Theme 12 Cognitive and Psychological Assessment and Support

COG-01 Screening for cognitive and behavioural change in amyotrophic lateral sclerosis/motor neuron disease: a systematic review of validated screening methods

N Simon¹, LH Goldstein²

¹School of Medical Education, ²Institute of Psychiatry, Psychology and Neuroscience; King’s College London, London, United Kingdom

Email address for correspondence: laura.goldstein@kcl.ac.uk

Keywords: cognitive impairment, behavioural impairment, screening tests

Background: Cognitive and behavioural change in Amyotrophic Lateral Sclerosis (ALS) is now well accepted. Several screening tools have been developed to aid in the detection of cognitive and/or behavioural change. Further guidance on their use may come from a consideration of the rigour in how they were validated.

Objective: This systematic review set out to critically appraise and present published data pertaining to the validation of six screening tools used to diagnose cognitive and behavioural change in patients with ALS. The screening tools included in this search included: The Edinburgh Cognitive and Behavioural ALS Screen (ECAS), The ALS Cognitive Behavioural Screen (ALS-CBS), The Motor Neurone Disease Behavioural Scale (MiND-B), The Frontal Behavioural Inventory ALS Version (FBI-ALS), The ALS Frontotemporal Dementia Questionnaire (ALS-FTD-Q) and The Beaumont Behavioural Inventory (BBI).

Methods: MEDLINE, EMBASE and PsycINFO were searched from inception until 3rd week of June 2017 with restrictions placed to only include studies in the English language. Included studies presented data on convergent validity and clinical validity. Study methodology was assessed on the basis of three domains. The first domain assessed was patient selection and representativeness of the general ALS population, as determined from published patient demographics. The blinding of the study was the second domain assessed. For a study to be blinded, those conducting the screening tool must have known the results of the neuropsychological battery or the patient’s diagnosis as per diagnostic criteria. The third domain determined whether validation was undertaken against a gold-standard neuropsychological battery or other diagnostic measures/criteria.

Results: The electronic search of MEDLINE, EMBASE and PsycINFO yielded 171 studies after limits were applied to studies in the English language and duplicates were removed. After screening, 14 eligible studies were included in the review. Papers generally either reported data concerning convergent validity or clinical validity. One measured concurrent validity. Clinical validity measures were presented in the form of data on sensitivity, specificity, positive predictive values (PPVs) and negative predictive values (NPVs). Convergent validity was reported using Pearson or Spearman correlation coefficients. The ECAS was validated in 35.7% of the studies, the ALS-CBS was validated in 21.4% of the studies and the ALS-FTD-Q, MiND-B and BBI were validated in the remaining 42.9% of the studies. No studies presented validation data of the FBI-ALS screening tool.

Conclusion: The ECAS and ALS-CBS may have strong clinical utility, although further work is needed to consider how their use will affect diagnosis according to current diagnostic guidelines. When screening for behavioural change only, it appears the BBI is more sensitive than the ALS-FTD-Q for mild impairment. Scores of sensitivity, specificity, PPV and NPV should be given considerable importance when considering which screening tools to incorporate into current clinical practice.

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COG-02 It’s NICE to ECAS: the impact of training health professionals to identify cognitive and behavioural change in ALS/MND

F Hodgins¹, S Bell², S Abrahams¹

¹University of Edinburgh, Edinburgh, United Kingdom, ²Motor Neurone Disease Association, Nationwide, United Kingdom

Email address for correspondence: faith.hodgins@ed.ac.uk

Keywords: cognitive/behavioural impairment, ECAS, training

Background: In the UK, the National Institute for Health and Care Excellence (NICE) guidelines for the assessment and management of MND recommend assessing patients for cognitive and behavioural change. The Edinburgh Cognitive and Behavioural ALS Screen (ECAS) is a multi-domain brief assessment developed for use by both neuropsychology and non-neuropsychology health professionals (1). This study of the impact of ECAS training forms part of a wider project, aiming to develop pathways to cognitive and behavioural screening for pwALS/MND.

