Original Article

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Assessment of symptom intensity and psychological well-being of patients with advanced cancer undergoing palliative care in a Brazilian public hospital: A cross-sectional study

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Abstract

Objectives. The characterization of clinical–emotional aspects of advanced cancer patients is essential for palliative care. To date, there is scarce information regarding the socio-demographic and clinical profiles, as well as the quality of care given to hospitalized patients under this condition, particularly in South American countries. The objectives of this study were to analyze the socio-demographic profile, symptoms (including psychological well-being), and the quality of life of advanced cancer patients admitted to the oncology ward of the General Hospital of the University of Campinas, Brazil.

Methods. In this cross-sectional study, patients were invited to fill the selected questionnaires such as Edmonton Symptom Assessment Scale (ESAS) and Palliative Care Outcome Scale (POS). Descriptive analyses were performed, regarding socio-demographic profile, symptoms, level of information over treatment aims, and quality-of-life scores.

Results. Fifty-nine patients were included, of whom 29 were male and 30 female, with a mean age of 58 years. Overall, 31.9% presented pain at the time of the interview, 52.5% depression, and 76.3% anxiety. The median individual scores for ESAS and POS (and interquartile range) were, respectively, 27 (17–41) and 14 (9–19). Patients with previous knowledge of treatment objectives reported worse depression scores in the ESAS (median 2 vs. 0, *p* 0.02), even when correcting for possible confounders.

Significance of results. In contrast to current literature, in which pain is a prevalent report, depression and anxiety were more evident in this specific population of hospitalized patients. This framework reflects the need for valuing not only physical but also emotional symptoms to achieve the integrality of care.

Introduction

Each year, an estimated 40 million people require palliative care, and 78% living in low- and middle-income countries (Bray et al., 2018). One-third of death events in palliative care are estimated to be secondary to cancer, highlighting the importance of oncology in the field (World Health Organization, 2018). Cancer patients can present debilitating manifestations either related to the disease or its specific treatment. Of the symptoms described, pain is the most frequent, accounting for 70–90% (van den Beuken-van Everdingen et al., 2007; Kamal et al., 2013; Freire et al., 2014). Additionally, most challenges faced by cancer patients are in the areas of social and emotional support, spiritual/philosophical view of life, and body image (Heydarnejad et al., 2011). These findings indicate that this population needs special multidisciplinary attention for clinical management (Temel et al., 2010).

Given the current impact of cancer on society and that many patients will develop the advanced stage of disease, it is essential to apply palliative care in a multidisciplinary scope and assess the current physical and emotional requirements. Several scales were created with this aim: among the clinical symptoms analysis tools available, the Edmonton Symptom Assessment Scale (ESAS) (Bruera et al., 1991) is one of the most used for its functionality, measuring the severity of common symptoms in those patients (Bakitas et al., 2009). On the other hand, for extended evaluations (physical, psychological, and spiritual scopes), it may be necessary to apply additional tools. The Palliative Care Outcome Scale (POS) includes aspects regarding symptom control, as well as family and patient psychosocial needs such as

communication and information (Hearn and Higginson, 1999). This questionnaire also provides space to list the main symptoms in the last three days (Albers et al., 2010).

Several studies have assessed the determinants of the quality of life (QoL) of patients with terminal cancer (Hodgson et al., 1997; Grov et al., 2005; Hui et al., 2011; Deeken et al., 2013), but assessments are still scarce for hospitalized patients, particularly in South America (Collins et al., 2015). Hospitalized patients face potentially higher rates of depression and anxiety, as well as lower overall QoL scores (Paiva et al., 2015; IsHak et al., 2017), justifying the need for assessing this population individually. Additionally, there is insufficient information regarding end-of-life support for the patient and caregivers (Elmstedt et al., 2019). Therefore, symptoms and quality measurements for cancer patients in this distinct environment are essential for treatment planning (Smith et al., 2012).

In this cross-sectional study, we aim to analyze the socio-demographic profile, symptoms, and QoL scores of advanced hospitalized cancer patients at the General Hospital of the University of Campinas, Brazil. We also sought possible socio-demographic or disease-related predictors, factors that could help improve the quality of care of advanced cancer patients through the identification of risk groups.

