

Palliative Care in Advanced Liver Disease: Similar or Different Palliative Care Needs in Patients with a Prospect of Transplantation? Prospective Study from a Portuguese University Hospital and Transplantation Center

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Keywords

Palliative care · End-stage liver disease · Liver transplantation

Abstract

Background and Aims: End-stage liver disease (ESLD) is an important cause of morbidity and mortality, comparable to a large extent to other organ insufficiencies. The need for palliative care (PC) in patients with ESLD is high. In Portugal, in the only identified study, more than 80% of patients hospitalized with ESLD had criteria for PC. No results specified which needs they identified or their transplantation prospect status. **Methods:** Prospective observational study including 54 ESLD patients who presented to a university hospital and transplantation center, between November 2019 and September 2020. Assessment of their PC needs through the application of NECPAL CCOMS-ICO[®] and IPOS, considering their transplantation perspective status. **Results:** Of the 54 patients, 5 (9.3%) were on active waiting list for transplan-

tation and 8 (14.8%) under evaluation. NECPAL CCOMS-ICO[®] identified 23 patients (n = 42.6%) that would benefit from PC. Assessment of PC needs by clinicians, functional markers and significant comorbidities were the most frequent criteria (47.8%, n = 11). IPOS also revealed a different sort of needs: on average, each patient identified about 9 needs (8.9 ± 2.8). Among the symptoms identified, weakness (77.8%), reduced mobility (70.3%), and pain (48.1%) stood out, as well as the psychoemotional symptoms of depression (66.7%) and anxiety (77.8%). There were no significant differences between the subgroups of patients analyzed. Only 4 patients (7.4%) were followed by the PC team. **Conclusion:** All the ESLD patients included, independently of the group they belonged to, presented with PC needs. No significant differences between the subgroups of patients were identified, confirming that even patients with a transplantation prospect have important needs for PC.

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Cuidados paliativos na doença hepática avançada – necessidades paliativas diferentes ou semelhantes no doente com perspetiva de transplante? Estudo prospetivo a partir de um hospital universitário português e centro de transplantação

Palavras Chave

Cuidados paliativos · Doença hepática avançada · Transplante hepático

Resumo

Introdução e objetivos: A doença hepática avançada (DHA) é uma causa importante de morbilidade e mortalidade, comparável em grande medida a outras insuficiências de órgão. A necessidade de cuidados paliativos (CP) em doentes com DHA é elevada. Em Portugal, no único estudo identificado até ao momento, mais de 80% dos doentes hospitalizados com DHA apresentavam critérios para CP. Não foram especificadas que necessidades de CP nem a perspetiva de transplante dos referidos doentes, que com o presente estudo se pretende ajudar a esclarecer. **Métodos:** Estudo prospetivo observacional incluindo 54 doentes com DHA assistidos num hospital universitário e centro de transplante, entre novembro de 2019 e setembro de 2020. Avaliação das necessidades de CP por meio da aplicação do NECPAL CCOMS-ICO[®] e IPOS, considerando a sua perspetiva de transplante. **Resultados:** Dos 54 doentes, cinco (9,3%) estavam em lista de espera ativa para transplante e oito (14,8%) em avaliação. O NECPAL CCOMS-ICO[®] identificou 23 doentes (n = 42,6%) que beneficiariam de CP. A avaliação das necessidades de CP por médicos, os marcadores funcionais e as comorbidades significativas foram os critérios mais frequentes (47,8%, n = 11). O IPOS também revelou diversas necessidades de CP: em média, cada doente identificou cerca de 9 necessidades (8,9 + -2,8). Entre os sintomas identificados, destacaram-se a fraqueza (77,8%), a mobilidade reduzida (70,3%) e a dor (48,1%), bem como os sintomas psicoemocionais de depressão (66,7%) e ansiedade (77,8%). Não houve diferenças significativas entre os subgrupos de doentes analisados. Apenas 4 doentes (7,4%) foram acompanhados pela equipa intra-hospitalar de CP. **Conclusão:** Todos os doentes com DHA incluídos, independentemente do grupo a que pertenciam, apresentaram necessidades de CP. Não foram identificadas diferenças significativas entre os subgrupos de doentes, confirmando que mesmo os doentes com perspetiva de transplante têm importantes necessidades de CP.