Objectives: To deliver an ENCALS-certified ECAS masterclass to >250 healthcare professionals (HCPs) in
the UK throughout 2017 and to evaluate the impact of the ECAS masterclass on HCPs’ knowledge of (i) cognitive and behavioural changes in MND and (ii) the ECAS. HCPs’ willingness to implement the tool.

Methods: A 1-day masterclass, advertised by the MND Association, took place in 9 UK locations. It was open to registered HCPs involved in the management of people with ALS/MND and included; a talk on cognition and behaviour change in ALS/MND and the development of the ECAS tool, an ECAS role play, a discussion of case studies and implementation of the ECAS in local contexts and a video-based competency task.

Trainees took a short pen-and-paper knowledge-based assessment at the start and end of the day. At the end of the training, an evaluation form was distributed which invited HCPs to indicate on a 5-point scale how confident they felt in administering the ECAS. The form also asked what they would take back to practice as a result of attending. Data from the knowledge assessment and evaluation forms were analysed descriptively.

Results: At the time of writing, pre- and post-training scores show increased knowledge of (i) cognition and behaviour change in MND and (ii) the ECAS tool. More than 70% of HCPs self-reported feeling either quite confident or extremely confident in using the ECAS by the end of the masterclass. HCPs also reported a desire to share the knowledge with their wider team and to implement the ECAS tool in their practice.

Discussion and conclusion: The masterclass was effective at increasing HCPs’ background knowledge and confidence in using the ECAS. We expect the training to facilitate development of new pathways to cognitive/behavioural screening for pwMND in the UK. Further research will evaluate the impact of the ECAS assessment on care pathways and patients’ lives.

Acknowledgments: This project was funded by the Motor Neurone Disease Association.

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COG-03 A new eye-tracking based measure of cognitive flexibility in amyotrophic lateral sclerosis

B Poletti1, L Carelli1, F Solca1, A Lafronza1, E Pedrol1, N Ticozzi1, P Meriggi1, P Cipresso2, G Riva2, A Faini6, S Abrahams7, V Silani1,3

1Department of Neurology and Laboratory of Neuroscience, 2Applied Technology for Neuropsychology Lab: IRCCS Istituto Auxologico Italiano, Milan, Italy, 3Department of Pathophysiology and Transplantation, ‘Dino Ferrari’ Center, Università degli Studi di Milano, Milan, Italy, 4ICT and Biomedical Technology Integration Unit, Centre for Innovation and Technology Transfer (CITT), Fondazione Don Carlo Gnocchi Onlus, Milan, Italy, 5Department of Psychology, Università Cattolica del Sacro Cuore, Milan, Italy, 6Department of Cardiovascular, Neural and Metabolic Sciences - IRCCS Istituto Auxologico Italiano, Milan, Italy, 7Euan MacDonald Centre for Motor Neuron Disease Research, Anne Rowling Regenerate Neurology Clinic, Centre for Cognitive Ageing and Cognitive Epidemiology, Human Cognitive Neuroscience-PPLS, University of Edinburgh, Edinburgh, United Kingdom

Email address for correspondence: b.poletti@auxologico.it

Keywords: cognitive assessment, eye-tracker, executive functions

Background: A consistent body of evidence supports the presence of executive deficits in patients with Amyotrophic Lateral Sclerosis (ALS). Such cognitive changes are also recognized as a relevant factor influencing the disease management and progression. However, standardized neuropsychological measures are often not feasible along the course of the disease, due to progressive physical disability.

Objectives: We present clinical data about a newly-developed measure of cognitive flexibility, administered by means of Eye-Tracking (ET) technology in order to bypass verbal-motor limitations. Relationship with other validated standard measures and with a recently proposed oculomotor driven neuropsychological battery have been analyzed, together with sensitivity in discriminating between ALS patients and healthy controls.

