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Citation for published version:

Newton, J, Jayaprakash, K, Glasmacher, SA, Mceleney, A, Bethell, A, Fraser, E, Hatrick, J, Haagenrud, H, Stott, G, Dakin, R, Chandran, S & Pal, S 2020, 'Excellent reliability of the ALSFRS-R administered via videoconferencing: A study of people with motor neuron disease in Scotland', *Journal of the Neurological Sciences*, vol. 416, pp. 116991. <https://doi.org/10.1016/j.jns.2020.116991>

Digital Object Identifier (DOI):

[10.1016/j.jns.2020.116991](https://doi.org/10.1016/j.jns.2020.116991)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

Journal of the Neurological Sciences

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Letter to the Editor

Excellent reliability of the ALSFRS-R administered via videoconferencing: A study of people with motor neuron disease in Scotland



ARTICLE INFO

Keywords:

Motor neuron disease
Amyotrophic lateral sclerosis
Tele-health
Videoconferencing
ALSFRS-R

Dear Editor,

Introduction

Motor neuron disease is characterised by progressive weakness and disability, meaning that travel to specialist MND care and research participation can quickly become difficult. Many pwMND, particularly those living in remote areas, face troublesome commutes to access care and to participate in research. Travel-related restrictions have been shown to impact on attrition in clinical trials [1] and are likely to contribute to drop-out of clinic-based assessment.

By improving accessibility, reducing costs and mitigating geographical distances, videoconferencing has the potential to improve clinical care for pwMND, increase retention in clinical trials and capture a more diverse cohort of pwMND [2].

Our aim is to enhance the incorporation of telehealth in research and clinical care by demonstrating that the amyotrophic lateral sclerosis functional rating scale (ALSFRS-R), a frequently used clinical instrument, can be reliably administered using videoconferencing. We also hope to show that videoconferencing has additional advantages over telephone-based assessments; for example, facilitating non-verbal communication and supporting pwMND with bulbar impairment to communicate remotely by typing free text. The ALSFRS-R can be reliably administered face-to-face or via telephone [3,4] but administration via videoconferencing has not been investigated.

We completed a service evaluation to determine the reliability of videoconferencing-based administration of the ALSFRS-R by comparing it to face-to-face administration. To distinguish between inter-rater and inter-method reliability, we assessed inter-rater reliability separately by comparing ALSFRS-R scores between videoconferencing assessments by different raters.

Methods

We recruited a convenience sample of pwMND between August 2018 and August 2019, residing in mainland Scotland and remote islands, with a range of disability. Participants were recruited from the

Scottish MND register, the Clinical Audit Research and Evaluation of MND (CARE-MND) platform. One group of participants completed assessments with the ALSFRS-R via face-to-face appointments and videoconferencing ($n = 20$) and another group completed videoconferencing assessments scored by two independent raters ($n = 20$); two participants underwent both. Face-to-face and videoconferencing administration of the ALSFRS-R occurred within a 15-day period and were performed by different raters. Raters used the European Network to Cure ALS (ENCALS) standards for administration [5]. Videoconferencing was undertaken via the NHS Attend Anywhere platform (attendanywhere®), which is approved for use by NHS Scotland. Participants views on the use of videoconferencing were also ascertained in a subset of participants ($n = 20$).

Statistical analysis

Internal consistency of ALSFRS-R was determined using Cronbach's coefficient alpha. Inter-rater and inter-method reliability were assessed using a two-way random effects model with single measures for absolute agreement (ICC) and graphically displayed using a Bland-Altman plot. The minimal detectable change (MDC) was calculated as follows: $MDC = 1.96 \times SD \times \sqrt{(1 - ICC) \times 2}$.

Effect measures are displayed with 95% confidence intervals (CIs) and summary statistics as mean and standard deviation (SD) or median and interquartile range (IQR). Analysis was undertaken in SPSS (version 25).

Results

38 pwMND were included. All had ALS, 81.6% (31/38) were male, mean age was 62.6 years ($SD \pm 12.2$). 81.6% had spinal onset (31/38) and 18.4% (7/38), had bulbar onset. The mean ALSFRS-R was 30.6 ($SD 13.0$, range 0–45).

