respectively). In contrast, the DSR was much lower for other symptoms, e.g., for significant nausea/vomiting it was 46% and 52%, for reduced appetite 44% and 51%, for dyspnea 40% and 42%, for fatigue 38%, and for impaired social functioning and impaired well-being both as low as 2%.

**Discussion**

We found considerable quantitative and qualitative discrepancy between symptom assessment by patients and by physicians. According to the patient-completed questionnaires, patients experience many symptoms, which do
not appear in their medical records (Table 2). The only exception was pain, which seems to be noted by the doctor whenever experienced by the patient (and even in some cases where the patients report little or no pain).

Physical symptoms seem to have a slightly better chance of being detected by the doctor than psychosocial “symptoms” (Table 2, column at right). As expected, symptoms scored high by the patient were more frequently detected by the doctor than symptoms reported as being less severe (compare columns in the middle of Table 2). For example, in the EORTC QLQ-C30 cognitive function scale, the DSR when the patient scored “not a problem” was 0%, for “a little” 6%, for “quite a bit” 17%, and for “very much” 64%.

As explained in the Methods section, the thresholds we had to define in order to categorize patients’ scores on the ESAS and EORTC QLQ-C30 were arbitrary: should the threshold between categories termed ‘a little’ and ‘quite a bit’ be 34 or something different? The important thing to note here is that these thresholds had little impact on the overall results of this study. In fact, the main use of thresholds was to make sure that the estimation of DSR was based on patients reporting at least some symptom intensity: otherwise we would ‘demand’ that symptoms were detected by the doctor even if the patient did not report the symptom. The use of categories in Table 2 (middle sections) illustrate that the probability of detection of a symptom increases by its severity. For most interpretations of the data, it is sufficient to inspect the three right columns of Table 2 which present the DSR for patients scoring 34 or above on the 0–100 scale.

Patient-reported severe nausea/vomiting (scores ranging from 67–100) was recognized by the doctor in 40% and 67% of cases (depending on the questionnaire). “Significant”

### Table 2

<table>
<thead>
<tr>
<th>Doctor's Symptom Recognition (DSR)</th>
<th>Not a problem/0–16.9</th>
<th>A little/17–33.9</th>
<th>Quite a bit/34–66.9</th>
<th>Very much/67–100</th>
<th>Significant/34–100</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EORTC QLQ-C30</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Physical function</td>
<td>57</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Role function</td>
<td>54</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Emotional function</td>
<td>55</td>
<td>3</td>
<td>1</td>
<td>33</td>
<td>20</td>
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<tr>
<td>Cognitive function</td>
<td>55</td>
<td>1</td>
<td>0</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>Social function</td>
<td>51</td>
<td>7</td>
<td>0</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Quality of life</td>
<td>52</td>
<td>2</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Fatigue</td>
<td>57</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>57</td>
<td>12</td>
<td>2</td>
<td>17</td>
<td>20</td>
</tr>
<tr>
<td>Pain</td>
<td>57</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>57</td>
<td>23</td>
<td>0</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>57</td>
<td>23</td>
<td>0</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Appetite reduction</td>
<td>56</td>
<td>6</td>
<td>1</td>
<td>17</td>
<td>9</td>
</tr>
<tr>
<td>Constipation</td>
<td>56</td>
<td>20</td>
<td>3</td>
<td>15</td>
<td>12</td>
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<tr>
<td>Diarrhoea</td>
<td>56</td>
<td>28</td>
<td>1</td>
<td>4</td>
<td>15</td>
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<tr>
<td>Financial difficulties</td>
<td>52</td>
<td>31</td>
<td>1</td>
<td>3</td>
<td>8</td>
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<tr>
<td><strong>ESAS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>55</td>
<td>5</td>
<td>4</td>
<td>80</td>
<td>6</td>
</tr>
<tr>
<td>Inactivity</td>
<td>55</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
<td>55</td>
<td>24</td>
<td>7</td>
<td>29</td>
<td>5</td>
</tr>
<tr>
<td>Depression</td>
<td>55</td>
<td>21</td>
<td>2</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Anxiety</td>
<td>55</td>
<td>20</td>
<td>2</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Drowsiness</td>
<td>55</td>
<td>6</td>
<td>1</td>
<td>17</td>
<td>7</td>
</tr>
<tr>
<td>Reduced appetite</td>
<td>55</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Impaired well-being</td>
<td>54</td>
<td>3</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>55</td>
<td>22</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td><strong>HADS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>51</td>
<td>24</td>
<td>2</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>51</td>
<td>17</td>
<td>3</td>
<td>18</td>
<td></td>
</tr>
</tbody>
</table>

The three columns at right should be inspected first. Np = the number of patients having a score of at least 34 on the symptom/problem; Nd = the number of patients for which it was mentioned in the patient’s case records; DSR = Nd/Np × 100%. In the middle twelve columns, these figures are shown separately according to the patient score. N = the number of patients completing the item.
psychological problems (e.g., depression, anxiety, cognitive impairment) and more diffuse physical problems (e.g., fatigue and impaired well-being), however, were reported far more often by the patients than by the doctors. This is in partial agreement with the results of Ng and von Gunten,\textsuperscript{10} who found that physicians reported pain and cognitive impairment more often and weakness, fatigue, anxiety etc. more rarely than their patients. In our study, however, cognitive problems also were reported less frequently by doctors than by patients.

When interpreting these results it should be noted that even though consecutive patients were asked to participate, the results only apply to those patients who participated in the study by completing questionnaires. Non-participants were generally those with most advanced disease or impaired cognitive function. It seems likely that the discrepancy between patients and physicians may be even larger for those patients. Therefore, we believe that the bias resulting from non-participation tends to minimize rather than exaggerate disagreement between patients and doctors.