Methods: 21 ALS patients and 21 age- and education-matched healthy participants underwent an ET-based cognitive assessment, including a newly-developed test of cognitive flexibility (Arrows Cognitive Test – ACT) and other oculomotor driven measures of cognitive functions. A standard screening of frontal and working memory abilities and global cognitive efficiency (Frontal Assessment Battery – FAB, Digit Sequencing Task; Montreal Cognitive Assessment – MoCA) was also administered, together with a psychological self-rated assessment. For patients, a clinical examination was also performed.

Results: ACT discriminated between patients and controls, mainly concerning execution times obtained at different sub-tests (ACT-1, ACT-2, ACT-4: \( p < 0.05 \)); a tendency towards a significant difference in ‘number of correct responses’ was observed for the last ACT trial, with lower scores in patients (ACT-4: \( p = 0.06 \)). A qualitative analysis performed on errors distribution in patients highlighted a lower prevalence of perseverative errors, with respect to other type of errors. Limited correlations were observed between ACT and standard ‘paper and pencil’ cognitive tests; correlations between ACT and other ET-based frontal-executive measures were significant and mainly regarded execution times.
Discussion and conclusion: The newly-developed ET-based measure of cognitive flexibility could provide a useful tool to detect slight frontal impairments in non-demented ALS patients, bypassing verbal-motor limitations according to the oculomotor driven administration. Sensitivity and validity components of the developed approach needs further evaluations with a larger sample of patients.

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COG-04 Apathy in ALS in the context of depression or FTD – a clinical evaluation

M Wüst, J Keller, HEA Aho-Özhan, I Uttner, AC Ludolph, D Lulé

University of Ulm, Ulm, Germany

Email address for correspondence: dorothee.lule@uni-ulm.de

Keywords: cognition, apathy, FTD

Background: There is vast evidence for clinical, genetic and pathophysiological associations of amyotrophic lateral sclerosis (ALS) and fronto-temporal dementia (FTD). Apathy is the most clinically reported behavioural alteration in ALS to be associated with FTD. However, apathy is also a clinical hallmark of affective disorders in the sense of depression which may involve in the course of ALS, especially shortly after diagnosis in the sense of reaction to the fatal news. The goal of the study was to investigate apathy in a subset of patients and to determine its association with either behavioural alteration in the sense of FTD or in the sense of an adjustment disorder.

Methods: In total, we included 88 subjects, of which 59 had the clinical diagnosis of ALS according to revised El Escorial criteria and nine received the clinical diagnosis of ALS-FTD. Additionally, 20 healthy subjects were included. Depression was determined with the ALS depression inventory 12 items (ADI 12) and the oculomotor driven administration. Apathy was determined using the apathy evaluation scale (AES). Signs of FTD were reported by caregivers using the Rascovsky criteria checklist and the behaviour checklist of the Edinburgh Cognitive and Behavioral ALS Screen (ECAS). Additionally, cognitive alterations were determined with the ECAS.

Results: Apathy was a clinical feature of both depression and FTD. Depressive symptoms explained 19% of variance in apathy. Behavioural alterations in the sense of FTD explained 23%. Furthermore, caregivers reported more frequently apathy to be present in ALS than became evident from the AES.

Conclusion: Apathy does not necessarily have to be associated with FTD in ALS. Instead it can be regarded in the context of an affective disorder. An affective disorder can evolve in the sense of adjustment disorder, especially in the first year after diagnosis, as known from previous research. Further longitudinal analysis is warranted to disentangle apathy, either in the context of passage reactive depression or in the context of progressive neurodegenerative disorder in the sense of FTD.

