Motor Neuron Disease Behaviour Scale Scoring Guide 2014

The Motor Neuron Disease Behaviour Scale (MiND-B) is a valid, sensitive and short instrument that detects and quantifies behavioural changes in Amyotrophic Lateral Sclerosis (ALS). It measures three behavioural domains: apathy, disinhibition and stereotypical behaviour. The questionnaire contains 9 questions with a total score of 36, which higher scores denoting absence or very mild behavioural symptoms. The MiND-B can be completed by a caregiver/family member or clinician.

To download the MiND-B as well as updates on publications and language translations, please go to the following website: http://www.neura.edu.au/forefront/MiND

Scoring and Cut-offs

The frequency of behavioural symptoms is rated for each question on a Likert scale (1-4).

1 = Behaviour is observed everyday
2 = Behaviour is observed a few times per week
3 = Behaviour is observed a few times in the month
4 = There is no change from normal behaviour

Scores for individual items are summed to obtain domain and total scores. Cut-offs are displayed in Table 1.

Table 1: Cut-off for Domain and Total Scores on the MiND-B

Behavioural Domain	Questions	Total	Control Mean (SD)[1]	Cut-offs
Disinhibition	1 to 4	16	14.9 (1.9)	Less than 13
Apathy	5 to 7	12	11.1 (1.9)	Less than 9
Stereotypical Behaviour	8 and 9	8	6.7 (1.9)	Less than 5
Total Score	1 to 9	36	35.1 (1.1)	Less than 34

[1] This is based on a control group: N=45, % male=51, mean age=67.2 ± 5.9, mean years of education=13.1 ± 2.9

Relationship with the Cambridge Behaviour Inventory

The MiND-B was derived from the Cambridge Behaviour Inventory-Revised [1], which is a behavioural scale that assess for behavioural features – including apathy, disinhibition and stereotypical behaviours – as well as changes in memory, everyday skills, self-care, eating habits, sleep and mood. The CBI-R differentiates between behavioural changes that are seen across dementia syndromes, including FTD. MiND-B items that overlap with the CBI-R are illustrated in Table 2.

Table 2: Items that overlap in the MiND-B and CBI-R

Item	MiND-B Question	CBI-R Question
Has temper outbursts	1	19
Is uncooperative when asked to do something	2	20
Makes tactless or suggestive remarks	3	22
Acts impulsively without thinking	4	23
Shows less enthusiasm for their usual interests	5	41
Shows little interest in doing new things	6	42
Fails to maintain motivation to keep in contact with family and friends	7	43
Is rigid in their ideas and opinions	8	37
Repeatedly uses the same expression or catch phrase	9	40

The CBI-R is scored on a Likert scale from 0 to 4: 0=never, 1=a few times per month, 2=a few times per week, 3=daily, 4=constantly. Higher scores on the CBI-R, therefore, reflect greater behavioural problems. In contrast, scoring on the MiND-B is reversed so that higher scores indicate no behavioural symptomatology. The conversion of scores between the MiND-B and CBI-R can be found in Table 3.

Table 3: Conversion of scores between the MiND-B and CBI-R

	MiND-B Score	CBI-R Score
No change from normal behaviour	1	0
A few times in the month	2	1
A few times per week	3	2
Every day	4	3 or 4

Interpretation of scores

It is now well recognised that ALS and Frontotemporal dementia (FTD) lie on a disease continuum [2-5]. However, many ALS patients without overlapping FTD can present with marked neuropsychiatric symptoms. In fact, a recent study showed that neuropsychiatric symptoms usually appear earlier than motor symptoms in MND [6].

It is therefore quite common to observe mild-to-moderate neuropsychiatric symptoms in ALS patients and these are usually first noticed by family members and friends. Apathy is the most common symptom (up to 75%), followed by disinhibition (up to 66%) and stereotypical behaviours (up to 58%)[7]. In an ALS clinic, a measure such as the MiND-B can help in detecting these symptoms and therefore guide the direction of clinical and allied health advice that is given to families.

The diagnosis of ALSFTD should be based on a combination with a thorough clinical assessment, neurophysiological, neuroimaging and comprehensive cognitive testing. Brief clinical tools, however, are useful in identifying individual patients who might need a more thorough assessment. A recent study by our group showed that 90% of FTDMND patients fall below the cut-off on the MiND-B and the M-ACE, a 5-minute cognitive screening tool that has been validated across dementia syndromes and is also freely available for clinical and research use [8]. Moreover, 75% of FTDMND patients fall below the cut-off on both of these two tests.

References:

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5. Stewart, H., et al., *Clinical and pathological features of amyotrophic lateral sclerosis caused by mutation in the C9ORF72 gene on chromosome 9p.* Acta Neuropathologica, 2012. **123**(3): p. 409-17.
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8. Hsieh, S., et al., *The Mini-Addenbrooke's Cognitive Examination: A new assessment tool for dementia.* Dementia and Geriatric Cognitive Disorders, 2014. **39**(1-2): p. 1-11.