Association between Patient-Reported Symptoms and Nurses' Clinical Impressions in Cancer Patients Admitted to an Acute Palliative Care Unit

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Abstract

Background: Clinicians typically rely on their own or the nurses' clinical impression (NI) of symptoms rather than patient self-reports. It is unclear whether these means of assessment yield similar results.

Objective: To prospectively compare patient-reported symptoms on a modified Edmonton Symptom Assessment System (ESAS) with NI scores.

Methods: Consecutive patients with advanced cancer admitted to our acute palliative care unit between April and July 2010 were studied. We collected the results of the ESAS on the day of admission (D1) to the unit and 2 days later (D3). We also collected the NI of each patient's physical and psychological distress on D1 and D3.

Results: One hundred eighteen patients completed the ESAS on D1 and 116 on D3. On D1 there was no significant association between NI score and ESAS assessment except for dyspnea, which was weakly correlated with NI score for physical distress ($r=0.22$, $p=0.02$). The median ESAS physical and psychosocial scores were 31 and 12 in patients with NI of low or no physical distress, versus 34 ($p=0.07$) and 15 ($p=0.18$) in patients with NI of moderate or severe distress, respectively. On D3, we found a significant association between ESAS and NI only for pain ($r=0.32$, $p<0.001$) and anxiety ($r=0.30$, $p=0.001$). Sensitivity and specificity of the NIs for ESAS scores were low on both days.

Conclusion: The clinical impression of highly trained palliative care nurses showed poor association with patient-reported symptom intensity. Validated symptom assessment tools are needed for bedside clinical assessment.

Introduction

INPATIENTS WITH ADVANCED CANCER develop multiple severe symptoms.¹⁻⁵ Effective treatment is only possible if appropriate symptom assessment take place.^{6,7} Physical symptoms such as pain, fatigue, dyspnea, anorexia, nausea, and sleep disorders are common, particularly at advanced stages of the illness.⁸ These symptoms are often associated with psychological distress, including depression and anxiety.⁹⁻¹¹

Use of the Edmonton Symptom Assessment Scale (ESAS)¹² in daily clinical practice has been reported to result in physicians' identifying symptoms earlier and more efficiently.¹³ However, most clinicians do not routinely use such symptom assessment tools in everyday practice and treat according to their or the nurse's clinical impression (NI) only.¹⁴⁻¹⁷ One of the reasons might be that some clinicians believe that it bur-

dens patients to ask them to complete questionnaires and similar reporting instruments,^{18,19} and that the patient can make errors when responding as a result of misinterpreting the question.²⁰

Therefore, in most clinical settings, decisions regarding the administration of rescue medication for pain, nausea, dyspnea, or the request for psychosocial support services are based on the clinical impression of the bedside nurse.

Patient-reported outcomes are self-reports by the patient (i.e., data are collected directly from the patient). The prevalence and severity of symptoms according to patient-reported outcomes compared with symptoms assessed by a third party (e.g., health care providers) tend to vary significantly,²¹⁻²⁷ which can make management decisions more complicated.

Our group had previously measured the association among ESAS done by the physicians, the patient, and the nurses, and

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we found that there were significant differences among all three, with consistent under-finding by the physician.⁹

In clinical practice, most physicians and nurses do not ask all ESAS questions to patients before making changes in pharmacological and/or nonpharmacological symptom management. Therefore in this prospective study, we decided to compare patient-reported symptoms on the ESAS with the overall NI of physical and emotional distress because it better reflects what is regularly done in bedside care.

Patients and Methods

The study was conducted at The University of Texas M. D. Anderson Cancer Center, a comprehensive cancer center in Houston, Texas. The Institutional Review Board at The University of Texas M. D. Anderson Cancer Center approved this study. All nurses who participated in this study signed the informed consent prior to enrollment. The Institutional Review Board provided waiver of consent for patient participation as we were using only the usual assessment used in daily practice in our unit.

The ESAS is used daily to assess all patients admitted to the M. D. Anderson Acute Palliative Care Unit (APCU), a 12-bed unit for patients experiencing acute symptoms related to their cancer or cancer treatment. Patients admitted in the unit have advanced cancer (i.e., metastatic solid tumor, locally/regionally advanced, or hematologic with refractory or relapse).