Methods

Sample and design

This study consisted of a cross-sectional evaluation of advanced cancer patients (patients with locally advanced or metastatic disease upon diagnosis or relapse) hospitalized under palliative care at the General Hospital of the University of Campinas, Brazil, between July 2019 and December 2019. Inclusion criteria consisted of malignant neoplasm confirmed by biopsy, advanced tumor or subsequent recurrence, age greater than 18 years, and hospitalization from clinical complications related to neoplastic disease or palliative treatment. The exclusion criteria involved patients with diagnosed cognitive alterations that could interfere with the appropriate completion of the questionnaires.

Ethical approval and informed consent

The present study was approved by the Ethics Committee of the University of Campinas (registration no: 42707815.6.0000.5404). The investigator obtained a written consent form of each patient before any specific activity of the study was performed.

Measurements on social, demographic, and clinical characteristics

Patients were identified according to their registration number and initials. A demographic and clinical report form was filled out by the investigators based on the medical record assessment. The demographic and social data collected were age, gender, ethnicity, and education level. It was questioned about the presence of a caregiver and, if there was any, the degree of kinship concerning the patient.

Regarding the neoplastic disease, the location of the primary tumor, date of diagnosis, knowledge on diagnosis and therapy objectives, tumor staging, and treatment status were also collected. Data regarding hospitalization were dates of entry and discharge or death, reason for hospitalization, and Eastern Cooperative

Oncology Group (ECOG) performance status at the time of hospitalization (ECOG-ACRIN, 2019).

Symptom and QoL measurement: instruments

Two reported measures were used for patient' assessments: the translated ESAS (Monteiro et al., 2013) to evaluate the most common physical symptoms and the POS (Portuguese version) for an extended evaluation around the quality of care. The questionnaires were filled out by the patient himself or read by the researcher according to their preference.

The ESAS consists of a numerical scale including nine symptoms most related by the patients (pain, activity, nausea, depression, anxiety, drowsiness, appetite, sensation of well-being, and shortness of breath) assessed from 0 to 10. It is intended that the patient matches the intensity of his symptom with a numerical classification, in which 0 corresponds to the "without the symptom" and 10 to the "maximum intensity". The resulting overall score is then obtained by the sum of all items, ranging from 0 to 90 (Bruera et al., 1991).

The POS questionnaire involves 10 items related to pain and other patient's symptoms, and caregivers' anxiety, as well as the quality of orientation given and waiting time. The responses of the POS questionnaire are evaluated with Likert scales from 0 to 4 with numerical and descriptive labels (Likert, 1932). The individual scores of the first 10 questions can be summarized in a total score ranging from 0 to 40, with 40 being the maximum impairment (Rugno and De Carlo, 2016).

The resulting data for the study population on ESAS and POS questionnaires in the present study were both analyzed through the individual scales as well as overall scores, either in medians or percentages (van Vliet et al., 2015).

Statistics

Statistical analyses were performed with the use of Stata IC 15.0 software (StataCorp LP®). Descriptive statistics were used to estimate the frequencies for binary and categorical variables, while means and standard deviations (SD) for age and medians, and interquartile range (IQR) for ordinal scores (particularly, the overall resulting scores from the ESAS and the POS). We performed Kruskal–Wallis tests and linear regression to assess possible associations between demographic (age, gender, race, and education level) or disease-related characteristics (location of primary or recurrence/metastatic cancer, tumor stage at diagnosis, distant metastasis, current chemotherapy, prior knowledge on treatment objectives, reason for hospitalization, and performance status), and the overall QoL in single and multivariate analyses. Variables with $p < 0.10$ were selected for multivariate regression models in exploratory analyses; to identify and correct potential confounders, both forward and backward stepwise approaches were performed. Values of $p < 0.05$ were considered significant.

Results

Demographic characteristics

During the 6-month study period, 59 patients were included for analysis. Out of 60 patients meeting the inclusion criteria, only one subject declined participation and no other participants were excluded. The mean duration of hospitalization was 10.2 days (SD ± 8.4), and the majority of patients (62.7%) had their

Table 1. Epidemiological and social characteristics of study participants

Variables	Mean (SD) or *n* (%)
Age	58.1 (11.8)
Gender	
Female	30 (50.8)
Male	29 (49.2)
Ethnicity	
White	46 (78.0)
Non-white	13 (22.0)
Education level	
Incomplete elementary school	31 (52.5)
Complete primary education	6 (10.2)
Complete high school or college	18 (30.5)
Absent	1 (1.7)
Unknown	3 (5.1)
Companions	
Spouse	30 (50.9)
Son or daughter	17 (28.8)
Siblings	5 (8.5)
Father or mother	2 (3.4)
Without companion	1 (1.7)
Unknown	4 (6.8)

SD, standard deviation; *n*, number of patients; %, percentage.

assessment performed on the first four days of admittance. The mean age ± SD was 58.1 ± 11.8 years, and gender was evenly distributed. Most patients were white (78%) and had incomplete elementary education. Ninety-one percent were accompanied by family members, mostly spouses. All were said to have practiced religious orientation. Epidemiological and social characteristics are further detailed in Table 1.