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Introduction

End-stage liver disease (ESLD) is associated with high mortality [1], with compensated cirrhosis survival estimated to be 10–13 years and about 2 years in decompensated patients [1]. This mortality is comparable to other organ insufficiencies such as heart failure [2] and chronic obstructive pulmonary disease [3]. The need for palliative care (PC) in patients with ESLD is presumed to be very relevant – a high prevalence of symptoms has been described, with about 80% of ESLD patients with at least one symptom of moderate to severe intensity and an average of 4.1 severe symptoms/patient [4]. These needs are also in line with similar symptom prevalence in other organ insufficiencies in advanced stages, namely for pain and dyspnea. In addition to physical needs, other needs – such as psychological, social, and even spiritual – may arise in patients with ESLD. These are often associated with chronic consumption of alcohol or other drugs, in a population that often is in full active life, and specific guidance would be beneficial for the patient, family, and caregivers [5].

Previous studies suggested benefits of PC in patients with ESLD, such as reduced hospital readmissions [6–8], less invasive treatments, shorter hospital length of stay [9, 10], and higher rates of advanced care planning [11]. In Portugal, in the only identified study [12], more than 80% of patients hospitalized with ESLD due to a decompensation episode had NECPAL CCOMS-ICO[®] [13] criteria for PC. The needs they referred and their transplantation perspective status were not specified.

PC referral rates in these patients remain very low, and the available data are scarce in this regard [9]. Very few studies addressed PC in ESLD patients with transplantation prospect, none including Portuguese population. In one of the few known studies, only 10% of patients excluded from the transplant list were referred to PC [14]. Low rates of advance care planning discussions persist among liver transplant candidates [15], and the current growing trend, of older age and with more comorbidities, poses greater complexity of their needs and care [16]. This subgroup of patients is also frequently the target of more aggressive treatment proposals and, consequently, at risk of greater complications and greater needs. Transplant candidates should not be excluded from PC studies [17].

The purpose of this study was to evaluate what are the specific PC needs of ESLD patients, including those with transplantation perspective, and to investigate whether there are significant differences in this subgroup. Given

the coexistence of cancer may have an impact, hepatocellular carcinoma (HCC) as a comorbidity was also considered.

Materials and Methods

Patient Selection

This is a single-center prospective study that included all consecutive adult patients (>18 years) diagnosed with ESLD who underwent hospital admission related to their liver disease (for acute decompensation or HCC treatment) at Centro Hospitalar e Universitário do Porto (Porto, Portugal), between November 2019 and September 2020. Patient identification was carried out twice a week by systematic search of the list of patients admitted to the Departments of Gastroenterology, Medicine, Hepato-Bilio-Pancreatic Transplant and Medical-Surgical Intermediate Care Units. Patients aged <18 years, with previous liver transplantation, or with isolated acute liver failure or with another terminal disease (except HCC) were excluded.

Data Collection

Demographic, functional (through the Palliative Performance Scale (PPS) [18]) and clinical characteristics were registered. Patients were screened for PC criteria using NECPAL CCOMS-ICO® [13]. It is an instrument capable of both identifying patients in need of PC and accurately predicting mortality, thus facilitating planning for end-of-life care [19]. NECPAL CCOMS-ICO® is a validated physician screening tool which combines the Surprise Question with additional indicators (request or need for PC, general clinical indicators of severity and progression, including comorbidity and resource use, and disease specific indicators, including ESLD). Patients with positive Surprise Question (if physician would not be surprised if the patient were to die in the next 12 months) were also considered NECPAL positive when they presented at least one additional parameter from the NECPAL tool. The questionnaire was answered by an internal medicine resident and reviewed by an internal medicine specialist with PC competence. Specific PC needs were assessed through the IPOS questionnaire [20]. This is also a validated instrument widely used globally and specifically developed for use among patients with advanced diseases including ESLD. IPOS questionnaire is a concise but comprehensive instrument, assessing not only symptoms (pain, shortness of breath, weakness or lack of energy, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, and poor mobility), but also extending to communication needs, practical concerns, anxiety or low mood, family anxieties and overall feeling of being at peace. IPOS has ten questions (17 items), for the majority of these, five response options are provided. The overall IPOS score is the sum of the scores from each question, ranging from zero to 68. It has two versions, to be completed by healthcare professional or patient, the last one was considered in the present study. When patients presented with encephalopathy (with West Haven grade II or more [21]), IPOS questionnaires were answered by the caregiver considered to be his/her legal representative. Subgroup comparative analysis was performed between ESLD patients with and without HCC and patients with a transplantation perspective (under evaluation or already awaiting liver transplantation) and patients without transplantation perspective (without

evaluation or already excluded for transplantation). The local ethics committee considered this study favorably and written informed consent was collected for all patients included, prior to data collection.