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COG-05 Wechsler measures of reasoning correlate with interpretation of emotional expressions and to family rating of change in apathy and executive functioning in the FTD prodrome

C Flaherty, A Hotz, K Slinkard, J Kraft, A Marino, Z Simmons

Penn State College of Medicine, Hershey, PA, USA

Email address for correspondence: cflahertycraig@gmail.com

Keywords: executive functioning, abstract reasoning, behavioral decline

Objectives: Similarities as a measure of abstract reasoning is recognized to associate in bvFTD with right anterior cingulate, right middle frontal and left superior frontal decline. We previously evidenced a relationship between Similarities and greater cognitive decline in female ciALS patients of low estrogen status. Our goal was to determine whether Similarities and Comprehension performance correlated with performance on a measure of interpretation of emotional expressions and with family ratings of behavioral change, as defined by the Frontal Systems of Behavior (FrSBe).

Methods: We administered a comprehensive neuropsychological assessment battery comprised of language and executive functioning measures, as well as the FrSBe, to a group of combined motor neurone disease (n=9) and non-motor neurone disease (n=20) patients. We applied 2-tailed Pearson correlations to evaluate the relationships between Wechsler Similarities and Comprehension and Guilford Expression Grouping, as well as FrSBe Index scores for Apathy, Disinhibition and Executive Dysfunction.

Findings: Significant positive correlations were found between both Similarities (p=0.002) and Comprehension (p=0.004) in comparison to Guilford Expression Grouping. Significant negative correlations were also found between Comprehension and the FrSBe post-illness Index T-scores for Apathy (p=0.023) and Executive Dysfunction (p=0.05). Trends were found for negative correlations between Similarities and the FrSBe post-illness Index T-scores for Apathy and Executive Dysfunction.
Conclusions: Findings support a relationship between the verbal reasoning measures of Similarities and Comprehension and recognized markers of behavioral change in emerging FTD, in both the presence and absence of motor neurone disease.

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COG-06 Use of coping strategies in motor neurone disease/amyotrophic lateral sclerosis: association with demographic and disease-related characteristics

D Schlüter1, R Mills2, C Young2–3, TONiC Study Group2

1Lancaster University, Lancaster, United Kingdom, 2Walton Centre NHS Trust, Liverpool, United Kingdom, 3University of Liverpool, Liverpool, United Kingdom

Email address for correspondence: d.schlueter@lancaster.ac.uk

Keywords: coping, quality-of-life, TONiC

Background: Coping has been shown to be inversely associated with anxiety, depression and social withdrawal in MND patients, which in turn have effects on quality-of-life (1). Understanding the use of coping strategies and which factors are predictors of strategy utilisation can help clinical staff support individuals to access coping strategies that lead to better psychosocial adjustment to MND.

Objective: To assess coping strategy use in the MND population and to examine associations of demographic and clinical characteristics with individual coping strategies.

Methods: In total, 233 participants with MND were recruited into the ongoing Trajectories of Outcomes in Neurological Conditions (TONiC) study from MND clinics across the United Kingdom. Participants completed a questionnaire pack collecting data on demographics and a range of patient reported measures including the Coping Orientations to Problems Experienced (COPE60) scale. Relationships between demographic and clinical characteristics and coping strategies were examined by multiple ordinal logistic regression with cumulative logits, to examine the effect of each potential predictor after adjustment for other possible covariates. Statistical significance was assessed with the Wald test and a threshold for significance of \( p < 0.05 \).

Results: The most commonly used strategy was Acceptance, with 79% of the individuals endorsing the usage with six or more on a scale from 0–12 and 16% endorsing it with 12. This is followed by Active Coping, Planning and Positive Re-interpretation and Growth. The least used strategies were Substance Use, which 82% endorsed with 0, Turning to Religion and Denial. Ten out of the 15 strategies showed significant associations with demographic and clinical characteristics. Most markedly, females were found to utilise certain strategies more than males. This was the case for Restraint (cumulative odds ratio (OR): 1.91 (1.13, 3.22)), Seeking Instrumental Social Support (OR: 1.99 (1.19, 3.31)), Seeking Emotional Social Support (OR: 2.52 (1.39, 3.88)), Focus on and Venting of Emotions (OR: 2.89 (1.71, 4.89)), Behavioural Disengagement (OR: 2.16 (1.28, 3.66)) and Mental Disengagement (OR: 2.55 (1.50, 4.32)). Other factors that were found to be associated with coping strategy use, although with smaller effect sizes, were functional deficits as captured by the ALSFRS-R bulbar and motor domains, as well as age and marital status.

