

Dietetic Practice and Education

Perceptions of nutrition interventions in individuals with Amyotrophic Lateral Sclerosis (ALS)

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Introduction: Amyotrophic Lateral Sclerosis (ALS) is an idiopathic and fatal degenerative disease of the motor neurons. Current literature lacks research on perceptions of nutrition interventions and priorities of care of individuals with ALS.

Objectives: The goal of this study was to determine the perceptions of individuals with ALS and their caregivers regarding nutrition interventions in ALS.

Methods: The research team developed 75 survey questions regarding the nutritional management of ALS. The SurveyMonkey® platform was used to host the survey. The questions were separated into two streams, one for individuals with ALS and one for their direct caregivers. Recruitment took place in February, 2021. An email containing the survey was sent to 37 attendees of the ALS clinic at Saskatoon City Hospital and was posted to the ALS Society of Saskatchewan's Facebook page. Data was analyzed using descriptive statistics and qualitative content analysis.

Results: Twelve respondents participated in the study. The majority of respondents (83.3%) were individuals with ALS between the ages of 39 and 75 years (mean: 64.3 years). Caregivers (16.7%) were between the ages of 42 to 47 years (mean: 44.5 years). The present study found nutrition was important to individuals with ALS and there was interest in trying diets and supplements for the management of ALS. Seventy percent of respondents had concerns involving nutrition. When asked if respondents would recommend consulting with a dietitian upon being diagnosed with ALS, 100% responded yes.

Conclusion: The findings suggest that individuals with ALS value consulting with a dietitian for nutrition management. It is concluded that dietitians are instrumental in the management of ALS by providing individualized support and education regarding nutrition interventions such as tube feeding and supplementation.

Significance: The results of this study suggest that increasing the accessibility of dietitians could positively impact the care of those diagnosed with ALS.