Data Analysis

Statistical significance was set at $p < 0.05$. Statistical analysis was performed using IBM SPSS Statistics 26. Baseline characteristics, PC criteria, and specific PC needs were compared between subgroups by the Mann-Whitney test.

Results

Study Population

From initial 73 patients considered, 54 were included (Table 1), with a mean age of 60.5 years. Nineteen patients were excluded because of previous liver transplantation ($n=7$), isolated acute liver failure ($n=2$), another terminal disease ($n=7$) or impossibility of completing the assessment ($n=3$). Alcohol was the most frequent etiology of ESLD patients (79.6%, $n=43$), nine of these in association with another etiology. Twenty-two patients were consuming alcohol (40.7%). Twenty-four patients (44.4%) presented at least with one current or previous ESLD complication, most frequently ascites (14.8%, $n=8$), followed by gastrointestinal bleeding (13.0%, $n=7$) and encephalopathy (11.1%, $n=6$). Three patients presented encephalopathy West Haven [20] grade II or more, and their IPOS questionnaires were answered by their legal representative. Twenty-one patients (38.9%) had at least one emergency department visit in the past 12 months, and 27.7% ($n = 15$) had at least one hospitalization in the same period. About 2/3 of the patients (68.5%, $n = 37$) were admitted with acute decompensation episode of ESLD. Regarding prognosis scores, 81.5% ($n = 44$) were admitted on Child-Pugh B or C, with a mean of 9.0 ± 2.4 points and with a Model for ESLD (MELD) of $15, 9 \pm 6.4$ points, and MELD-Na of 18.6 ± 6.5 points, respectively. Eleven patients (20.4%) had HCC, almost 2/3 in Barcelona Clinic Liver Cancer (BCLC) stages C-D ($n = 7$). As to comorbidities, 11 patients (20.4%) presented with another associated organ failure (cardiac, renal, or respiratory). Most patients (51.9%, $n = 28$) presented PPS >70, even though 18.5% ($n = 10$) presented with significant level of dependence (PPS <50). Length of stay was on average 22.1 ± 19.3 days (minimum of 2 and maximum of 99 days).

Table 1. Baseline main demographic and clinical characteristics of the study population (n=54)

Features	N (%)	Features	N (%)
Age (mean), years	60.5 (±10.9)	MELD (mean at admission)	15.9 (±6.4)
Sex, male	39 (72.2)	MELD-Na (mean at admission)	18.6 (±6.5)
Etiology		Acute ESLD decompensation	37 (68.5)
Alcohol	34 (63.0)	HCC	
Viral	3 (5.6)	BCLC A	3 (27.3)
Autoimmune	2 (3.7)	BCLC B	1 (9.1)
Alcohol+viral	7 (13.0)	BCLC C	6 (54.5)
Alcohol+autoimmune	2 (3.7)	BCLC D	1 (9.1)
NASH	2 (3.7)	Comorbidities	
Others	4 (7.4)	Other organ failure	11 (20.4)
Past alcohol consumption	23 (42.6)	Dementia	1 (1.9)
Current alcohol consumption	22 (40.7)	HIV	1 (1.9)
ESLD complication (acute or previous)		PPS	
Ascites	8 (14.8)	>70	28 (51.9)
Encephalopathy	6 (11.1)	50–70	16 (29.6)
Digestive hemorrhage	7 (13.0)	30–50	8 (14.8)
SBP	2 (3.7)	0–30	2 (3.7)
Hydrothorax	1 (1.9)	Length of stay	
None	30 (55.6)	Minimum	2
Emergency department visits (in past 12 months)	21 (38.9)	Maximum	99
Hospitalizations (in the past 12 months)	15 (27.8)	Mean	22.1 (±19.3)
Child-Pugh (admission)		Evaluation for transplantation	
A	10 (18.5)	No or excluded	41 (75.9)
B	21 (38.9)	Under evaluation	5 (9.3)
C	23 (42.6)	On active waiting list	8 (14.8)

NASH, nonalcoholic steatohepatitis; ESLD, end-stage liver disease; SBP, spontaneous bacterial peritonitis; MELD model for end-stage liver disease; HCC, hepatocellular carcinoma; BCLC Barcelona Clinic Liver Cancer; PPS Palliative Performance Scale.