There was excellent reliability and internal consistency in ALSFRS-R scores between videoconference and face-to-face administration by two independent raters (ICC = 0.99, 95%CIs 0.99, 0.99; Cronbach's alpha = 0.99, Fig. 1). The limits of agreement were ± 3 and the MDC

<https://doi.org/10.1016/j.jns.2020.116991>

Received 7 May 2020; Received in revised form 1 June 2020; Accepted 13 June 2020

Available online 21 June 2020

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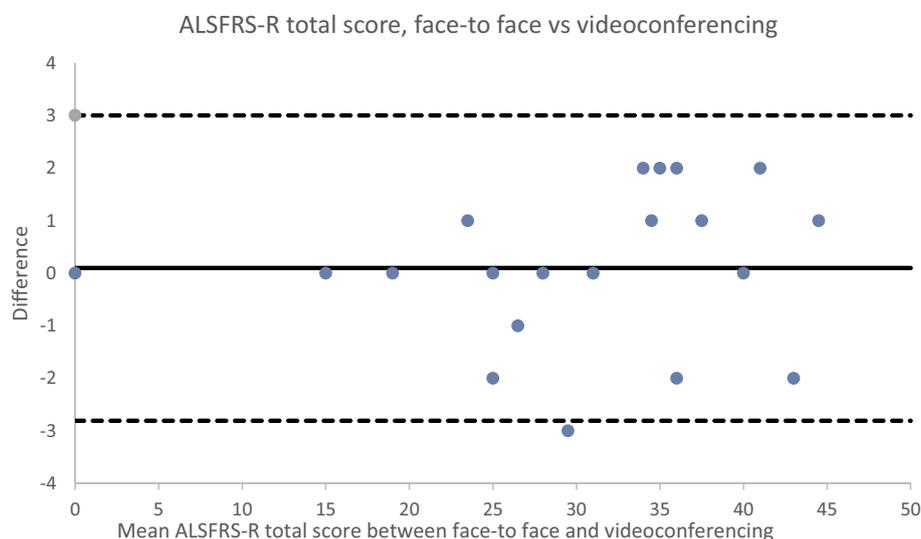


Fig. 1. Bland-Altman plot for face-to-face vs videoconferencing administration of ALSFRS-R.

was 3.6, that is, the smallest change in ALSFRS-R score that is not due to chance. Assessments took place within a median of 0 days (IQR 0–6). The inter-rater reliability and internal consistency between videoconferencing administration of ALSFRS-R by two independent raters was also excellent (ICC = 0.99, 95% CI 0.99, 0.99; Cronbach's alpha = 0.99).

Two participants utilised Eyegaze® software in conjunction with their PC and participated in ALSFRS-R scoring by typing responses in the chat box through the videoconferencing software.

90% (18/20) of pwMND described the set up as simple and 85% (17/20) rated the call quality as “good” or “excellent”; none felt that any disruption adversely affected the consultation. Participants positively commented on the convenience, reduction in travel time and flexibility of timing and location associated with videoconferencing. All participants were keen to use videoconferencing for future consultations although 35% (7/20) wished to continue face-to-face consultations.

Discussion

Our results support the incorporation of videoconferencing-based ALSFRS-R assessments into research and clinical practice. By reducing burden of participation, telehealth facilitates involvement in trials by pwMND who may not otherwise be able to participate, for example, those with severe disability and those living remotely. A recent telehealth versus usual care trial reports that several commonly identified barriers to research participation, time, fatigue and the impact of research on day-to-day life, were not an issue for the pwMND allocated to the telehealth group. The investigators recommended telehealth as a cost-effective and low-burden tool for collection of outcome measures [2].

In keeping with our findings, previous feasibility studies report that pwMND have a positive attitude towards videoconferencing and enjoy working with technology [6]. Moreover, videoconferencing was found to contribute to a sense of increased enablement amongst pwMND [7]. It enables local therapists [8] and relatives living separately to attend the consultation. Compared to telephone consultations, videoconferencing offers several practical advantages for pwMND: We found that the ability to type free text improved the ease of communication for pwMND with bulbar impairment and that people using assistive communication devices were able to use the chat facility in conjunction with their devices. Alternatively, one might consider a self-administered version of the ALSFRS-R, which was found to be highly reliable [9].

Despite the multitude of benefits associated with videoconferencing consultations, participants in this study felt that face-to-face consultations remain an important part of their care. Others reported that pwMND did not feel comfortable discussing sensitive topics, such as end-of-life care, via videoconferencing [8] or commented on the lack of “touch” [10].

In conclusion, ALSFRS-R administered through videoconferencing is reliable and has the potential to reduce burden of clinical reviews for pwMND and increase engagement and retention in clinical trials. Videoconferencing has additional advantages over telephone-based assessments by allowing pwMND with bulbar impairment to type free text. Nonetheless, face-to-face assessment remains an important component of clinical care.

Funding statement

Funding for this project was provided by the Anne Rowling Regenerative Neurology Clinic.

Ethical approval

Ethical approval for CARE-MND was provided by the South East Scotland Research Ethics Committee (Approval: 15/SS/0126). The CARE-MND ethics approval includes cover for prospective collection of routine clinical data including ALSFRS-R. The satisfaction with videoconferencing study was a quality improvement project and did not require ethical approval.

Declaration of Competing Interest

The authors declare that there are no conflicting interests.

Acknowledgements

S.C. is supported by the Euan MacDonald Centre and the UK Dementia Research Institute (DRI), which receives its funding from UK DRI Ltd., funded by the MRC, Alzheimer's Society and Alzheimer's Research UK.

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