Do the findings of low DSRs indicate that doctors have insufficient insight in their patients’ situation—or can they be caused by problems in our methodology? Three factors should be considered:

First, the medical record is not meant to describe the patient’s functional status in all details, but rather to sum up the patient’s most important problems. Therefore, the “deficiencies” in the medical records should not just be interpreted as inadequacy. It is impossible for the doctor to be equally detailed as the questionnaires, and he might judge some symptoms or findings too obvious or clinically irrelevant to mention. The medical record also tends to be problem- or action-orientated, emphasizing problems or symptoms for which it is important or simple to take immediate action. As Leder\textsuperscript{11} puts it, “the doctor looks not only for disease \textit{per se} but especially for \textit{treatable} diseases.” The inclination to describe obvious problems or problems for which the doctor finds that there is little to do, may be limited.

Second, the record was written on day 0, whereas the questionnaires were filled in on day 0 or 1. If the patient waited until day 1, he might have collected his thoughts and revealed hitherto unmentioned needs in the questionnaires. Symptoms not mentioned in the initial medical record may surface in the following days. Looking at the magnitude of discrepancy between patient questionnaires and medical records, it seems unlikely that this mechanism is a major explanation of discrepancy. However, if the medical records of the following days were also analyzed, the DSRs would probably increase. The same applies if we had extended the review to not only covering the medical records, but also including other possible documentation (e.g., order sheets, nurses’ records): in some cases, treatments may have been given but not documented in the medical record.

Finally, the patient may withhold information or answer incorrectly (in the questionnaires or in the interview for the medical record), and this will be wrongly interpreted as an error made by the doctor.

In all, however, we do not find that these mechanisms are sufficient to explain the often large discrepancies between patients’ recording of symptoms and their recognition by the doctor. The disagreement found here is larger than those found in other studies of patient-physician agreement.\textsuperscript{2} However, the results cannot be directly compared, as our comparison of patient-assessment with medical records must be expected to produce a higher discrepancy: comparing patient self-assessment with medical records is quite a rigorous way of evaluating the doctor’s ability to detect palliative needs in his patient. If, like in Cull et al.,\textsuperscript{3} patient self-assessment on psychological distress is compared with assessment performed by the doctor, there is a bigger chance that distress will be revealed, because the doctor is asked specifically if he thinks that the patient is suffering from psychological problems. Slevin et al.\textsuperscript{12} compared quality of life measurements (HADS among others) performed by patients and their doctors, and they, too, found low correlations. To our knowledge, the present study is the first to directly compare patient self-assessed symptomatology with the contents of the medical record.

If patients are systematically interviewed for example about depression, there is a better chance of revealing a “case” than if the patient has to spontaneously disclose his mood disturbance. However, questioning in search of a depression will take place only if the doctor suspects the patient of suffering from depression.
The most interesting of the present results concern the palliative needs which might be successfully treated but which—according to the comparison of patient report against doctor record—are often overlooked: fatigue, nausea/vomiting, dyspnea, sleeplessness, poor appetite, constipation and diarrhea, as well as anxiety and depression, are all palliative needs for which there are potential treatments, but they are recognized by the doctor in 15–52% of cases only. Sleeplessness is recognized by the doctor in only 10% of cases reported by patients as severe.

The medical record in our department of palliative medicine is quite long and more focused on symptomatology than seen generally in other medical or surgical departments in Denmark. Therefore, we anticipate that DSRs are even lower in departments of other specialties. There is no formal specialist education in palliative medicine in Denmark. It is not possible to tell in advance how the present results would compare to a similar study in other countries, but it could be interesting to investigate this.

The present study is in line with the results of other studies suggesting that more systematic screening for symptoms in the initial interview—or systematic use of data from questionnaires filled in by patients—may benefit the patients. For example, Detmar and Aaronson carried out a study in which cancer patients filled in EORTC QLQ-C30 before their outpatient appointment. A summary of the scores on the questionnaire was available for the doctor at the consultation. The availability of the summary did not lengthen the duration of the consultation, and it seemed that the quality of life assessments stimulated the physicians to inquire more into specific aspects of the patient’s health and well-being. Schuit et al. suggested that better symptom recognition might be achieved if symptoms were actively assessed.

Is it ethically correct not to use the information given by patients in questionnaires? This is disputable and should be discussed when a study is planned. It is common practice in most similar studies we know that questionnaires completed by patients for research purposes are not routinely reviewed by the physician and that patients are informed about this. In each new study, it must be decided whether this practice will be followed, or whether all completed questionnaires will be reviewed by the physician on a daily basis. In fact, to do this would be a considerable, additional work. Even though the results of the present study suggest that it may be beneficial, it is still not known whether a systematic review of all completed questionnaires would in fact translate into improved palliative care.

The important thing is that patients must know whether or not their responses are seen by their physician. If patients are told that responses are seen, a procedure to secure that this is actually done must be established. If completed questionnaires are not reviewed on a daily basis, this must be made clear to patients.

The participation in research of patients with a limited life time expectancy is controversial, one of the reasons being that frequent completion of questionnaires may burden the patients. However, information from patient self-assessment questionnaires might be a valuable supplement to medical records, thus enhancing the probability that the patient’s palliative needs are fully recognized by the doctor. If this is the case, the efforts made by the patients completing the questionnaires may translate into improved care for the individual patient. We are planning a prospective investigation of the issue.

In summary, we have found low concordance between symptomatology as assessed by the patients and the appearance of the same symptoms in the medical records of patients with advanced cancer. We discuss ways to improve doctor’s detection of symptoms.

Acknowledgments

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References


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