

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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What is already known about the topic?

- ❖ End-stage liver disease (ESLD) is associated with high mortality - compensated cirrhosis survival is estimated to be 13 years and about 2 years in decompensated patients.
- ❖ The need for palliative care (PC) in patients with ESLD is relevant – about 80% of ESLD patients presents with at least one symptom of moderate to severe intensity and an average of 4.1 severe symptoms/patient.
- ❖ Reduced hospital readmissions, less invasive treatments, shorter hospital length of stay and higher rates of advanced care planning are some of the benefits described of PC in patients with ESLD.
- ❖ Only a minority of ESLD patients excluded from the transplant list are referred to PC.

What this paper adds?

- ❖ 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). Spiritual dimension assessed through the feeling of peace was also relevant for 74.1% (n = 40).
- ❖ Weakness (77.8%), reduced mobility (70.3%), somnolence (61.1%), and pain (48.1%) were the most prevalent physical symptoms.
- ❖ More often several needs were 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
- ❖ PC needs assessed by NECPAL CCOMS-ICO © and IPOS revealed no significant differences between ESLD patients with and without transplantation prospect. 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 the last ones.

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.

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.

Implications for practice?

- ❖ This paper points out that PC is relevant in most patients with ESLD, including those with transplantation prospect.
- ❖ 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.