Conclusion: Clinical staff should be aware of several disease and demographic characteristics that predict use of potentially maladaptive coping strategies or the under-utilisation of coping strategies that may lead to better psychosocial adjustment.

Acknowledgements: We thank our participants for their contribution, and the Motor Neurone Disease Association (UK) and NIHR for support.

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COG-07 Empathy and trust among people with MND sharing information, experiences and emotions in an online discussion forum

S Hargreaves1, P Bath1, S Duffin1, J Ellis1, M Lovatt2

1University of Sheffield, Sheffield, United Kingdom, 2University of Stirling, Stirling, United Kingdom

Email address for correspondence: p.a.bath@sheffield.ac.uk

Keywords: trust, empathy, online discussion forum

Background: There are increasing opportunities for people with Motor Neurone Disease (MND) to seek and share information, experiences and knowledge online. Whilst some studies have focussed processes of information exchange within online forums (1), the processes of information sharing and experience have received little attention. The role of trust and empathy in mediating sharing within an illness-based context is under-researched (2).

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1. Gibbons C, Thornton E, Ealing J, et al. Amyotroph Lateral Scler Frontotemporal Degener. 2013;14(7–8): 537–45.

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Objective: The aim of this research was to explore the experiences and perceptions of people with MND who use the MND Association online forum and to examine the meaning of trust and empathy within the forum.

Methods: We utilised a qualitative methodology to thematically analyse a sample of 54 threads and three message boards from the MND Association forum and semi-structured interviews with five forum-users living with MND.

Results: Interactions within the forum are influenced by experiences within the real world. This lived experience informed perceptions about whether the forum could be trusted initially and through ongoing interactions. Lived experience informed how users interacted with each other and shaped their understanding of how best to support each other through the illness. Empathy formed a key element of this support, provided with great sensitivity and respect for the needs of others. Key to this was understanding the unwritten rules of sharing, respecting MND stage, the emotional impacts of having the condition and individual wishes. Trust and empathy breaking down can negatively impact users.

Discussion and conclusion: The study provides new understanding about how interactions within the online forum are informed by external influences, which shape how trust and empathy are enacted within the online space. Users trusted the online space because it offered a contrast to real-world experience. This interaction was a key element in making the forum a person-focused space, valued by users. These findings are important both for charitable organisations and health professionals, and other support services for people with MND.

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COG-08 Physical and mental factors affecting perceived stigma amongst people with motor neurone disease/amyotrophic lateral sclerosis

R Edge1, A Tennant2, S Haddad3, C Young3,4, TONiC Study Group5

1Lancaster University, Lancaster, United Kingdom, 2Swiss Paraplegic Research, Nottwil, Switzerland, 3Walton Centre NHS Trust, Liverpool, United Kingdom, 4University of Liverpool, Liverpool, United Kingdom

Email address for correspondence: r.edge@lancs.ac.uk

Keywords: stigma, self-esteem, TONiC

Background: Studies have shown that quality-of-life (QoL) is significantly lowered by the presence of perceived stigma (1). A better understanding of internalised stigma and stigma resistance amongst people with MND/ALS may ameliorate the negative impact of stigmatisation.

Objectives: In this cross-sectional study, we examined stigma and associated physical, mental and social factors amongst people with MND. First, we evaluated covariates associated with a resistance to stigma. Second, we evaluated the covariates associated with stigma severity, given one has stigma.

Methods: Data collected in the national TONiC study includes: demographic information such as age, sex, marital status, duration of illness since diagnosis and onset type. Measures used were; ALSFRS-R, Hospital Anxiety and Depression scale and the Rosenberg self-esteem scale. Participants were also asked about their social support. Stigmatisation was assessed using the Stigma Scale for Chronic Illness (2). Logistic regression was used to evaluate the factors associated with stigma severity, given one has stigma.