Evaluation for Transplantation

Of the 54 patients, more than 3/4 had no evaluation for transplantation or had been already excluded from this proposal (n = 41, 75.9%), five (9.3%) were on active waiting list for transplantation and 8 (14.8%) under evaluation. One patient had been withdrawn from the list due to the development of multifocal HCC.

PC Needs Assessment

Regarding the Surprise Question “Would I be surprised if the patient died in the next 12 months?”, in almost half of the patients (48.1%, n = 26), the clinician would not be surprised (Table 2). NECPAL CCOMS-ICO[®] questionnaire identified 23 patients (n = 42.6%) as benefiting from PC. In those patients, the assessment of PC needs by clinicians, functional markers, and significant comorbidities were the most frequent criteria (47.8%, n = 11). PC recognition by patient versus by clinician was significantly higher in the latter (p<0.05), particularly in

patients without transplantation perspective (0% vs. 58.8%).

The IPOS questionnaire also revealed a different sort of needs (Table 3). On average, each patient identified about 9 needs (8.9 ± 2.8). Psychoemotional symptoms, as a group, were the most prevalent, firstly due to patient's anxiety (77.8%, n = 42), followed by family/friends' anxiety (72.2%, n = 39) and depression (66.7%, n = 36). Concerning physical symptoms, weakness was the most prevalent (77.8%, n = 42), followed by reduced mobility (70.3%, n = 38), somnolence (61.1%, n=33), pain (48.1%, n = 26) and poor appetite (37.0%, n = 20). Regarding other needs, emphasis was placed on the lack of peace (74.1%, n = 40) and the difficulty in communicating with family/friends (57.4%, n = 31). In contrast, the difficulty in communicating with the medical team (25.9%, n = 14), assessed by access to medical information, was one of the least prevalent needs. Intensity evaluation of needs revealed that 43 (79.6%) patients had at least one severe

Table 2. NECPAL results (N = 54)

	All ESLD patients (n = 54)	ESLD patients with transplantation perspective (n = 13)	ESLD patients without transplantation perspective (n = 41)	p value*	ESLD patients with HCC (n = 11)	ESLD patients without HCC (n = 43)	p value*
NECPAL+	23 (42.6%)	6 (46.2%)	17 (41.5%)	>0.05	4 (36.4%)	19 (44.2%)	>0.05
Surprise question	26 (48.1%)	8 (61.5%)	18 (43.9%)	>0.05	5 (45.4%)	19 (35.2%)	>0.05
Self or caregiver's request of palliative care	1 (4.3%)	1 (16.7%)	0 (0%)	>0.05	0 (0%)	1 (5.3%)	>0.05
Health professional assessment need for palliative care	11 (47.8%)	1 (16.7%)	10 (58.8%)	>0.05	0 (0%)	11 (57.8%)	>0.05
Nutritional markers	8 (4.8%)	4 (66.7%)	5 (29.4%)	>0.05	0 (0%)	9 (47.4%)	>0.05
Functional markers	11 (47.8%)	3 (50.0%)	8 (47.1%)	>0.05	1 (25.0%)	10 (52.6%)	>0.05
Other disease markers of severe frailty	0 (0%)	0 (0%)	0 (0%)	>0.05	0 (0%)	0 (0%)	>0.05
Psychological suffering	5 (21.7%)	3 (50.0%)	2 (11.8%)	>0.05	0 (0%)	5 (26.3%)	>0.05
Additional Factors in Resource Usage	8 (34.8%)	5 (83.3%)	3 (17.6%)	<0.05	0 (0%)	8 (42.1%)	>0.05
Comorbidities	11 (47.8%)	0 (0%)	13 (64.7%)	<0.05	3 (75.0%)	8 (42.1%)	>0.05
Advanced cirrhosis	7 (40.4%)	4 (66.7%)	3 (17.6%)	<0.05	0 (0%)	7 (36.8%)	>0.05
HCC stage C or D (BCLC)	4 (17.4%)	1 (16.7%)	3 (17.6%)	>0.05	4 (100%)	0 (0%)	<0.05

* p value - statistical significance was set at $p < 0.05$ ESLD, end-stage liver disease; HCC, hepatocellular carcinoma; BCLC, Barcelona clinic liver cancer.

need (intensity 3), and 19 (35.2%) at least one very severe (intensity 4). Finally, given that both questionnaires, NECPAL CCOMS-ICO[®] and IPOS, are based on different methodologies, it was found that patients with positive NECPAL CCOMS-ICO[®] had an average IPOS of 19.7 ± 8.5 (minimum of 7 and maximum of 41), while those with a negative NECPAL CCOMS-ICO[®] presented an average IPOS of 13.5 ± 6.2 (minimum of 1 and maximum of 26).

