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The nutritional management of people living with Amyotrophic Lateral Sclerosis (ALS): a cross-sectional survey of UK Dietitians'

S. White¹, N. Zarotti², D. Beever³, M. Bradburn³, P. Norman⁴, E. Coates³, T. Stavroulakis², D. White², A. McGeachan², I.A. Williams⁴, G. Hackney³, V. Halliday³, and C. McDermott² on behalf of the HighCALS research group.

¹ Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, S10 2JF, UK.

² Sheffield Institute for Translational Neuroscience (SITraN), The University of Sheffield, Sheffield, S10 2HQ, UK.

³ School of Health and Related Research (ScHARR), The University of Sheffield, Sheffield, S1 4DA, UK.

⁴ Department of Psychology, The University of Sheffield, Sheffield, S1 2LT, UK.

People living with Amyotrophic Lateral Sclerosis (pwALS) face many challenges to taking adequate nutrition and hydration (1). Reduced dietary intake, combined with raised resting energy expenditure (REE) (2), contribute to the high prevalence of malnutrition in ALS (3), with low BMI and weight loss being independent prognostic indicators of survival (4). There is a lack of evidence focusing on the nutritional management of people living with ALS.

This study reports the responses of UK dietitians to a survey exploring the nutritional management of pwALS. The survey was distributed online using snowball sampling technique between September and November 2018.

Of the 130 dietitians responding to the survey, 87% were currently providing dietetic care to pwALS. Dietitians most frequently reported (66%) that pwALS formed 20% of their total patient caseload. Less than half (42%) of dietitians reported that nutritional screening took place in their organisation and 44% reported referrals were made too late. With regards nutritional assessment, the majority (83%) used predictive equations for resting energy expenditure (REE) not validated in ALS. Most dietitians (91%) reported that they would set a weight gain goal for pwALS with a BMI under 18.5kg/m². However, only 28% reported that they would set a weight gain goal for those with a BMI between 18.5 and 25.0, and none would do so for those with a BMI greater than 25kg/m², instead recommending weight maintenance or even weight loss. Only 23% of dietitians reported that the 'food first' approach was effective in ALS. Most dietitians (43%) reported that pwALS were not weighed frequently enough.

The reported lack of nutritional screening and late referral for dietetic input may result in the risk factors associated with malnutrition in ALS not being identified in a timely way. Reliance on estimates of REE not validated for pwALS and setting conservative weight goals may not be in line with the current evidence base. Further research is required to better understand the optimal nutritional management in ALS and the development of nutritional interventions to improve outcomes for pwALS.

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