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HOME PARENTERAL NUTRITION AND AMYOTROPHIC LATERAL SCLEROSIS: RETROSPECTIVE COHORT STUDY

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Background

Nutritional supprot is a crucial aspect of the multidisciplinary management in Amyotrophic Lasteral Sclerosis (ALS) patients. The recommended method consists of enteral nutrition with PEG/RIG, however, if enteral nutrition is not feasible, parenteral nutrition is the nutritional support of choice. However, to date, parenteral nutrition is a little explored field of research in this population of patients.

Objective

To characterize home parenterale nutrition (HPN) in ALS patients in terms of survival, complications and outcomes, sorting patients by site of onset, cognitive profile and use of ventilatory support

Methods

Fifty-five patients between 2015 and 2022 with diagnosis of ALS have been included. Patients were classified according to site of onset (bulbar/spinal), cognitive phenotypes (Cognitive Normal/Cognitive Impaired) and use of ventilatory support (Not Invasive Ventilation/Invasive through tracheostomy)

Table 3:
HPN characteristics by cognitive phenotype

Cognitive status	Normal n 20	Impaired n 32	p
Time from diagnosis to HPN start days, median (range)	654 (30-3600)	435 (301440)	0.19
Survival (time from HPN start) days, median (range)	138.5 (20-544)	56 (4-409)	0.24
Complications n (%)	6 (35.3%)	10 (58.8%)	0.17

Table 4:
HPN characteristics by ventilatory support

	NIV n 44	Tracheostomy n 11	p
Time from diagnosis to HPN start days, median (range)	480 (30-3780)	720 (180-1980)	0.37
Survival (time from HPN start) days, median (range)	70 (4-544)	135.5 (17-224)	0.016
Comlications n (%)	12 (71%)	5 (29%)	0.016

Table 1: Overall HPN characteristics

HPN indications (%)	EN contraindication (20.0)/EN refusal (20.0)/ EN intolerance (16.0) /waiting for EN (6.0) / cognitive impairment (38.0)		
Time between diagnosis and HPN start	Median 480 days	Min 30 days	Max 3780 days
Survival from HPN start	Median 70 days	Min 4 days	Max 544 days

Table 2: HPN characteristics by site of onset

	Bulbar onset	Spinal onset	p
Time from diagnosis to HPN start days, median (range)	480 (30-378)	540 (30-3600)	0.41
Survival (time from HPN start)	56 (4-372)	87-5 (18-544)	0.23
Compliations n (%)	8 (47%)	9 (53%)	0.73

Results

Bulbar onset was present in 50.9% of patients and cognitive/behavioral impairment in 58.2%. Eighty-nine percent of patients showed severe dysphagia, 20% had tracheostomy. The interval between diagnosis and HPN start was shorter in bulbar onset (480 days) compared to spinal onset ones (540 days), and in patients with cognitive impairment (435 days) compared to those without (645 days). Complications were more common in the former (58.8%) and in those with bulbar onset (47%) but significantly less frequent (29%, p=0.016) in patients with invasive ventilation. Complications were CVC-relatd (infections, thrombosis, dislocation) or systemic (hyperglycemia and cholestasis).
The overall mean survival was 119 days, shorter in bulbar onset and cognitive-impaired patients (56 days) compared to spinal onset (87 days) and patients without cognitive impairment (138 days).

Conclusions

In ALS patients with cognitive and behavioural impairment, strong comorbidities, and tracheostomy, HPN is a useful nutritional support. HPN was started earlier in bulbar onset and cognitive impaired patients. Complications were more prevalent in cognitively impaired patients and less prevalent in tracheostomized patients; this may be likely related to the more intensive setting of care assistance of this subgroup. The mean survival after HPN start was shorter in bulbar onset and cognitively impaired groups, due to the fact that cognitive impaired patients less compliant to nutritional indications and treatment methods such as NIV. Moreover, a cognitive or behavioural impairment is often associated with bulbar phenotype, specifically with dysphagia.

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