

CONFERENCE ABSTRACT

Augmentative and Alternative Communication Systems in Amyotrophic Lateral Sclerosis: Applicability and Utility in Patients, Caregivers and Healthcare Professionals

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Introduction:

The Augmentative and Alternative Communication Systems are essential for improving the quality of life of people with communication issues, like the ALS patients. Being an incurable neurodegenerative disease, from which motor skills progressively deteriorate, causing physical, emotional, and psychological suffering, the continuous accompaniment from Palliative Care becomes fundamental. The ability to communicate through speech, handwriting or electronic devices is compromised in these patients. The reduced number of studies on different communication means and its utility, not only for patients, but for caregivers and healthcare professionals too, made this investigation meaningful.

Aims:

This study has the main objective of identify the applicability and utility of Augmentative and Alternative Communication Systems from the patients, caregivers and healthcare professionals perspective.

Methodology:

The sample includes 40 patients, 38 caregivers and 19 health professionals in the area of Amyotrophic Lateral Sclerosis. For data collection, the ALSFRS-R functional evaluation scale was applied to the patients, as well as three distinct inquiries for the patients, caregivers and healthcare professionals. The investigation was performed on Associação Portuguesa de Esclerose Lateral Amiotrófica and Hospital de Santo António – Centro Hospitalar e Universitário do Porto. Ethical and formal procedures were abided by, acquiring the institutional clearances and the informed consent of the study participants.

Results and conclusions:

The results showed that the utility perception of Augmentative and Alternative Communication Systems is elevated. It was noticed that there are main factors for a higher systems utility. Still, the knowledge on this subject is diminished, showing the need for a greater theme consciousness.