

Cognitive and Behavioral Impairment may influence Shared Care Planning and Treatment Decisions in ALS: An Observational Single-Center Study

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INTRODUCTION

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disorder affecting both upper and lower motor neurons, often accompanied by cognitive and/or behavioral impairments. These non-motor symptoms can significantly affect decision-making capacity, particularly regarding consent to life-sustaining treatments. Shared Care Planning (SCP), involving collaborative decision-making between patients and clinicians, helps align treatments with patient values. However, the impact of cognitive and behavioral deficits on the SCP process remains underexplored.

This study aimed to investigate potential associations between neuropsychological impairment and treatment decisions, particularly regarding PEG/RIG and tracheostomy placement.

METHODS

We included 118 ALS patients referred to our Multidisciplinary Center (2017–2025). Patients underwent neuropsychological assessment, including the Edinburgh Cognitive and Behavioral ALS Screening (ECAS), and were invited to participate in SCP discussions per clinical practice, addressing NIV, PEG/RIG, and tracheostomy placement.

RESULTS

Patients were classified as follows: 59.3% ALS with normal cognition (ALS-NC); 22% with behavioral impairment (ALS-BI); 6.8% with cognitive impairment (ALS-CI); 5.1% with both (ALS-CBI); and 6.8% were with ALS-FTD. SCP discussions were initiated with 78% of patients. NIV was accepted by nearly all patients to whom it was proposed, while PEG or RIG was accepted by 63.9%, and tracheostomy by 17.8%. Patients who accepted PEG/RIG were more frequently female ($p=0.047$) and had significantly lower adjusted scores on the total ECAS ($p=0.027$), ALS-specific domains ($p=0.020$), verbal fluency ($p=0.012$), and semantic fluency ($p=0.042$), compared to patients who refused PEG/RIG. Acceptance of tracheostomy was more common among younger patients ($p<0.001$) and those with cognitive or behavioral impairments, showing a trend toward significance ($p=0.083$). A binary logistic regression analysis (Table), using tracheostomy acceptance as the dependent variable and age, sex, and Strong's diagnostic categories as independent variables, revealed a significant negative association with age ($p=0.002$) and with certain Strong's categories, particularly ALS-CBI ($p=0.026$).

	B	S.E.	Wald	df	p-value	Exp(B)	95% C.I. for EXP(B)
Sex	0.699	0.841	0.692	1	0.406	2.012	0.387 10.459
Age at diagnosis (years)	-0.115	0.038	9.326	1	0.002	0.891	0.828 .960
Strong categories			6.806	4	0.147		
ALS-BI	1.556	.857	3.294	1	0.070	4.738	0.883 25.416
ALS-CI	3.090	1.620	3.641	1	0.056	21.983	0.919 525.680
ALS-CBI	2.573	1.191	4.671	1	0.028	13.109	1.271 135.228
ALS FTD	-17.392	26977.523	0.000	1	0.999	0.000	0.000 .
Constant	4.109	1.976	4.326	1	0.038	60.883	

CONCLUSION

Cognitive and behavioral impairments in ALS may affect patients' willingness to undergo invasive treatments. We emphasize the need to account for cognitive deficits and to investigate the decision-making process using validated tools in this population.



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