

**Table S-I- Density of expression: median number of words ( $\pm 95\%$  CI) pronounced per need, emotion or medical requirement expressed**

Item		Mild Disease (MD)	Intermediate Spinal (IS)	Intermediate Bulbar (IB)	Severe Disease (SD)	Total	P [a]	
<b>Needs</b>	carers	149 [86-207]	199 [174-378]	536 [283-697]	150 [112-233]	184 [142-233]	0.489	
	patients	159 [70-236]	166 [82-366]	–	–	165 [82-236]		
	<b>total</b>	157 [93-207]	186 [158-366]	536 [283-697]	150 [112-233]	170 [142-207]		
	P [b]	0.022						
	P [c]	status=0.935; burden=0.003; interaction=0.684						
<b>Emotions</b>	carers	88 [67-135]	248 [158-347]	570 [373-697]	107 [69-190]	112 [92-190]	0.126	
	patients	77 [51-118]	157 [82-228]	–	–	82 [61-130]		
	<b>total</b>	83 [67-104]	203 [95-304]	570 [373-697]	107 [69-190]	102 [84-138]		
	P [b]	<0.001						
	P [c]	status=0.309; burden = <0.001; interaction=0.871						
<b>Medical Requirements</b>	carers	193 [86-303]	347 [166-541]	264 [188-574]	203 [90-294]	203 [177-294]	0.968	
	patients	254 [130-412]	220 [82-228]	–	–	228 [130-276]		
	<b>total</b>	205 [138-297]	224 [158-378]	264 [188-574]	203 [90-294]	213 [177-267]		
	P [b]	0.596						
	P [c]	status=0.923; burden =0.832; interaction=0.144						

[a] Mann-Whitney test for status

[b] Kruskal-Wallis test for burden

[c] bootstrapping ANOVA (2000 replicates)

**Table S-II – Number of subjects expressing needs and number of expressions per subject, stratified by status**

Need	Number of subjects expressing (% of subjects)			total number of expressions (% of total expressions)		mean number of expressions per expressing subject	
	carers	patients	Fisher P	carers	patients	carers	patients
<b>Assistance</b>	12 (36.4%)	7 (63.6%)	0.1639	24 (19.5%)	14 (28.6%)	2.00	2.00
<b>Reference Person</b>	10 (30.3%)	2 (18.2%)	0.6983	18 (14.6%)	2 (4.1%)	1.80	1.00
<b>Knowledge</b>	6 (18.2%)	6 (54.5%)	0.0451	6 (4.9%)	7 (14.3%)	1.00	1.17
<b>Planning</b>	10 (30.3%)	1 (9.1%)	0.2409	13 (10.6%)	2 (4.1%)	1.30	2.00
<b>Support</b>	7 (21.2%)	3 (27.3%)	0.6922	10 (8.1%)	4 (8.2%)	1.43	1.33
<b>Scientific Advancement</b>	4 (12.1%)	2 (18.2%)	0.6302	9 (7.3%)	3 (6.1%)	2.25	1.50
<b>Autonomy</b>	4 (12.1%)	2 (18.2%)	0.6302	4 (3.3%)	2 (4.1%)	1.00	1.00
<b>Clarity</b>	4 (12.1%)	1 (9.1%)	1.0000	7 (5.7%)	2 (4.1%)	1.75	2.00
<b>Comprehension</b>	3 (9.1%)	2 (18.2%)	0.5855	3 (2.4%)	2 (4.1%)	1.00	1.00
<b>Outpouring</b>	4 (12.1%)	1 (9.1%)	1.0000	4 (3.3%)	1 (2.0%)	1.00	1.00
<b>Sharing</b>	4 (12.1%)	1 (9.1%)	1.0000	4 (3.3%)	1 (2.0%)	1.00	1.00
<b>Relying</b>	2 (6.1%)	2 (18.2%)	0.2565	2 (1.6%)	3 (6.1%)	1.00	1.50
<b>Listening</b>	3 (9.1%)	1 (9.1%)	1.0000	3 (2.4%)	1 (2.0%)	1.00	1.00
<b>Belonging/Normality</b>	3 (9.1%)	0 (0.0%)	0.5615	7 (5.7%)	0 (0.0%)	2.33	.
<b>Doing</b>	2 (6.1%)	1 (9.1%)	1.0000	2 (1.6%)	3 (6.1%)	1.00	3.00
<b>Reassurance</b>	3 (9.1%)	0 (0.0%)	0.5615	4 (3.3%)	0 (0.0%)	1.33	.
<b>Control/Power</b>	2 (6.1%)	1 (9.1%)	1.0000	2 (1.6%)	1 (2.0%)	1.00	1.00
<b>Respect</b>	1 (3.0%)	1 (9.1%)	0.4419	1 (0.8%)	1 (2.0%)	1.00	1.00
<b>Total</b>	33	11		123	49	1.46	1.44

