

This is a repository copy of CMS-55 Development of the OptiCALS nutritional support intervention for people with amyotrophic lateral sclerosis.

White Rose Research Online URL for this paper: https://eprints.whiterose.ac.uk/183022/

Version: Published Version

Proceedings Paper:

White, S., Baird, O., Beever, D. orcid.org/0000-0001-9063-3677 et al. (9 more authors) (2021) CMS-55 Development of the OptiCALS nutritional support intervention for people with amyotrophic lateral sclerosis. In: Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. 32nd International Symposium on ALS/MND, 07-10 Dec 2021, Virtual conference. Taylor & Francis , pp. 232-233.

https://doi.org/10.1080/21678421.2021.1985802

© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group, on behalf of the Research Group on Motor Neuron Diseases and the World Federation of Neurology. Abstract available under the terms of the CC BY License (http://creativecommons.org/licenses/by/4.0).

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here: https://creativecommons.org/licenses/

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.







Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/iafd20

Theme 12 - CLINICAL MANAGEMENT, SUPPORT AND INFORMATION

To cite this article: (2021) Theme 12 - CLINICAL MANAGEMENT, SUPPORT AND INFORMATION, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 22:sup2, 202-233, DOI: 10.1080/21678421.2021.1985802

To link to this article: https://doi.org/10.1080/21678421.2021.1985802

6 © 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group, on behalf of the Research Group on Motor Neuron Diseases and the World Federation of Neurology.



Published online: 17 Nov 2021.

	Submit your article to this journal	ľ
--	-------------------------------------	---

Article views: 405



💽 View related articles 🗹

View Crossmark data

combination to predict FVC by evaluating the correlations of different combinations of ABG parameters (carbon dioxide, pCO₂; carbonate, HCO₃⁻) and respiratory symptoms (dyspnea and orthopnea were present if ALSFRS-r items 10 and 11 were <4, respectively) with FVC. Patients were grouped into 3 groups according to ABG values (group 1: normal ABG; group 2: either pCO₂ or HCO₃⁻ increased; group 3: both pCO₂ and HCO₃⁻ increased), to compare clinical features between patients with and without respiratory symptoms. For a proper comparison, general impairment was evaluated by ALSFRS-r score without the respiratory domain (ALSFRS-r36) and thus, disease progression rate as Δ ALSFRS36.

Results: The best combination to predict FVC was: $pCO_2 + HCO_3^- + ALSFRS-r$ item 10 (R = 0.430, p < 0.001). In all groups patients with dyspnea showed a more severe general impairment, a higher disease progression rate and lower FVC values. Patients with normal ABG complaining of dyspnea had a reduced survival in comparison with patients without dyspnea (0.91 years, IQR 0.46–1.91 vs 1.46 years, IQR 0.89–2.29, p = 0.002). Cognitive dysfunction did not influence the complaining of dyspnea (OR 1.009, 95% CI 0.837–1.215, p = 0.927). Among all groups patients with normal ABG and dyspnea showed the highest progression rate (fast progressors; $\Delta ALSFRS36 = 0.86$, IQR 0.44–1.25); on the other side, patients not complaining of dyspnea despite having a respiratory failure at ABG had the lowest progression rate (slow progressors; $\Delta ALSFRS36 = 0.38$, IQR 0.26–0.52).

Discussion: The ability of ABG to predict FVC increases by adding the clinical evaluation of dyspnea. At equal ABG values, the complaining of dyspnea is associated with lower FVC values. The presence of dyspnea differs according to disease phenotypes, being more frequently experienced by patients with a worse motor impairment and a faster disease progression. A close respiratory monitoring should be set up for fast progressors complaining of dyspnea to look for an initial diaphragm weakness and for slow progressors even without dyspnea because they could show a respiratory failure at ABG.

Conclusions: Combining ABG with clinical evaluation of dyspnea improves the ability to assess early respiratory dysfunction in ALS, especially in patients with bulbar or cognitive impairment.

amariaclaudia.torrieri@gmail.com

Reference

1. Manera U, Torrieri MC, Moglia C, et al. JNNP. 2020;91(9): 999–1000.

CMS-55 Development of the OptiCALS nutritional support intervention for people with amyotrophic lateral sclerosis

S. White¹, W. Baird², D. Beever², L. Brading², E. Coates², G. Hackney², H. Hartley², A. Quinn³, T. Stavroulakis², D. White², P. Norman² and C. McDermott²; On behalf of the HighCALS group ¹Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, United Kingdom; ²University of Sheffield, Sheffield, United Kingdom; ³Sheffield Motor Neurone Disease Research Advisory Group, Sheffield, United Kingdom

Background: Weight loss is common in people with Amyotrophic Lateral Sclerosis (pwALS) and is a predictor of poor outcomes (1). There is encouraging evidence that increasing calorie intake may affect disease progression (2). Significant variability has been identified in the provision of nutritional management of pwALS across the UK (3). There is a need for evidence-based nutrition support interventions to improve the outcomes of pwALS.

Objective: To develop a complex nutrition support intervention to support pwALS to increase their calorie intake.

Methods and Results: A Portal Development Group (PDG), including academics, healthcare professionals (HCPs), webdevelopers and public involvement representation were tasked with developing an online portal to provide a personalised experience to pwALS including presenting individualised feedback on calorie intake and weight, and information on nutrition support strategies.

The online nutritional analysis software, myfood24, was integrated into the portal, allowing an individuals' calorie intake to be presented in real time. Intervention content was based on systematic reviews and interviews with pwALS, carers and HCPs identifying the key enablers and barriers to increasing calorie intake in pwALS, using the COM-B model as an overarching theoretical framework. These were then targeted by specific behaviour change techniques in the intervention. The intervention was developed through a series of 'think aloud' interviews with pwALS, carers and HCPs, across six iterations. The PDG made changes to the intervention between each iteration, in response to the feedback received. The online portal was further developed with three rounds of user testing, involving pwALS and their carers engaging with the portal for one month following being trained by HCPs. All participants and HCPs taking part in the user testing were interviewed, with their feedback being used to further refine the portal and training. The final portal, named OptiCALS, is now being evaluated in a multi-centre randomised controlled trial.

Discussion: The development of an online complex nutritional intervention requires significant time and resources. An iterative process of 'develop-test-listen-refine-repeat' involving effective communication with key stakeholders at all stages, is essential in helping to establish an intervention's acceptability and feasibility.

sean.white@sheffield.ac.uk

Acknowledgements

This project is funded by the National Institute for Health Research (NIHR) Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-1016-20006).

References

- Desport J, Preux P, Truong T, et al. Nutritional status is a prognostic factor for survival in ALS patients. Neurology. 1999;53:1059–63.
- 2. Dupuis L, Oudart H, René F, et al. Evidence for defective energy homeostasis in amyotrophic lateral sclerosis: benefit of a high-energy diet in a transgenic mouse model. Proc Natl Acad Sci USA. 2004;101(30):11159–64.
- Halliday V, Zarotti N, Coates E, et al. Delivery of nutritional management services to people with amyotrophic lateral sclerosis (ALS). Amyotroph Lateral Scler Frontotemporal Degener. 2021;1–10.