ESLD with and without Transplantation Perspective

Global PC needs assessed by NECPAL CCOMS-ICO[®] and IPOS revealed no significant differences between ESLD patients with and without transplantation prospect (Tables 2 and 3). However, regarding specific PC needs applying NECPAL CCOMS-ICO[®] questionnaire, the presence of comorbidities, advanced cirrhosis, and emergency department visit in the last 12 months were significantly more frequent ($p < 0.05$) in patients without transplantation prospect. The IPOS questionnaire revealed a total score marginally higher in patients with transplantation prospect (16.9 ± 11.0 vs. 15.9 ± 6.6). Prevalence of specific needs according to this questionnaire came out as globally similar between groups, with weakness or lack of energy being the only ones significantly higher in patients without prospect for transplantation ($p < 0.05$).

ESLD with and without HCC

ESLD patients with HCC were less frequently identified with PC needs ($p > 0.05$) by NECPAL CCOMS-ICO[®] (Table 2). None of these patients identified psychological distress as other groups did. Presence of HCC was the only PC need that stood out. Regarding IPOS, ESLD patients with and without HCC showed no difference on the total IPOS score (14.5 ± 7.8 vs. 16.6 ± 7.8 , respectively, with vs. without HCC patients) or on the mean number of PC needs (7.6 ± 3.3 vs. 9.2 ± 2.6 , respectively, with vs. without HCC patients) (Table 3). Depression was the only PC need significantly more prevalent in patients without HCC ($p < 0.05$).

Subsequent Health Resource Use and Mortality

Hospital mortality was 11.1% ($n = 6$), higher in the group of patients without transplantation prospect versus with (12.2 vs. 7.7%) and in patients without HCC versus with (14.0% vs. 0), but in both cases $p > 0.05$ (Table 4). Follow-up by the PC team occurred only in 4 patients, all of whom died during hospitalization. Six months after discharge, mortality increased to 33.3% ($n = 18$), particularly in the group of HCC patients (54.5%, $n = 6$). In the

Table 3. IPOS results (N = 54)

	All ESLD patients (n = 54)	ESLD patients with transplantation perspective (n = 13)	ESLD patients without transplantation perspective (n = 41)	p value*	ESLD patients with HCC (n = 11)	ESLD patients without HCC (n = 43)	p value*
Total IPOS score	16.1±7.8	16.9±11.0	15.9±6.6	>0.05	14.5±7.8	16.6±7.8	>0.05
Number of identified needs	8.9±2.8	7.8±3.6	9.2±2.4	>0.05	7.6±3.3	9.2±2.6	>0.05
Pain	26 (48.1%)	7	19	>0.05	4	22	>0.05
Dyspnea	15 (27.8%)	3	32	>0.05	3	12	>0.05
Weakness	42 (77.8%)	6	36	<0.05	7	35	>0.05
Nausea	18 (33.3%)	3	15	>0.05	4	14	>0.05
Vomiting	8 (14.8%)	3	5	>0.05	3	5	>0.05
Poor appetite	20 (37.0%)	3	17	>0.05	3	17	>0.05
Constipation	19 (35.2%)	5	14	>0.05	5	14	>0.05
Sores or dry mouth	21 (38.9%)	4	17	>0.05	4	17	>0.05
Somnolence	33 (61.1%)	6	27	>0.05	15	28	>0.05
Poor mobility	38 (70.4%)	7	31	>0.05	8	30	>0.05
Anxiety	42 (77.8%)	10	32	>0.05	8	34	>0.05
Family and friends anxiety	39 (72.2%)	10	36	>0.05	9	38	>0.05
Depression	36 (66.7%)	5	31	>0.05	5	31	<0.05
Lack of peace	40 (74.1%)	10	30	>0.05	5	35	>0.05
Difficulties in sharing with family and friends	31 (57.4%)	7	24	>0.05	5	26	>0.05
Difficulties in medical information	14 (25.9%)	3	11	>0.05	1	13	>0.05
Difficulties in solving practical problems	21 (38.9%)	7	14	>0.05	3	18	>0.05

*p value - statistical significance was set at $p < 0.05$. ESLD, end-stage liver disease; HCC, hepatocellular carcinoma.

same period, 21 (43.8%) of the patients that were discharged alive went to the emergency department at least once and 27.0% (n = 13) required at least one subsequent hospitalization.

