Concordance of Symptom Perception Between Advanced Cancer Patients and Their Caregivers in Loja, Ecuador

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ABSTRACT

Methods

A cross-sectional, descriptive study, involving 63 palliative care patients and their primary caregivers. The Edmonton Symptom Assessment Scale (ESAS-FS) and the Patient-Reported Outcome Measurement Information System (PROMIS-10) were employed to evaluate symptom intensity and quality of life. Data were analyzed using non-parametric and parametric tests, establishing statistical significance at p < 0.05.

Results

Caregivers generally reported a higher intensity of symptoms than patients, with significant differences noted in pain perception. While caregivers overestimated most physical and psychosocial symptoms, the discrepancies were not statistically significant across other domains. PROMIS-10 assessments highlighted higher caregiver-reported emotional challenges compared to patients. No significant correlations emerged between demographic variables and symptom or quality-of-life scores.

Conclusions

The study highlights caregivers' tendency to overestimate patients' symptom burden. These findings underscore the reliability of caregiver input as a complementary data source in symptom management. Integrating caregiver perspectives in clinical assessments could optimize palliative care strategies, particularly in low-resource settings.

INTRODUCTION

Cancer represents a major public health issue, causing severe suffering in 90% of affected individuals. It is estimated that by 2060, 48 million people will die experiencing serious health-related suffering. Moreover, over 80% of these deaths will occur in low- and middle-income countries, where cancer will be the leading cause of death, with a projected increase of 109% when comparing the years 2016 and 2060 [1,2].

Palliative care (PC) offers an approach to alleviate the symptomatic burden in cancer patients, enhancing their quality of life, and should be considered an essential component of healthcare. For this reason, the American Society of Clinical Oncology (ASCO) recommends the early integration of PC into treatment protocols for both adults and children [3].

Patients with advanced cancer at the end of life experience a wide range of physical, emotional, and spiritual symptoms that can become intense, complex, and variable, significantly impairing their quality of life [4,5]. Therefore, it is important to assess whether the symptom intensity perceived by primary caregivers aligns with the patients' actual experiences.

Objective
To compare the perceived symptom intensity between patients with advanced cancer receiving palliative care and their primary caregivers.

METHODS AND MATERIALS

Design: Cross-sectional and descriptive study
Sample: 63 patients with stage IV cancer and their 63 primary caregivers who received care at the SOLCA Hospital, Loja branch – Ecuador.

Instruments:

Edmonton Symptom Assessment Scale (ESAS-FS)
PROMIS-10 Global Health Measure
The intensity of symptoms reported by patients on both scales was compared with the intensity perceived by their primary caregivers.

To calculate the mean differences between patients and caregivers on the PROMIS-10 scale, the t-test was used. For the ESAS scale, due to the non-normal distribution of the data, the non-parametric Wilcoxon test was applied. Statistical significance was established at a p-value < 0.05.