Results: In total, 627/632 individuals provided information about their stigmatisation; 83 (13.2%) individuals reported no feelings of stigma, these people were deemed to be resistant to stigmatisation. An increased likelihood of having feelings of stigma was associated with worse depression, longer disease duration, more anxiety, poorer ALSFRS-R bulbar score and poorer communication (in order of statistical significance). Among those perceiving themselves to be stigmatised, more severe stigma was associated with lower self-esteem, worse anxiety, younger age, poorer ALSFRS-R bulbar score, less social support and longer disease duration.

Discussion: Some individuals showed no feelings of stigmatisation – the effects of mood were particularly important in determining resistance to stigmatisation. It is likely that some of the relationships between variables are feedback loops. For example, individuals experiencing stigmatisation may internalise these feelings, leading to lower self-esteem and a greater risk of stigma.
Longitudinal work will show if greater social support helps reduce stigmatisation and maintain QoL.

**Conclusion:** Our models of stigma and its associated factors amongst those with MND suggest that each domain investigated (physical, mental and social) maintains a unique and important contribution.

**Acknowledgments:** We thank our participants for their contribution, and the Motor Neurone Disease Association (UK) and NIHR for support.

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**COG-09 Problems and metaphors shown in narratives of family caregivers of patients with amyotrophic lateral sclerosis**

K Mukaoka

Juntendo University, Faculty of Health Care and Nursing, Urayasu, Japan

*Email address for correspondence:* k-mukaoka@juntendo.ac.jp

*Keywords:* caregiver, family, narrative

**Background:** In care for patients with Amyotrophic Lateral Sclerosis (ALS) during long-term recuperation, respite care hospitalization has been offered and comprehensive support systems have been enhanced in Japan. Previous studies have elucidated that ALS care is characterized as emotional work. It has been clarified that the disease impacts family caregivers. The purpose of this study was to examine narratives of family caregivers in order to highlight problems that they had in their daily life and to interpret metaphors that were concealed in their narratives.

**Methods:** Design: A grounded theory approach comprising in-depth qualitative interviews was used in this study. Participants: seven family caregivers of patients with ALS participated.

**Results:** The results of the analysis clarified that the first problem that caregivers had in their daily life was that they were not able to have a break for relaxation. In one case, even though the family caregiver of an ALS patient (requiring full-time or intensive care) had access to an artificial respirator in the car, she did not ask for a home-care worker and took the patient with the artificial respirator in the car. The second problem that family caregivers gave was that they felt hesitation and even a sense of guilt, especially when they were backed into an emotional corner, and eventually used outside help to take care of their own business. Almost all the caregivers stated that they had not been out of the home for two months and had a strong feeling that they were isolated from society because they had to concentrate on caring for their patients. Some caregivers mentioned that they had symptoms of nausea and vertigo caused by chronic fatigue. The third problem was that routinization of professional care could put caregivers at risk. Diversified contrivances have been performed for caring for patients. For example, a home-visit nurse and a home-visit worker coordinated their schedules to overlap 30 minutes in order to work together to make the bed, bath and change clothes easier. While this kind of routinization of care could provide high quality of smooth recuperation, there could be a risk of taking away free and open time from caregivers.

**Conclusion:** Nurses must be attentive to see whether caregivers of ALS patients feel as if the purpose of their life or their existence was only to care for patients because of pre-occupation. To solve problems where caregivers tend to feel a sense of guilt for going out by themselves and even for enjoying their meals at home, this study found that timely support must be sought.