Discussion

All the ESLD patients included in this study, including ESLD patients with transplantation prospect, presented with PC needs, assessed either by the NECPAL CCOMS-ICO[®] or the IPOS questionnaires. The NECPAL CCOMS-ICO[®] questionnaire, which refers to information provided by the healthcare professional, reassured this through the Surprise Question, in which almost half of the patients (48.1%, n = 26) scored, and by 42.6% (n = 23) of patients that also had a positive final score. Regarding the criteria identified by this questionnaire, the recognition of PC needs by the clinician (47.8%, n = 11) stands out, as opposed to the recognition by the patients themselves (4.3%, n = 1) ($p < 0.05$). This difference might be a consequence of a lack of information about their prognosis or PC, insufficient communication with the health care team, or of limitations of the questionnaire itself to assess this dimension. Of the remaining criteria, the most frequently identified

were the functional ones, followed by the presence of comorbidities and Child-Pugh C stage. IPOS questionnaire, which directly assesses PC needs by the patient or caregiver, identified psychoemotional needs as the most prevalent, namely patient's anxiety (77.8%, n = 42). Of the remaining needs, the spiritual dimension assessed through the feeling of peace was also relevant for 74.1% (n = 40). In contrast, communication with the health care team was a problem pointed out by only 25.9% (n = 14) of the patients.

This study broadens the knowledge about the PC needs of patients with ESLD, in different contexts, including patients with transplantation prospect as suggested by few other studies [9, 22]. Similar to the study published by Carvalho et al. [12], this study reassures, through the NECPAL CCOMS-ICO[®] questionnaire, a high prevalence of PC needs in the hospitalized ESLD patients. To our knowledge, no previous studies have suggested that patients with ESLD themselves fail to identify their need for PC, so these findings must be further researched. Through the IPOS questionnaire, this study also suggests the notion that more often several needs are dealt with simultaneously (average of 8.9 ± 2.8): more than $\frac{3}{4}$ of the patients (79.6%, n = 43) had at least one severe need and about $\frac{1}{3}$ (35.2%, n = 19) of the patients had a very severe one.

Table 4. Subsequent health resource use and mortality (N = 54)

	All ESLD patients (n = 54)	ESLD patients with transplantation perspective (n = 13)	ESLD patients without transplantation perspective (n = 41)	ESLD patients with HCC (n = 11)	ESLD patients without HCC (n = 43)	p value*
Mortality during hospitalization	6 (11.1%)	1 (7.7%)	5 (12.2%)	0	6 (14.0%)	>0.05
Mortality 6 months after discharge	12 (25.0%)	3 (25.0%)	9 (25%)	6 (54.5%)	6 (16.2%)	>0.05
Total mortality	18 (33.3%)	4 (30.8%)	14 (34.1%)	6 (54.5%)	12 (27.9%)	>0.05
Patients with 1 or more emergency department resources 6 months after discharge	21 (43.8%)	4 (33.3%)	17 (47.2%)	3 (27.3%)	18 (48.6%)	>0.05
Patients with 1 or more hospitalizations 6 months after discharge	13 (27.0%)	5 (41.7%)	7 (19.4%)	3 (27.3%)	10 (27.0%)	>0.05

* p value - statistical significance was set at $p < 0.05$. ESLD, end-stage liver disease; HCC, hepatocellular carcinoma.