Table S-III - Number of subjects expressing needs, stratified by disease burden

Need	Number of subjects expressing (% of subjects)				chi square P
	Mild Disease (MD)	Intermediate Spinal (IS)	Intermediate Bulbar (IB)	Severe Disease (SD)	
Assistance	8 (40.0%)	4 (50.0%)	2 (50.0%)	5 (41.7%)	0.9560
Reference Person	4 (20.0%)	1 (12.5%)	2 (50.0%)	5 (41.7%)	0.2947
Knowledge	5 (25.0%)	2 (25.0%)	1 (25.0%)	4 (33.3%)	0.9590
Planning	5 (25.0%)	0 (0.0%)	2 (50.0%)	4 (33.3%)	0.2173
Support	3 (15.0%)	3 (37.5%)	0 (0.0%)	4 (33.3%)	0.3056
Scientific Advancement	4 (20.0%)	0 (0.0%)	0 (0.0%)	2 (16.7%)	0.4443
Autonomy	3 (15.0%)	1 (12.5%)	0 (0.0%)	2 (16.7%)	0.8577
Clarity	2 (10.0%)	0 (0.0%)	0 (0.0%)	3 (25.0%)	0.2850
Comprehension	2 (10.0%)	0 (0.0%)	0 (0.0%)	3 (25.0%)	0.2850
Outpouring	4 (20.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)	0.3722
Sharing	1 (5.0%)	2 (25.0%)	0 (0.0%)	2 (16.7%)	0.3722
Relying	1 (5.0%)	2 (25.0%)	0 (0.0%)	1 (8.3%)	0.3528
Listening	0 (0.0%)	2 (25.0%)	1 (25.0%)	1 (8.3%)	0.1281
Belonging/Normality	2 (10.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)	0.7434
Doing	0 (0.0%)	1 (12.5%)	1 (25.0%)	1 (8.3%)	0.2620
Reassurance	1 (5.0%)	1 (12.5%)	0 (0.0%)	1 (8.3%)	0.8383
Control/Power	2 (10.0%)	1 (12.5%)	0 (0.0%)	0 (0.0%)	0.5943
Respect	1 (5.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)	0.8066
<b>Total</b>	20	8	4	12	

**Table S-IV – Number of subjects expressing emotions, number of expressions stratified by status**

Emotion	Number of subjects expressing (% of total subjects)			Number of expression (% of total expressions)		mean number of expressions per subject expressing	
	carer	patient	Fisher P	carer	patient	carer	patient
<b>Desperation</b>	16 (48.5%)	5 (45.5%)	1.0000	29 (19.3%)	7 (7.1%)	1.81	1.40
<b>Anger</b>	12 (36.4%)	8 (72.7%)	0.0777	34 (22.7%)	34 (34.3%)	2.83	4.25
<b>Sadness</b>	12 (36.4%)	6 (54.5%)	0.3141	18 (12.0%)	12 (12.1%)	1.50	2.00
<b>Fear</b>	12 (36.4%)	5 (45.5%)	0.7244	12 (8.0%)	8 (8.1%)	1.00	1.60
<b>Disorientation</b>	7 (21.2%)	4 (36.4%)	0.4247	10 (6.7%)	9 (9.1%)	1.43	2.25
<b>Anxiety/Apprehension</b>	8 (24.2%)	1 (9.1%)	0.4108	10 (6.7%)	1 (1.0%)	1.25	1.00
<b>Resignation</b>	6 (18.2%)	3 (27.3%)	0.6686	6 (4.0%)	4 (4.0%)	1.00	1.33
<b>Frustration</b>	4 (12.1%)	2 (18.2%)	0.6302	4 (2.7%)	3 (3.0%)	1.00	1.50
<b>Hope</b>	3 (9.1%)	2 (18.2%)	0.5855	5 (3.3%)	3 (3.0%)	1.67	1.50
<b>Sarcasm</b>	1 (3.0%)	4 (36.4%)	0.0105	1 (0.7%)	7 (7.1%)	1.00	1.75
<b>Gratitude</b>	4 (12.1%)	1 (9.1%)	1.0000	5 (3.3%)	1 (1.0%)	1.25	1.00
<b>Rejection</b>	4 (12.1%)	1 (9.1%)	1.0000	4 (2.7%)	1 (1.0%)	1.00	1.00
<b>Acceptance</b>	3 (9.1%)	1 (9.1%)	1.0000	4 (2.7%)	1 (1.0%)	1.33	1.00
<b>Disappointment</b>	2 (6.1%)	2 (18.2%)	0.2565	2 (1.3%)	3 (3.0%)	1.00	1.50
<b>Exasperation</b>	3 (9.1%)	1 (9.1%)	1.0000	4 (2.7%)	1 (1.0%)	1.33	1.00
<b>Renunciation</b>	1 (3.0%)	2 (18.2%)	0.1495	1 (0.7%)	2 (2.0%)	1.00	1.00
<b>Surprise</b>	0 (0.0%)	1 (9.1%)	0.2500	0 (0.0%)	2 (2.0%)	.	2.00
<b>Pride</b>	1 (3.0%)	0 (0.0%)	1.0000	1 (0.7%)	0 (0.0%)	1.00	.
<b>Total</b>	33	11		150	99	1.52	2.02

