

Supplementary Material

Content Validity of the Friedreich Ataxia Rating Scale in Patients with

Spinocerebellar Ataxia

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Supplementary Table 1. Cognitive debrief of FARS-ADL.

FARS-ADL HCP cognitive debrief (<i>N</i> =8), <i>n/N</i> (%)									
Aspect of debriefing	Item 1: Speech	Item 2: Swallowing	Item 3: Cutting Foods and Handling Utensils	Item 4: Dressing	Item 5: Personal Hygiene	Item 6: Falling	Item 7: Walking	Item 8: Quality of Sitting Position	Item 9: Bladder Function
Understanding of overall FARS-ADL instructions: 8/8 (100.0)									
Correct understanding of item	7/7 (100.0)	8/8 (100.0)	7/7 (100.0)	8/8 (100.0)	8/8 (100.0)	8/8 (100.0)	8/8 (100.0)	8/8 (100.0)	8/8 (100.0)
Response options									
Level 0									
Correct interpretation	8/8 (100.0)	6/6 (100.0)	6/6 (100.0)	7/7 (100.0)	8/8 (100.0)	8/8 (100.0)	6/6 (100.0)	7/7 (100.0)	6/6 (100.0)
Clarity	6/7 (85.7)	8/8 (100.0)	7/7 (100.0)	8/8 (100.0)	8/8 (100.0)	7/8 (87.5)	7/7 (100.0)	5/6 (83.3)	8/8 (100.0)
Level 1									
Correct interpretation	7/7 (100.0)	8/8 (100.0)	7/7 (100.0)	7/7 (100.0)	7/7 (100.0)	8/8 (100.0)	7/7 (100.0)	7/7 (100.0)	8/8 (100.0)

FARS-ADL HCP cognitive debrief (N=8), n/N (%)									
Aspect of debriefing	Item 1:	Item 2:	Item 3:	Item 4:	Item 5:	Item 6:	Item 7:	Item 8:	Item 9:
	Speech	Swallowing	Cutting Foods and Handling Utensils	Dressing	Personal Hygiene	Falling	Walking	Quality of Sitting Position	Bladder Function
Clarity	8/8 (100.0)	7/8 (87.5)	7/7 (100.0)	7/8 (87.5)	8/8 (100.0)	6/8 (75.0)	6/8 (75.0)	4/6 (66.7)	8/8 (100.0)
Level 2									
Correct interpretation	6/6 (100.0)	8/8 (100.0)	8/8 (100.0)	8/8 (100.0)	8/8 (100.0)	8/8 (100.0)	7/7 (100.0)	8/8 (100.0)	8/8 (100.0)
Clarity	7/8 (87.5)	7/8 (87.5)	5/6 (83.3)	6/8 (75.0)	6/8 (75.0)	7/8 (87.5)	6/8 (75.0)	3/4 (75.0)	5/8 (62.5)
Level 3									
Correct interpretation	6/6 (100.0)	7/7 (100.0)	7/7 (100.0)	7/7 (100.0)	8/8 (100.0)	7/7 (100.0)	7/7 (100.0)	7/7 (100.0)	8/8 (100.0)
Clarity	7/8 (87.5)	8/8 (100.0)	7/7 (100.0)	6/8 (75.0)	7/8 (87.5)	5/7 (71.4)	6/8 (75.0)	3/4 (75.0)	5/8 (62.5)
Level 4									

FARS-ADL HCP cognitive debrief (N=8), n/N (%)									
Aspect of debriefing	Item 1: Speech	Item 2: Swallowing	Item 3: Cutting Foods and Handling Utensils	Item 4: Dressing	Item 5: Personal Hygiene	Item 6: Falling	Item 7: Walking	Item 8: Quality of Sitting Position	Item 9: Bladder Function
Correct interpretation	7/7 (100.0)	8/8 (100.0)	7/7 (100.0)	6/6 (100.0)	5/5 (100.0)	7/7 (100.0)	7/7 (100.0)	8/8 (100.0)	8/8 (100.0)
Clarity	7/8 (87.5)	8/8 (100.0)	6/7 (85.7)	5/8 (62.5)	7/7 (100.0)	8/8 (100.0)	6/8 (75.0)	3/5 (60.0)	7/8 (87.5)
Ease of response selection	7/8 (87.5)	8/8 (100.0)	8/8 (100.0)	7/8 (87.5)	7/8 (87.5)	7/7 (100.0)	6/8 (75.0)	8/8 (100.0)	7/8 (87.5)
Basis of response selection									
Patient observation	2/8 (25.0)	3/8 (37.5)	0	0	0	0	1/8 (12.5)	3/8 (37.5)	0
Clinical tests	1/8 (12.5)	0	0	0	0	0	0	0	0
Patient's response	1/8 (12.5)	4/8 (50.0)	3/8 (37.5)	3/8 (37.5)	6/8 (75.0)	7/8 (87.5)	6/8 (75.0)	5/8 (62.5)	3/8 (37.5)

FARS-ADL HCP cognitive debrief (N=8), n/N (%)									
Aspect of debriefing	Item 1: Speech	Item 2: Swallowing	Item 3: Cutting Foods and Handling Utensils	Item 4: Dressing	Item 5: Personal Hygiene	Item 6: Falling	Item 7: Walking	Item 8: Quality of Sitting Position	Item 9: Bladder Function
Caregiver's response	5/8 (62.5)	5/8 (62.5)	7/8 (87.5)	7/8 (87.5)	5/8 (62.5)	5/8 (62.5)	4/8 (50.0)	3/8 (37.5)	6/8 (75.0)
Combination	1/8 (12.5)	0	2/8 (25.0)	3/8 (37.5)	0	0	0	0	2/8 (25.0)
Agreement with FARS-ADL response categories as meaningful									
Response category	7/8	7/8	7/8	6/8	8/8	5/5	3/5	4/5	4/5
agreement	(87.5)	(87.5)	(87.5)	(75.0)	(100.0)	(100.0)	(60.0)	(80.0)	(80.0)

In cases where the participant was not asked or did not answer the question, this is reflected in the denominator.

FARS-ADL, Friedreich Ataxia Rating Scale – Activities of Daily Living; HCP, healthcare professional.