All patients admitted to the APCU are placed under the primary care of a team of board-certified palliative medicine specialists, specially trained bedside nurses, and an interdisciplinary team consisting of counselors, social workers, a chaplain, occupational therapists, physiotherapists, and a pharmacist. All patients are assessed by all members of the team during their inpatient hospital stay.

All adults patients admitted to the APCU were potentially eligible for the study. The only exclusion criteria were delirium and unresponsiveness that precluded completion of ESAS.

Data collection

To standardize documentation of clinical data, we provided training sessions for all APCU clinical staff nurses who agreed to participate in this study. All the nurses who participated in this study had specialist orientation to palliative care nursing and were full-time palliative nursing staff. To minimize missing data, our study coordinators brought the APCU nurses study forms daily to ensure that they were completed in a timely fashion. We collected various nurses' characteristics including age, sex, years of clinical experience, and years of palliative care experience.

We only assessed the nurses' impression about the physical and emotional distress because the nurses at the bedside make many decisions regarding contacting the physicians, administering rescue medications for different symptoms, calling others disciplines for counseling, and so forth. NI was not collected using a specific tool but by scoring distress as follows: no distress=0, low distress=1, moderate distress=2, and severe distress=3.

We collected the NI of each patient's physical and psychological distress on day of admission (D1) and 2 days later (D3). The nurses gave two scores, one for physical distress and the other for psychological distress.

We decide to collect NI even though it's not a validated tool because it is what guides the care, including the use of as-needed medications at the bedside. These NI scores were collected at the end of the nurses' shifts at 4–6 a.m. or 4–6 p.m.

For each patient, we documented demographic characteristics, including age, sex, ethnicity, religion, marital status, education, and cancer diagnosis. Patients completed ESAS forms on D1 and on the third day of hospitalization in the APCU (D3), if possible.

The ESAS is a self-report tool that allows patients with advanced cancer to document the intensity of nine common¹² symptoms (pain, nausea, tiredness or fatigue, drowsiness, loss of appetite, shortness of breath or dyspnea, depression, anxiety, and diminished feeling of well-being). For this study, we added a 10th symptom, sleep disturbance. The modified ESAS, like the original, is designed to document changes in symptom profiles over time by repeated quantitative measurements of symptom intensity. It has been shown to have good test–retest reliability.^{28–30} The ESAS asks patients to rate the intensity of these symptoms over the past 24 hours using an 11-point numeric rating scale, which runs from 0 (no symptom) to 10 (worst possible symptom).

The ESAS yields a total score and two subscale scores. These scores have been validated in advanced cancer patients with good reliability when compared with others tools.^{28–32} The total symptom distress score (TSDS) is the sum of the scores for the 10 symptoms for a total score of 0 to 100.¹² The physical distress subscore (PHS) was the sum of scores for seven symptoms (pain, nausea, tiredness or fatigue, drowsiness, appetite, shortness of breath or dyspnea, and sleep), and the psychological distress subscore (PSS) was the sum of scores for three symptoms (depression, anxiety, and feeling of well-being).³³ The results of the ESAS were recorded separately by our research coordinator. The assessment was completed either by the patients unassisted or by the patients assisted by the research coordinator. The nurses asked for an NI rating were blinded to the patients' responses.

D1 assessment was done independently, without the nurses' having knowledge of the results of the ESAS. Similarly, D3 assessment was done independently by the nurse who was in charge of the patient, who did not have knowledge of the results of the D1 assessment or of the day's score on the ESAS.

The assessment was completed by the nurse in charge of the patient that day. The nurse was not always the same person because the study was designed to reflect standard daily practice.

Statistical analysis

Standard descriptive statistics, including mean, median, standard deviation, range, proportion, and frequency, together with 95% confidence intervals, were calculated for patient and nurse characteristics and survey outcomes. A nonparametric Mann-Whitney test (two-sided) and Spearman's rank correlation analysis (two-sided) were used to assess the association between ESAS score and NI.

In our analysis of the sensitivity and specificity of the NI to ESAS items scores, we used optimal ESAS item cut scores reported in the literature, ranging from 2 to 5, to define classes. For most of the symptoms, we used a cut score of 3; however, for depression and anxiety the cut score was 2, and for fatigue, the cut score was 5.^{34–36}

We used the SPSS statistical package version 17.0.2 for Windows (SPSS, Inc., Chicago, IL) for all statistical analyses. For all our statistical analyses, a p value of <0.05 was considered to be statistically significant.