Disease-related data

The main sites of primary cancer were gastrointestinal (52.5%), followed by head and neck cancer patients (8.5%). Forty-four percent had localized tumor stage at diagnosis, therefore relapsing or progressing during the treatment or follow-up. Upon current hospitalization, most had distant metastasis, and the main locations were liver, peritoneum, and lungs. Nearly 70% had knowledge regarding the non-curative aim of treatment, while 44.1% were hospitalized in consequence of cancer-related complications. Near one-third of cases had ECOG performance status III or IV upon admission (Table 2).

ESAS results

The median overall ESAS score was 27, with interquartile range (IQR) of 17–41 (Table 3). When assessing ESAS individual scores, 32.0% of patients had pain at the time of the interview, and most patients reported some degree of asthenia (57.6%), nausea (35.5%), depression (52.5%), anxiety (76.3%), drowsiness (71.2%), anorexia (69.5%), decreased sense of well-being

Table 2. Disease- and hospitalization-related data legend

Variables	*n* (%)
Main location of primary cancer	
Colon-rectum	13 (22.0)
Pancreas	10 (16.9)
Stomach	8 (13.6)
Head and neck	5 (8.5)
Soft-tissue sarcoma	4 (6.8)
Prostate	4 (6.8)
Others	15 (25.4)
Tumor stage at diagnosis	
II	13 (22.0)
III	13 (22.0)
IV	29 (49.2)
Unknown	4 (6.8)
Locoregional relapse without surgery or radiotherapy proposals	
Yes	27 (45.0)
No	33 (55.0)
Distant metastasis upon admission	
Yes	41 (69.5)
No	18 (30.5)
Main locations of distant recurrence or metastasis	
Liver	17 (28.8)
Peritoneum	15 (25.4)
Lung	14 (23.7)
Bone	9 (15.3)
Lymph node	8 (13.6)
Current target therapy or chemotherapy	
Yes	34 (57.6)
No	25 (42.4)
Knowledge regarding non-curative aim of treatment	
Yes	41 (69.5)
No	16 (27.1)
Unknown	2 (3.4)
Reason for hospitalization	
Chemotherapy (infusional chemotherapy)	20 (33.9)
Complications related to neoplasia[a]	35 (59.3)
Complications related to chemotherapy treatment	4 (6.8)
ECOG performance status upon admission	
0	4 (6.8)
I	16 (27.1)
II	15 (25.4)
III	13 (22.0)
IV	8 (13.6)

(Continued)

Table 2. (*Continued.*)

Variables	*n* (%)
Unknown	3 (5.1)

N, number of patients; %, percentage.
[a]Thromboembolism in 2 (3.4%), infectious complications in 9 (15.3%), and unspecified events in 24 patients (40.7%).

(78.0%), and dyspnea (37.3%). Regarding the severity of distress symptoms, 20.7% reported scores higher than 7 for depression and 35.6% for anxiety.

No differences in the overall ESAS score and ESAS individual scores regarding age, gender, race, education level, caretaker, tumor stage at diagnosis, distant metastasis, or reason for hospitalization were observed. The time of data collection was not determinant for overall ESAS in this analysis (linear regression coefficient 0.24; 95% CI −0.27 to 0.76; *p* 0.34). Patients under current target therapy or chemotherapy (median 33 vs. 25.5) and with knowledge of palliative aim of treatment (median 30 vs. 19) had higher ESAS scores than others; a tendency of the association of ECOG performance with higher ESAS overall scores in 1.81 for every status increase was also found (Supplementary Table S1). However, the differences were not confirmed after the correction of possible confounders (Supplementary Table S2).

The ECOG status was higher in untreated patients than in those under target therapy or chemotherapy (median 2.0 vs. 1.0). The ESAS overall score (median 33.0 vs. 25.5) and individual scores for asthenia (median 3.0 vs. 0.0), depression (median 3.0 vs. 0.0), sleep disturbance (median 5.0 vs. 3.0), and dyspnea (median 1.0 vs. 0.0) were higher in untreated patients than in those under treatment (Supplementary Table S3).