**Table S-V– Number of subjects expressing emotions, stratified by disease burden**

Emotion	N° of subjects expressing (% of total subjects)				chi square P
	Mild Disease (MD)	Intermediate Spinal (IS)	Intermediate Bulbar (IB)	Severe Disease (SD)	
Desperation	9 (45.0%)	3 (37.5%)	0 (0.0%)	9 (75.0%)	0.0544
Anger	9 (45.0%)	1 (12.5%)	2 (50.0%)	8 (66.7%)	0.1262
Sadness	12 (60.0%)	0 (0.0%)	0 (0.0%)	6 (50.0%)	0.0084
Fear	7 (35.0%)	5 (62.5%)	1 (25.0%)	4 (33.3%)	0.4772
Disorientation	6 (30.0%)	0 (0.0%)	0 (0.0%)	5 (41.7%)	0.1095
Anxiety/Apprehension	6 (30.0%)	3 (37.5%)	0 (0.0%)	0 (0.0%)	0.0835
Resignation	5 (25.0%)	2 (25.0%)	0 (0.0%)	2 (16.7%)	0.6846
Frustration	2 (10.0%)	2 (25.0%)	1 (25.0%)	1 (8.3%)	0.6091
Hope	2 (10.0%)	2 (25.0%)	0 (0.0%)	1 (8.3%)	0.5447
Sarcasm	3 (15.0%)	1 (12.5%)	0 (0.0%)	1 (8.3%)	0.8266
Gratitude	1 (5.0%)	2 (25.0%)	1 (25.0%)	1 (8.3%)	0.3722
Rejection	4 (20.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)	0.3722
Acceptance	2 (10.0%)	0 (0.0%)	2 (50.0%)	0 (0.0%)	0.0176
Disappointment	3 (15.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)	0.5614
Exasperation	1 (5.0%)	0 (0.0%)	1 (25.0%)	2 (16.7%)	0.3528
Renunciation	1 (5.0%)	1 (12.5%)	0 (0.0%)	1 (8.3%)	0.8383
Surprise	1 (5.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0.7463
Pride	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (8.3%)	0.4354
Total	20	8	4	12	

**Table S-VI - Number of subjects expressing medical requirements and number of expressions per subject, stratified by status**