Results

Nurses characteristics

Twenty nurses participated to this study with a median age of 44 years. Seventeen (85%) of them were women. The median years of clinical practice was 9 (interquartile range 3 to 18 years) and the median years of palliative care experience was 2 (interquartile range 1 to 7 years).

Patient characteristics

One hundred fifty-one patients were admitted to the APCU between April and July 2010, and a total of 118 patients were enrolled in this study. The other 33 patients were not able to complete the ESAS on D1 because they were unresponsive and so were excluded. Patient demographics are reported in Table 1. The patients' median age was 58 years (range, 18 to 85 years), and most were non-Hispanic white. Gastrointestinal, respiratory, breast, and gynecologic malignancies were the most common diagnoses.

ESAS score and NI

One hundred eighteen patients were able to complete the ESAS on D1, and 116 completed it on D3 (two patients developed cognitive impairment that precluded completion of the second assessment).

TABLE 1. PATIENT CHARACTERISTICS ON APCU ADMISSION (N=118)

Patient characteristics	N (%)
Female sex	78 (66)
Ethnicity	
Caucasian	77 (65)
African American	13 (11)
Hispanic	23 (20)
Other	5 (4)
Christian religion	102 (86)
Married	69 (59)
Highest education level	
High school or below	51 (43)
Any College undergraduate education	33 (28)
Any advanced postgraduate education	14 (12)
Age (in years), median (range)	58 (18–85)
Cancer diagnosis	
Breast	18 (15)
Dermatologic	7 (6)
Gastrointestinal	26 (22)
Genitourinary	7 (6)
Gynecologic	18 (15)
Head and neck	5 (4)
Hematologic	13 (11)
Respiratory	19 (16)
Other	5 (4)

APCU, acute palliative care unit.

On D1 there was no significant association between NI scores of physical and psychological symptom distress and any ESAS item score, with the exception of dyspnea score. This score was weakly correlated with NI score for physical distress ($r=0.22$, $p=0.02$); the group with an NI physical distress score of 0 or 1 had a median ESAS dyspnea score of 3, and the group with an NI physical distress score of 2 or 3 had a median ESAS dyspnea score of 5 (Table 2).

The median PHS and PSS were 31 and 12, respectively, in patients with NI scores of 0 or 1 for physical and psychological distress and were 34 ($p=0.07$) and 15, respectively, in patients with NI scores of 2 or 3 for physical and psychological distress. These data and the results of correlation analysis are shown in Tables 2 and 3.

There was no association between NI score of physical and psychological distress and TSDS ($p=0.1$), with median TSDS score of 44 and 45 in patients with NI scores of 0 or 1 for physical and psychological distress and of 50 and 48 in patients with NI scores of 2 or 3 for physical and psychological distress, respectively.

On D3 there were significant associations between pain and NI scores for physical distress ($r=0.32$, $p<0.001$; Table 4), anxiety and NI scores for psychological distress ($r=0.30$, $p=0.001$, Table 5), anxiety and NI scores for physical distress ($r=0.32$, $p=0.001$), TSDS and NI score for physical distress ($r=0.27$, $p=0.003$) (Table 4), and PHS and NI score for physical distress ($r=0.22$, $p=0.02$) (Table 4).

NI score sensitivity and specificity to ESAS item scores

On D1, the NI score had low sensitivity to ESAS item score, ranging from 0.57 to 0.65, and low specificity, ranging from 0.42 to 0.57. The results were similar on D3.

Discussion

In this study, we compared bedside NIs of advanced cancer patients' symptom distress with the patients' own reports (as captured in ESAS scores) for multiple symptoms. We observed no significant association between NI and ESAS for the vast majority of symptoms on the day of admission and only slightly better performance/correlation on the patient's third day in the unit, probably related to a larger amount of clinical information collected by the team at D3 (Tables 2–5). In addition, there was no significant difference between the ESAS scores of patients considered to be in no or low physical and psychological distress by nurses and patients considered to be in moderate to severe distress at the time of admission (Tables 1–3). These data suggest poor association between nurses' impressions of patient symptoms and the patients' own experiences of those symptoms. This finding is particularly striking because the participating nurses had been specially trained in palliative care; in other settings, nurses' impressions of patient symptoms might be expected to be even less accurate.