The patients with knowledge of palliative aims of therapy had higher ECOG status than those without (median 2.0 vs. 1.0). The ESAS overall score (median 30.0 vs. 19.0) and individual scores for asthenia (median 2.0 vs. 0.0) and depression (median 2.0 vs. 0.0) were also higher in those patients than in others (Table 3, Figure 1, and Supplementary Table S4). Patients with knowledge

of the palliative aim of therapy were prone to a higher ESAS depression score (median 2 vs. 0) (Supplementary Table S5 and Figure 1), even when correcting for possible confounders (*p* 0.02) (Supplementary Table S6).

POS results

The median POS overall score was 14, with IQR 9–19 (Table 4). About 70% of patients reported feeling anxious or worried about their disease or treatment, with 39% reporting Likert scores 3 or 4. Pain was present in 58%, and other limiting disease-related symptoms in 67.8%. The most predominant concern was related to the anxiety involving friends and relatives (median 4, IQR 2–4), where 62.7% scored the maximum scale. The least influential aspect in this population was related to the practical, financial, or personal problems resulting from the disease, with 11.9% reporting unresolved issues. Other concern addressed by the POS questionnaire was the feeling about life as being worthwhile, where 32.2% responded to never or occasionally.

There was no clinical or social factor associated with POS overall score or items (Supplementary Table S7), and previous knowledge of palliative aim of the therapy in this case did not alter the final score, although there was a trend for more expressive worry (median 2 vs. 1, *p*-value for Kruskal–Wallis 0.07) (Supplementary Table S8). The overall POS score was not influenced by the time of data collection in this study (linear regression coefficient −0.08, 95% CI −0.34 to 0.16, *p* 0.48).

Discussion

In this specific population of hospitalized cancer patients, the median overall ESAS score was comparable to other similar studies, one performed in Turkish general wards (median 24) (Ulas et al., 2018) and an evaluation of patients under palliative care in the USA (mean 23 in the control group) (Zimmermann et al., 2014). Nonetheless, another Brazilian study assessing the reliability of a translated version of ESAS in cancer patients

Table 3. Edmonton symptom assessment scale (ESAS) results

Symptoms	Total group (n = 59) Median (IQR)	Patients without knowledge of the palliative aim of the treatment (n = 16)[a] Median (IQR)	Patients with knowledge of the palliative aim of the treatment (n = 41)[a] Median (IQR)	*p*-value
Pain	0 (0–3)	0 (0–0.5)	0 (0–3)	0.24
Tiredness	1 (0–5)	0 (0–2)	2 (0–5)	0.049
Nausea	0 (0–2)	0 (0–1.5)	0 (0–3)	0.61
Depression	2 (0–5)	0 (0–0.5)	2 (0–6)	0.016
Anxiety	5 (1–8)	4.5 (0–7)	5 (2–8)	0.37
Drowsiness	5 (0–6)	2 (0–6.5)	5 (1–6)	0.42
Anorexia	5 (0–8)	3.5 (0–9)	5 (0–8)	0.58
Decreased sense of well-being	5 (1–7)	4 (0–5.5)	5 (2–7)	0.26
Shortness of breath	0 (0–3)	0 (0–2.5)	0 (0–2)	0.61
Overall score	27 (17–41)	30 (22–41)	19 (12.5–26)	0.027