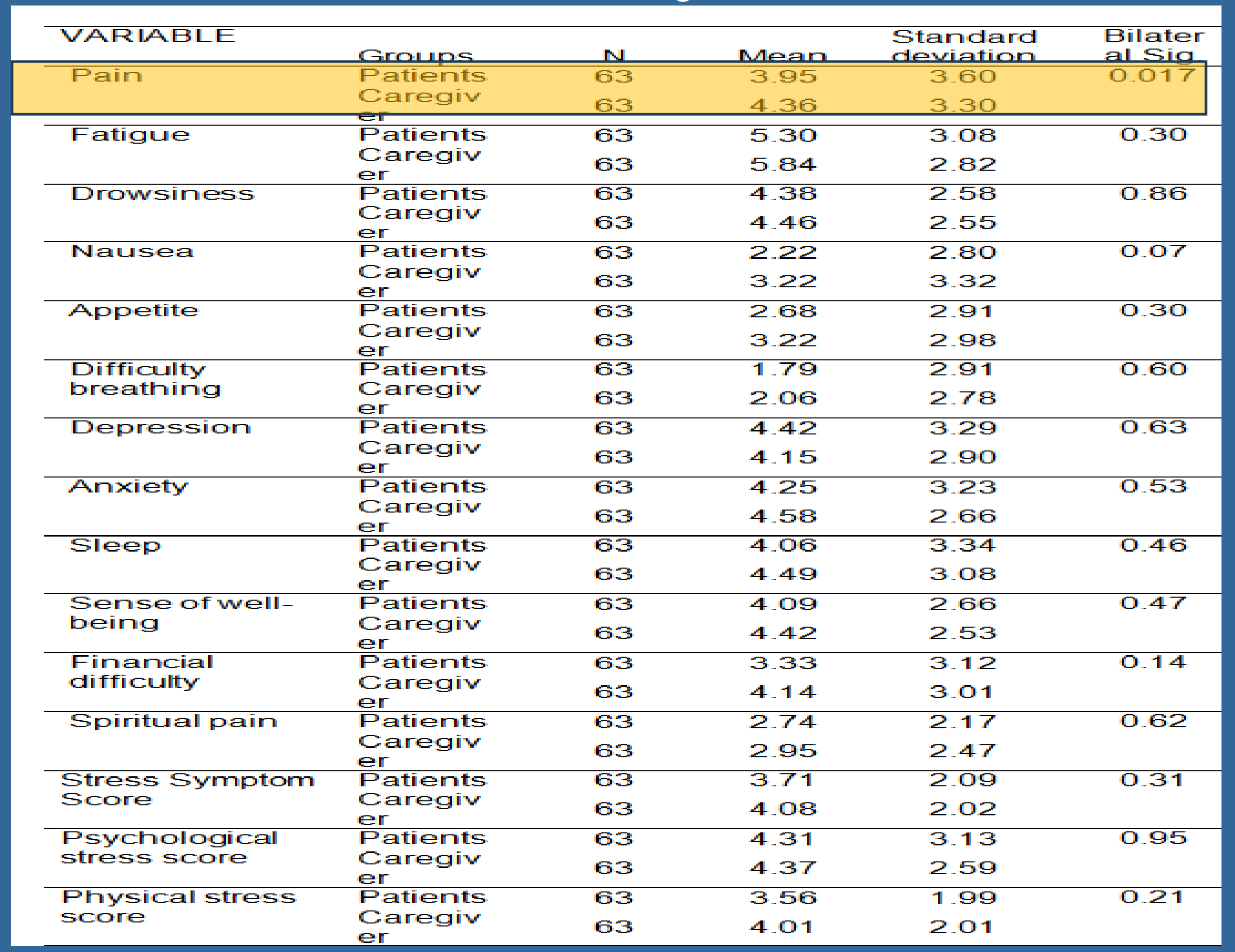
RESULTS

Symptom Perception (ESAS-FS)

Overall, caregivers perceived symptoms as more intense than the patients themselves.
Only pain showed a statistically significant difference between patients and caregivers (p = 0.017).
No significant differences were found for other symptoms.

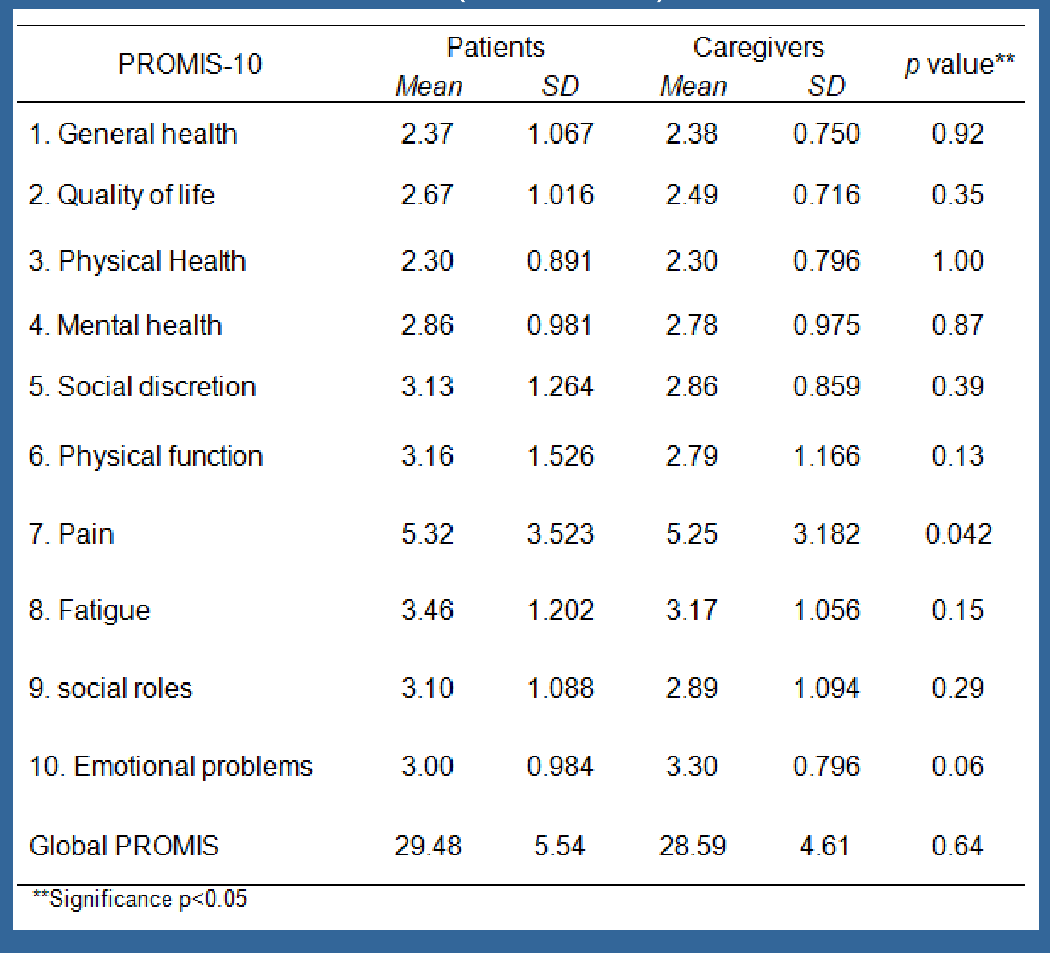
Quality of Life (PROMIS-10)
Patients reported higher scores in quality of life, physical health, mental health, and social functioning.
Caregivers reported a greater perception of emotional problems.
No statistically significant differences were found between the two groups, except in the perception of pain.