The implications of these findings reflect an important unmet (and heretofore largely unrecognized) need in palliative care—the possibility that suboptimal care is being provided because of erroneous assumptions about the accuracy of third parties' impressions of cancer patients' distress, both physical and psychological. NIs have a strong impact on patients' receipt of pharmacological interventions, such as extra doses of opioids, antiemetics, or other agents for the management of

TABLE 2. ESAS SCORE CATEGORIZED ACCORDING TO NI OF PHYSICAL DISTRESS AND CORRELATION BETWEEN NI AND ESAS ON D1

ESAS item/ subscale/total score	NI of physical distress		P value*	Correlation between NI and ESAS ^a
	None – mild distress (0–1) N=50	Moderate – severe distress (2–3) N=68		
	median ESAS score	median ESAS score		
Fatigue	6	7	0.07	$r=0.14$; $p=0.14$
Drowsiness	4	4	0.14	$r=0.39$; $p=0.68$
Appetite	5	5	0.80	$r=0.15$; $p=0.10$
Nausea	2	1	0.67	$r=-0.74$; $p=0.43$
Pain	4.5	5	0.41	$r=0.66$; $p=0.49$
Dyspnea	3	5	0.02	$r=0.22$; $p=0.18$
Sleep	5	5	0.40	$r=0.09$; $p=0.34$
PHS	31	34	0.07	$r=0.18$; $p=0.07$
TSDS	44	50	0.10	$r=0.15$; $p=0.10$

ESAS, Edmonton Symptom Assessment System; NI, nurses' clinical impressions; PHS, physical distress subscore; TSDS, total symptom distress score.

*Mann-Whitney U test.

^aPearson's correlation.

symptoms such as pain, dyspnea, and nausea; receipt of nonpharmacological interventions such as counseling; and access to other members of the interdisciplinary team such as counselors, chaplains, and rehabilitation specialists.

Nurses' evaluations also have great influence on physicians' use of pharmacological and nonpharmacological interventions. Our findings suggest that decisions based on clinical impression alone have the potential to be biased and less effective than they could be. Thus, overall impression has very low accuracy to detect patients' distress, and we should probably ask questions regarding specific symptoms. Our findings suggest that from the perspective of patient care, regular symptom assessment using formal validated tools is very important for determining the levels of physical and psychosocial distress in patients admitted to an APCU. In most inpatient settings in the United States there is no regular patient-reported symptom assessment. Instead, treatment decisions are made based on nurses' and physicians' clinical impressions. Our group and others^{9,15,21,22,24,25} previously found that there is limited association between symptoms

ratings by patients and by health professionals, but in those previous studies, the sample size was smaller and the patient group was mixed (age, type of cancer, cancer extension). Another difference with previous studies is that they have used the same tools for the symptoms ratings by patients and by health professionals. This is not what is done in clinical practice, and this can also explain some of the discrepancies found between our results and the previous study we have conducted on this topic.⁹ In our previous study, nurses were able to rate the ESAS closer to the patients' rating than did the physician, but still there were differences when compared with patients' rating. In this study, we chose the global impression rather than the ESAS, because asking every element of the ESAS would have been more artificial to what is the real clinical scenario. In the clinical setting, what guides our interventions is clinical impression, and so we wanted to have an assessment of the value of the clinical impression rather than an ESAS scenario. Our current results strongly confirm those data in a prospective study with consecutive patients.

TABLE 3. ESAS SCORE CATEGORIZED ACCORDING TO NI OF PSYCHOLOGICAL DISTRESS AND BETWEEN NI AND ESAS ON D1

ESAS item/ subscale/total score	NI of psychological distress		P value*	Correlation between NI and ESAS ^a
	None – mild distress N=52	Moderate – severe distress N=66		
	median ESAS score	median ESAS score		
Depression	4	5	0.34	$r=0.09$; $p=0.34$
Anxiety	5	5	0.29	$r=0.10$; $p=0.29$
Feeling of well-being	5	6	0.20	$r=0.12$; $p=0.20$
PSS	12	15	0.18	$r=0.13$; $p=0.19$
TSDS	45	48	0.22	$r=0.11$; $p=0.22$

ESAS, Edmonton Symptom Assessment System; NI, nurses' clinical impressions; PSS, psychological distress subscore; TSDS, total symptom distress score.

*Mann-Whitney U test.

^aPearson's correlation.