Numerical scale ranges from 0 (best) to 10 (worst) for each item and 0 (best) to 90 (worst) for overall items.
IQR, interquartile range.
[a]Knowledge of the purpose of care of two patients is unknown. Analyses were performed using the Kruskal–Wallis one-way analysis of variance.
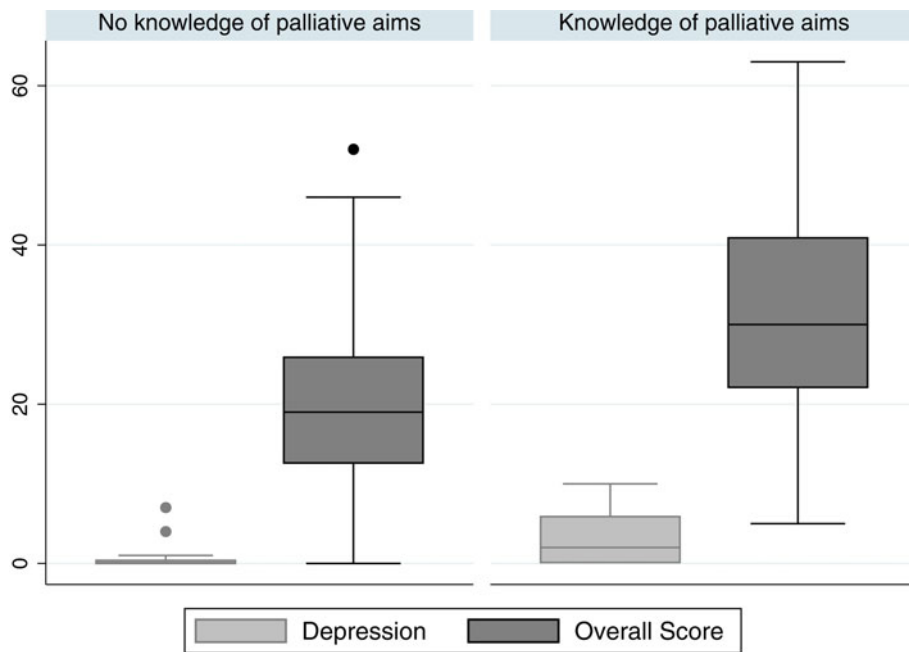
Fig. 1. Box plot representing the ESAS depression and overall scores according to knowledge over palliative, non-curative aim of treatment. Median [IQR] for the overall score was 19 [12.5–26] and 30 [22–41] according to the knowledge of treatment aims and no knowledge, respectively (Kruskall–Wallis, *p*-value of 0.027). Median [IQR] for the depression score was 0 [0–0.5] and 2 [0–6] (Kruskall–Wallis, *p*-value of 0.016).

retrieved higher scores for an inpatient population of 49 subjects (37, IQR 17–53.5) (Paiva et al., 2015). Although both institutions are oncology wards, attending mainly public health patients in Latin America, this surprising difference may be explained by population heterogeneity, in particular the different purposes of hospitalization and primary tumor site. As previously mentioned, one-third of the patients interviewed in our study were hospitalized for infusional chemotherapy due to the scarcity of domestic infusion devices in our Institution. Additionally, in descending order, gastrointestinal and head and neck tumors were the most

frequent primary sites seen in our patients, also in contrast to the population studied by Paiva et al. (2015), where 34% had the diagnosis of breast cancer.

In contrast to what was found in the overall literature, in which pain is prevalent in more than 50% of cancer patients (van den Beuken-van Everdingen et al., 2007), some degree of emotional distress was most frequently reported in this analysis. At least one quarter of patients reported relevant symptoms, either depression or anxiety. Besides, a lower proportion of patients complained of nausea and fatigue, while the prevalence from

Table 4. POS results

Item	(based on preceding three days)	4	3	2	1	0
1	Have you been affected by pain?	6 (10.2)	11 (18.6)	8 (13.6)	9 (15.3)	25 (42.4)
2	Have other symptoms (nausea, cough, constipation) seemed to be affecting how you feel?	9 (15.3)	15 (25.4)	3 (5.0)	13 (22.0)	19 (32.2)
3	Have you been feeling anxious or worried about your illness or treatment?	9 (15.3)	14 (23.7)	10 (17.0)	9 (15.3)	17 (28.8)
4	Have any of your family or friends been anxious or worried about you?	37 (62.7)	7 (11.9)	5 (8.5)	2 (3.4)	8 (13.6)
5	How much information have you and your family or friends been given?	3 (5.0)	1 (1.7)	10 (17.0)	4 (6.8)	41 (69.5)
6	Have you been able to share how you are feeling with your family or friends?	6 (10.2)	5 (8.5)	5 (8.5)	10 (17.0)	33 (56.0)
7	Have you felt that life was worthwhile?	11 (18.6)	8 (13.6)	6 (10.2)	8 (13.6)	26 (44.0)
8	Have you felt good about yourself as a person?	4 (6.8)	4 (6.8)	8 (13.6)	13 (22.0)	30 (50.9)
9	How much time do you feel has been wasted on appointments relating to your healthcare?	17 (28.8)	_	7 (11.9)	_	35 (59.3)
10	Have any practical matters resulting from your illness, either financial or personal, been addressed?	7 (11.9)	_	7 (11.9)	_	45 (76.3)

Values in table are presented as the number of patients with the percentage in parenthesis.
Questions 1, 2, 3, 4: 0: no; 1: slightly; 2: moderately; 3: severely; 4: overwhelmingly.
Question 5: 0: a lot; 1: hard to understand information; 2: desire to have more information; 3: little information; 4: no information provided.
Questions 6, 7, 8: 0: always; 1: most of the time; 2: sometimes; 3: occasionally; 4: never.
Question 9: 0: none; 2: almost half a day spent; 4: more than a half-day spent.
Question 10: 0: problems solved or had no problems; 2: problems will be solved; 4: unresolved issues.