The symptoms identified more frequently – weakness (77.8%), reduced mobility (70.3%), somnolence (61.1%), and pain (48.1%) – are in line with those described by Peng et al. [4]. Similarly, the psychoemotional symptoms of depression (66.7%) and anxiety (77.8%) were very common, the latter more frequent than previously described by Peng et al. [4]. This result, combined with the needs identified in the spiritual domain, relevant in 74.1% (n = 40) of the patients, suggests an important psychoemotional and existential suffering in this population, an aspect that deserves to be better clarified and supported. Contrary to what was described by Low et al. [23], who identified the existence of significant communication difficulties among patients with ESLD, their families, and healthcare professionals, this was not observed in the present study, being pointed out by only 25.9% (n = 14) of the patients. However, this result must be carefully analyzed, namely if we consider the aforementioned psychoemotional and existential suffering described that can denounce communication deficiencies. A more careful assessment of communication needs may be justified. Comparing the results obtained by the two questionnaires, in addition to the fact that all patients with positive NECPAL CCOMS-ICO[®] scored in the IPOS questionnaire, it was also found that even patients with negative NECPAL CCOMS-ICO[®], also scored at least one in the IPOS questionnaire, revealing that they had at least one need/problem that fits in the palliative scope. This result is not surprising given the different methodologies associated with each questionnaire, as well as the diversity of needs/problems identified, and their high prevalence also reported by Peng et al. [4]. The use of both these instruments might complement each other and suggests that frequently patients with still negative NECPAL CCOMS-ICO[®] might already present some PC needs, identified by IPOS.

Analysis by groups showed no statistically significant difference in the total scores of the NECPAL CCOMS-ICO[®] and IPOS questionnaires. These results suggest that even patients with ESLD with transplantation prospect also have important PC needs, as described by Baumann et al. [22], who showed the benefit of an early PC intervention in these patients. In the present study, there was a lower tendency for positive NECPAL CCOMS-ICO[®] and IPOS scores in the group of patients with HCC versus without. These results are probably because most of the patients with HCC have been admitted for elective procedures, without criteria for acute liver decompensation. Regarding specific criteria, the use of health care services in the 12 months prior to hospitalization, the pres-

ence of comorbidities, advanced cirrhosis, and symptoms like weakness and depression, were significantly higher in ESLD patients without perspective for transplantation. This is probably in agreement with greater clinical deterioration of these patients compared to patients with transplantation perspective. When comparing specific criteria of PC needs in patients with HCC versus without HCC, depression came out as the only significantly more prevalent symptom in patients without HCC, probably for the reason mentioned previously. Yet, these results suggest that ESLD itself poses no less need for PC than HCC associated to ESLD, as is sometimes supposed.

Limitations

This study presents some limitations. The sample consisted of patients admitted to a single hospital, even though it includes patients with some geographical diversity, as it is a liver transplantation center. The recruitment of patients was conditioned in terms of time and access to patients because it occurred in overlap with the SARS-CoV-2 pandemic, resulting in a prolonged recruitment period and in a sample of 54 patients. This sample also presented with a heterogeneous distribution among the subgroups considered, and this may also introduce some analysis bias. Finally, PC needs assessment, as it is evaluated in a single moment, does not allow to reflect their dynamical nature.

Issues for the Future

For future research, it will be relevant to evaluate methodologies that allow for the access of different groups of patients with ESLD to PC, including patients with transplantation prospect, identifying the main needs and barriers to its implementation and allowing this access to occur as early as desirable [24].

Conclusion

The present study affirms important PC needs in patients with ESLD. It amplifies the knowledge about these, suggesting that most patients present several needs simultaneously, often of severe or very severe intensity and with wide diversity. Of the identified symptoms, psychoemotional ones stand out, as they are no less frequent than weakness, reduced mobility, and pain, which seem to be the most frequent physical symptoms. This study also found no relevant difference between the different subgroups of patients considered and, therefore, points out that PC is relevant in most patients with ESLD, including those with transplantation prospect.

Statement of Ethics

This study protocol was reviewed and approved by Comissão de Ética do Centro Hospitalar Universitário do Porto, approval number 194-19 (160-DEFI/166-CE). Written informed consent was obtained from participants or their legal representatives.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

S.V.S. contributed to the conception of the work, the acquisition analysis, interpretation of data, drafting the work and final approval of the version to be published. P.B. contributed to the acquisition analysis, interpretation of data, drafting the work and final approval of the version to be published. I.F. contributed to the acquisition analysis, interpretation of data, drafting the work and final approval of the version to be published. E.F. contributed to the interpretation of data, revising the work critically and final approval of the version to be published. H.P.M. contributed to the interpretation of data, revising the work critically and final approval of the version to be published.

Data Availability Statement

All data generated or analyzed during this study are included in this article and its supplementary material files. Further enquiries can be directed to the corresponding author.

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