Results of the Edmonton Symptom Assessment Scale (ESAS-FS) in patients and caregivers.



VARIABLE	Groups	N	Mean	Standard deviation	Bilateral Sig
Pain	Patients	63	3.95	3.60	0.017
	Caregiver	63	4.36	3.30	
Fatigue	Patients	63	5.30	3.08	0.30
	Caregiver	63	5.84	2.82	
Drowsiness	Patients	63	4.38	2.58	0.86
	Caregiver	63	4.46	2.55	
Nausea	Patients	63	2.22	2.80	0.07
	Caregiver	63	3.22	3.32	
Appetite	Patients	63	2.68	2.91	0.30
	Caregiver	63	3.22	2.98	
Difficulty breathing	Patients	63	1.79	2.91	0.60
	Caregiver	63	2.06	2.78	
Depression	Patients	63	4.42	3.29	0.63
	Caregiver	63	4.15	2.90	
Anxiety	Patients	63	4.25	3.23	0.53
	Caregiver	63	4.58	2.66	
Sleep	Patients	63	4.06	3.34	0.46
	Caregiver	63	4.49	3.08	
Sense of well-being	Patients	63	4.09	2.66	0.47
	Caregiver	63	4.42	2.53	
Financial difficulty	Patients	63	3.33	3.12	0.14
	Caregiver	63	4.14	3.01	
Spiritual pain	Patients	63	2.74	2.17	0.62
	Caregiver	63	2.95	2.47	
Stress Symptom Score	Patients	63	3.71	2.09	0.31
	Caregiver	63	4.08	2.02	
Psychological stress score	Patients	63	4.31	3.13	0.95
	Caregiver	63	4.37	2.59	
Physical stress score	Patients	63	3.56	1.99	0.21
	Caregiver	63	4.01	2.01	

Self-assessment of the patient and their caregiver, according to the global health measure (PROMIS-10).



PROMIS-10	Patients		Caregivers		*p* value**
	Mean	*SD*	*Mean*	*SD*	
1. General health	2.37	1.067	2.38	0.750	0.92
2. Quality of life	2.67	1.016	2.49	0.716	0.35
3. Physical Health	2.30	0.891	2.30	0.796	1.00
4. Mental health	2.86	0.981	2.78	0.975	0.87
5. Social discretion	3.13	1.264	2.86	0.859	0.39
6. Physical function	3.16	1.526	2.79	1.166	0.13
7. Pain	5.32	3.523	5.25	3.182	0.042
8. Fatigue	3.46	1.202	3.17	1.056	0.15
9. social roles	3.10	1.088	2.89	1.094	0.29
10. Emotional problems	3.00	0.984	3.30	0.796	0.06
Global PROMIS	29.48	5.54	28.59	4.61	0.64

**Significance p<0.05

DISCUSSION

Although caregivers tended to overestimate both physical and emotional symptoms, no significant differences were found in most of the symptoms assessed by the ESAS-FS scale or in the quality of life dimensions measured by the PROMIS-10. This suggests that, while caregivers may exaggerate symptom intensity, their perceptions remain relatively close to those of the patients.

Previous studies have similarly found that caregivers are generally reliable evaluators of the patient's condition, particularly regarding physical symptoms. However, it has also been documented that they tend to overestimate psychological symptoms. Additionally, financial and emotional stress experienced by caregivers may influence their perceptions, potentially affecting communication and decision-making at the end of life.

The study acknowledges limitations such as the small sample size and its conduct in a single hospital, which limits the generalizability of the findings. Nevertheless, it highlights as strengths the use of validated tools (ESAS-FS and PROMIS-10) and the fact that it is the first study of its kind in the region

CONCLUSIONS

The results of this study allow the scientific community to confirm that information regarding symptom intensity, as perceived through the ESAS-FS and PROMIS-10 scales and reported by primary caregivers, is reliable and closely reflects the patients' actual experiences.

This supports the use of caregiver-reported information in clinical decision-making within palliative care settings.

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