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**COG-10 Factor analysis of the Zarit burden interview for amyotrophic lateral sclerosis (ALS) caregivers**

S Carney1,2, M Galvin1, N Pender1,2, A Staines3, O Hardiman1,2

1Trinity College Dublin, Dublin, Ireland, 2Beaumont Hospital Dublin, Dublin, Ireland, 3Dublin City University, Dublin, Ireland

*Email address for correspondence:* carneysl@tcd.ie

*Keywords:* Zarit Burden Interview, factor-analysis, informal caregivers

**Background:** It is suggested that caregiver burden encompasses 2 dimensions; 1) objective burden, reflecting tasks required of carers or time spent caregiving (1) and 2) subjective burden, the perceived impact of the objective burden and caregivers perception of the negative experience of their caregiving roles (1). The Zarit Burden Interview (ZBI) is widely used in the measurement of caregiver burden. However, it remains unclear how many factors underpin the ZBI instrument in assessing burden, (2). Understanding the number of factors is essential for the interpretation of burden for research purposes and in healthcare settings.

**Objectives:** The aims of this research included exploring the usefulness of the ZBI instrument in assessing burden, an examination of the underlying factor structure and assessing the change over time in the estimated burden on a cohort of ALS caregivers.
Methods: Data was collected as part of a large longitudinal study of ALS patients and their caregivers. The study was granted ethical approval from Beaumont Hospital Medical Ethics Committee. This analysis is based on the participation of 83 caregivers at time 1, 57 at time 2 and 40 at time 3, who completed the ZBI. Analyses were completed over a number of stages, using principal component analysis (PCA), exploratory factor analysis (EFA), confirmatory factor analysis (CFA) and Item Response Theory (IRT).

Results: Results suggest a 2-factor solution, corresponding to the factors labelled as Role strain and Personal strain in earlier work, is optimal. IRT analysis, based on this structure, suggests that several items perform poorly in measuring the overall score of burden in ALS caregivers. There is evidence of an increase over time in both ZBI scores, using estimates from random effects models.

Discussion and conclusion: Analysis confirms a 2-factor model underpins the ZBI score and the ZBI is capable of detecting changes in burden over time for ALS caregivers. However, our data, combined with that of Siegert et al. (3), suggests that many of the items in the questionnaire perform poorly as a measurement of burden in ALS caregivers. We suggest a reconsideration of the ZBI score, based on a larger study, is overdue.

This work is necessarily preliminary. Further research should carry out an analysis on a significantly larger dataset, of several hundred people. Nonetheless, this is the first time the ZBI has been psychometrically evaluated within an Irish ALS caregiver group.

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COG-11 Frequency of neuropsychiatric symptoms in first and second degree relatives of patients with amyotrophic lateral sclerosis (ALS)

M Ryan, E Costello, M Heverin, O Hardiman
Trinity College Dublin, Dublin, Ireland

Email address for correspondence: ryanm65@tcd.ie

Keywords: psychosis, CAPE-P15, relatives

Background: Psychotic symptoms, particularly delusions, are common in patients with ALS-FTSD (1,2). In addition, an increased incidence of schizophrenia/psychotic illness and suicide has been reported in family members of patients with ALS (3). The recent finding of the presence of a polygenic overlap of 14% between ALS and schizophrenia based on combined GWAS analyses (4) supports the concept that sub-groups of ALS, FTD and schizophrenia share pathobiological mechanisms.

Objectives: To examine the neuropsychiatric profiles of first and second relatives of patients with ALS.

Methods: ALS kindreds at high risk of neuropsychopathology were identified for detailed phenotyping studies. Neuropsychiatric status was determined using UK Biobank Thoughts and Feelings Questionnaire. Additional assessments, including the Community Assessment of Psychic Experiences (CAPE-15), were used to further assess individuals as deemed appropriate. Our primary analysis compares the results with those from reported population based normative data. We plan also to analyse the results against Irish population based control data.