other published data is reported in up to 90% (Yennurajalingam et al., 2011). This difference may be explained by the focus on physical symptom control performed by the hospital staff during hospitalization, with clinical assessments from the medical team being performed at least twice daily, in addition to nurse evaluations every 6 h. It is important to point that most evaluations previously published are directed to outpatient settings. On the other hand, most public national hospitals lack psychologists for regular evaluations on their wards, which was the case for this institution. Additionally, following the completion of data collection (December 2019), the coronavirus pandemic began and most medical services focused on ensuring basic care for cancer patients. Thus, no enhancing measures in palliative care based on our analyses were taken during this period in our service and, therefore, we consider that our results remain valid for the population studied.

Emotional complaints were reported by many patients and in more significant percentages, not only reflecting the need for the treatment of physical symptoms, but also emphasizing the importance of multidisciplinary care (Yokoo et al., 2014). Especially for patients aware of the palliative objective of treatment, our results suggested that this population may present higher incidence of depression. These findings should be validated in larger analyses; nonetheless, a special attention may be beneficial for this subgroup.

Regarding anxiety, the same pattern of higher proportion (65%) was also described by Paiva et al. (2015), when comparing outpatient vs. inpatient subgroups, with statistical significance, therefore confirming the contact with hospitalization as a possible predictor for worse scores. It could also explain the higher prevalence of anxiety in our analysis, in comparison to the overall literature findings. Anxiety decreased sense of well-being and depression negatively affects the QoL, and therefore should be worked on.

The mean of the individual scores for the POS was similar in relation to the international (15.9) (Bausewein et al., 2005) and the national literature (12.2) (Correia, 2012). Considering that the maximum score for injury is 40 (Correia, 2012) in a study involving 68 participants, the current result is not regarded as alarming. There are still scarce data evaluating POS questionnaires in Latin America, which limits further comparisons (Collins et al., 2015). The average of the answers of the question with the worse score (concern of relatives and friends about the patient) was similar for both the Brazilian study cited and the current one (Correia, 2012). This result corroborates the research by Sales et al. (2010), discussing how members of a family with an advanced cancer member are subjected to stress and anxiety, suffer from fear of losing family members, feel helpless, and even develop depression. It is therefore recommended that health professionals be attentive to the needs of their patients and their relatives; with the intention that they do not overburden themselves and can maintain the QoL (Bausewein et al., 2005; Correia, 2012; Krug et al., 2016). The majority of patients in this analysis (91%) was accompanied by family members during hospitalization.

This study has limitations, especially the sample size, in line with other previous studies (Correia, 2012), and the possible challenge in generalizing data for other population not treated in a public hospital, as well as with distinct disease presentations. A possible working bias is that hospitalized patients may be reluctant to express all their dissatisfaction with the health service when answering the POS questionnaire for fear of being treated differently. Another point to be raised was the lack of standardized time to apply the questionnaires, either in the first or last day of hospitalization. One could argue that the answers could vary if applied at a distinct moment, considering the design of a cross-sectional evaluation. Notwithstanding, most patients had their questionnaire applied on the first days of admittance, and there was no statistically significant influence observed from the time of data collection to ESAS and POS final results. Also taking into account the generalizability of data provided, up to the elaboration of this study, the institutional structure and human resources involving multidisciplinary support in the ward have remained constant and in similarity to other Latin American hospitals.

Furthermore, the perception of terms "depression" and "anxiety" and even other terminology included in QoL questionnaires could be variable among subjects (Marquis et al., 2004). Larger, multicentric studies would be ideal to validate its results.

Nonetheless, by analyzing these current findings in addition to previously published studies, it is possible to indicate that patients under hospitalization may share a special need in regards to dealing with the emotional aspects of the disease. Special attention may be given to those fully aware of their treatment status, consequently with a higher risk of depression. There is still scarce descriptive information covering advanced cancer patients under palliative care in Latin American public wards (Collins et al., 2015), justifying the need for larger analyses.

The symptoms most reported by cancer patients in palliative care interviewed in this study were predominately emotional. The hospitalization and knowledge of palliative aims may be predictors for higher risk of depression. This framework reflects the need for more psychological support to improve the QoL in the oncology wards.

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