TABLE 4. ESAS SCORE CATEGORIZED ACCORDING TO NI OF PHYSICAL DISTRESS AND CORRELATION BETWEEN NI AND ESAS ON D3

ESAS item/ subscale/total score	NI of physical distress		P value*	Correlation between NI and ESAS ^a
	None – mild distress (0–1) N=46 median ESAS score	Moderate – severe distress (2–3) N=70 median ESAS score		
Fatigue	5	6	0.07	$r=0.14$; $p=0.13$
Drowsiness	4	5	0.27	$r=0.09$; $p=0.30$
Appetite	5	5	0.14	$r=0.17$; $p=0.07$
Nausea	1	1	0.30	$r=-0.09$; $p=0.34$
Pain	2	4	0.001	$r=0.32$; $p<0.001$
Dyspnea	3	3.5	0.85	$r=0.02$; $p=0.85$
Sleep	4	5	0.24	$r=0.14$; $p=0.14$
PHS	27	30	0.02	$r=0.22$; $p=0.02$
TSDS	39	45	0.003	$r=0.27$; $p=0.003$

ESAS, Edmonton Symptom Assessment System; NI, nurses' clinical impressions; PHS, physical distress subscore; TSDS, total symptom distress score.

*Mann-Whitney U test.

^aPearson's correlation.

Many studies have shown that the ESAS is a simple tool that can be completed by patients or their families in a couple of minutes.^{12,30} However, it is still not used in daily practice in the vast majority of clinical settings.³⁷ A recent paper explored the journey of the ESAS from initial publication to its yet-unrealized widespread uptake and its use in patient assessment.³⁷ That paper clearly explained the negative consequences of delays in the adoption of clinical tools such as the ESAS. The low level of nurses' impression sensitivity is particularly concerning because it's more serious that nurses fail reporting to the team existing problems (sensitivity) than reporting problems that are not present (specificity). Future research should address ways in which the sensitivity of nurses' assessment can be improved, likely by the use of regular tools rather than clinical impression.

Power consideration were less important in the case of this study because we observed differences, and power might have been a consideration of more importance if we had observed that there were no difference between patients' assessment and NI. However, given information from 118

patients, we would have been able to declare as significant correlation coefficients that were 0.26 or higher, assuming 80% power and a two-sided significance level of 0.05. Given the two group category sizes for patients (e.g., regarding NI for psychological distress on D3; $n=47$ and $n=69$), we would have been able to detect differences between groups that were at 0.53 standard deviations or greater (effect size 0.53) for continuous variables, assuming 80% power and a two-sided significance level of 0.05. Then, our sample size would have been sufficient to find, if there was one, an association between the ESAS and NI.

The use of systematic patient-reported assessment is not enough to ensure improvements in palliative care for patients with advanced cancer. Improving symptom management of cancer patients will also require training of health care professionals and regular documentation of assessment findings.¹³ These changes may be challenging for some already overburdened clinical teams.³⁸ Nevertheless, it is likely that such changes can be made: our findings suggest that efforts toward incorporating symptom assessment in daily practice

TABLE 5. ESAS SCORE CATEGORIZED ACCORDING TO NI OF PSYCHOLOGICAL DISTRESS AND CORRELATION BETWEEN NI AND ESAS ON D3

ESAS item/ subscale/total score	NI of psychological distress		P value*	Correlation between NI and ESAS ^a
	None – mild distress (0–1) N=47 median ESAS score	Moderate – severe distress (2–3) N=69 median ESAS score		
Depression	3	4	0.37	$r=0.06$; $p=0.53$
Anxiety	6	7	0.001	$r=0.30$; $p=0.001$
Feeling of well-being	5	5	0.18	$r=-0.08$; $p=0.40$
PSS	14	16	0.20	$r=0.13$; $p=0.18$
TSDS	42	42	0.85	$r=0.02$; $p=0.85$

ESAS, Edmonton Symptom Assessment System; NI, nurses' clinical impressions; PSS, psychological distress subscore; TSDS, total symptom distress score.

*Mann-Whitney U test.

^aPearson's correlation.

should be done because there is very poor association between patient-reported outcomes and the clinical impression of a specialized palliative care nurse. More research is necessary to identify the tools that are adequate for making these assessments in the context of different symptoms and settings and to develop the training needed by health care providers to integrate these tools and the information they yield into their clinical practice.

Conclusion

The clinical impressions of palliative care nurses showed poor association with patient-reported symptom intensity. Therefore, validated tools are needed for daily clinical assessment of physical and psychosocial distress in advanced cancer patients.

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