Medical Requirements	N° of subjects expressing (% of total subjects)			N° of expression (% of total expressions)	
	carer	patient	Fisher P	carer	patient
<b>Difficult Communication</b>	11 (33.3%)	4 (36.4%)	1.0000	13 (13.7%)	7 (18.9%)
<b>Welfare Assistance</b>	8 (24.2%)	3 (27.3%)	1.0000	10 (10.5%)	5 (13.5%)
<b>Psychological Support</b>	9 (27.3%)	1 (9.1%)	0.4082	17 (17.9%)	1 (2.7%)
<b>New Drug Research</b>	5 (15.2%)	3 (27.3%)	0.3911	6 (6.3%)	6 (16.2%)
<b>Architectural Barriers</b>	4 (12.1%)	2 (18.2%)	0.6302	4 (4.2%)	3 (8.1%)
<b>Rehabilitation</b>	1 (3.0%)	4 (36.4%)	0.0105	1 (1.1%)	8 (21.6%)
<b>PEG Aids</b>	5 (15.2%)	0 (0.0%)	0.3092	6 (6.3%)	0 (0.0%)
<b>Dedicated Home Staff</b>	4 (12.1%)	1 (9.1%)	1.0000	4 (4.2%)	1 (2.7%)
<b>Correct Information</b>	3 (9.1%)	1 (9.1%)	1.0000	6 (6.3%)	1 (2.7%)
<b>Reference Persons</b>	3 (9.1%)	1 (9.1%)	1.0000	5 (5.3%)	1 (2.7%)
<b>Tracheal Aids</b>	2 (6.1%)	2 (18.2%)	0.2565	3 (3.2%)	3 (8.1%)
<b>Territorial Services</b>	3 (9.1%)	0 (0.0%)	0.5615	7 (7.4%)	0 (0.0%)
<b>Care Integration</b>	3 (9.1%)	0 (0.0%)	0.5615	5 (5.3%)	0 (0.0%)
<b>Psychological Problems</b>	3 (9.1%)	0 (0.0%)	0.5615	5 (5.3%)	0 (0.0%)
<b>Dedicated Hospital Staff</b>	2 (6.1%)	0 (0.0%)	1.0000	2 (2.1%)	0 (0.0%)
<b>Autonomy</b>	1 (3.0%)	0 (0.0%)	1.0000	1 (1.1%)	0 (0.0%)
<b>Euthanasia</b>	0 (0.0%)	1 (9.1%)	0.2500	0 (0.0%)	1 (2.7%)
<b>Total</b>	33	11		95	37

Table S-VII – Number of subjects expressing medical requirements, stratified by burden

Medical Requirements	N° of subjects expressing (% of total subjects)				chi square P
	Mild Disease (MD)	Intermediate Spinal (IS)	Intermediate Bulbar (IB)	Severe Disease (SD)	
<b>Difficult Communication</b>	4 (20.0%)	4 (50.0%)	2 (50.0%)	5 (41.7%)	0.3305
<b>Welfare Assistance</b>	5 (25.0%)	1 (12.5%)	1 (25.0%)	4 (33.3%)	0.7744
<b>Psychological Support</b>	2 (10.0%)	3 (37.5%)	1 (25.0%)	4 (33.3%)	0.3056
<b>New Drug Research</b>	3 (15.0%)	2 (25.0%)	0 (0.0%)	3 (25.0%)	0.6481
<b>Architectural Barriers</b>	3 (15.0%)	1 (12.5%)	0 (0.0%)	2 (16.7%)	0.8577
<b>Rehabilitation</b>	4 (20.0%)	1 (12.5%)	0 (0.0%)	0 (0.0%)	0.3153
<b>PEG Aids</b>	0 (0.0%)	1 (12.5%)	2 (50.0%)	2 (16.7%)	0.0315
<b>Dedicated Home Staff</b>	1 (5.0%)	1 (12.5%)	0 (0.0%)	3 (25.0%)	0.3153
<b>Correct Information</b>	0 (0.0%)	1 (12.5%)	1 (25.0%)	2 (16.7%)	0.2436
<b>Reference Persons</b>	0 (0.0%)	1 (12.5%)	1 (25.0%)	2 (16.7%)	0.2436
<b>Tracheal Aids</b>	3 (15.0%)	0 (0.0%)	1 (25.0%)	0 (0.0%)	0.2540
<b>Territorial Services</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (25.0%)	0.0353
<b>Care Integration</b>	0 (0.0%)	0 (0.0%)	2 (50.0%)	1 (8.3%)	0.0031
<b>Psychological Problems</b>	1 (5.0%)	0 (0.0%)	0 (0.0%)	2 (16.7%)	0.4212
<b>Dedicated Hospital Staff</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (16.7%)	0.1335
<b>Autonomy</b>	0 (0.0%)	1 (12.5%)	0 (0.0%)	0 (0.0%)	0.2031
<b>Euthanasia</b>	1 (5.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0.7463
<b>Total</b>	20	8	4	12	