Results: In total, 34 first and 24 second degree relatives have been evaluated from 10 familial ALS kindreds; 39/58 (67%) of participants were female. A bimodal age distribution was present with younger and older median ages of 33.5 and 55 years old, respectively. No participants had clinical evidence of ALS or FTD; 30/58 (51.7%) of participants reported experiencing significant psychotic like experiences (PLEs) (CAPE P15 frequency >1.5) (5); 12/30 (40%) reported suffering significant distress due to their experiences (CAPE P15 distress >1.5) (5); 7/58 (12%) had psychotic like experiences often or nearly always; 30/30 (100%) of those reporting PLEs experienced persecutory ideation; 10/30 reported bizarre experiences; and 6/30 reported perceptual abnormalities. This contrasts with reported lifetime prevalence estimates of psychotic experiences in a general adult population of 17.5% (6).

Discussion and conclusion: First and second degree relatives of ALS probands experience a high burden of psychotic like episodes (PLEs). PLEs can result in significant distress and put affected individuals at higher risk of psychosis, depression and suicide (7–9). These findings support the presence of a biological overlap between ALS, FTD and psychotic disorders. Further studies are warranted to determine whether PLEs may assist in the development of an ALS endophenotype.

Acknowledgments: We would like to thank all patients and family members taking part in this study.

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COG-12 Symptoms of psychiatric disorders in people living with ALS and their family members

C McHutchison¹, M Ryan², M Heverin², L Stephenson¹, S Coville¹, S Pal¹, S Chandran¹, O Hardiman², S Abrahams¹

¹University of Edinburgh, Edinburgh, United Kingdom, ²Trinity College Dublin, Dublin, Ireland

Email address for correspondence: s1264013@sms.ed.ac.uk

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Background: Changes in behaviour and cognition are present in ~50% of people living with Amyotrophic Lateral Sclerosis (ALS), with 15% meeting criteria for frontotemporal dementia (FTD) (1). These changes include an increase in apathy, disinhibition, loss of sympathy/empathy and changes in social cognition (1). In the early stages of ALS and FTD, behavioural changes are similar to those seen in psychiatric disorders such as psychosis, anxiety, autism and obsessive compulsive disorder (OCD) (2). Furthermore, family members of patients with ALS have an increased incidence of psychosis and suicide amongst first degree relatives (3), suggesting an under-recognized overlap between ALS and neuropsychiatric disease.

Objectives: We aimed to examine the frequencies of neuropsychiatric symptoms, cognitive impairment and behaviour change in people living with ALS and in their family members compared to the general population.

Methods: In Scotland, 60 people living with ALS and as many of their first and second degree family members as possible were recruited through the Scottish national MND register. In addition, healthy controls and their family members were recruited through the University of Edinburgh Volunteer Panel. A series of questionnaires measuring symptoms of neuropsychiatric disorders was administered. Each proband completed a brief cognitive screen and, where possible, behavioural information was collected from an informant in a semi-structured interview.

Results: In preliminary analysis, 27 people living with ALS and 16 of their family members, along with 47 healthy controls and 13 of their family members completed the neuropsychiatric questionnaires. Behavioural information was available for 18 participants with ALS and 25 healthy controls. The frequency of symptoms of depression and anxiety were similar across ALS participants, ALS patients’ family members, controls and controls’ family members. Impulsivity was less common in people living with ALS (M=48.00, SD=5.20) compared with ALS patients’ family members (M=52.37, SD=4.53), controls (M=52.17, SD=6.11) and controls’ family members (M=53.38, SD=5.84). Cognitive scores were lower in ALS patients (M=114, SD=7.13) compared to controls (M=123.39, SD=6.02). In ALS patients, apathy was the most common behavioural change (n=12), followed by loss of sympathy or empathy (n=5).

Discussion and conclusions: The frequency of symptoms of neuropsychiatric disorders in people living with ALS and their family members is generally low compared to the general population; however, cognitive and behavioural changes are present. Currently, the number of participants is low, so these results should be interpreted with caution. Future analysis will look more closely at the relationship between the frequency of symptoms of various psychiatric disorders and the clinical characteristics of the participants with ALS.

References
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