

Table S1. Duration and characteristics of specialized palliative care in our sample.

Number of Patients	Description of SPC	Details
<i>n</i> = 29	None	-
<i>n</i> = 7	SOPC team, home visits; prescribed at the Motoneuron disease specialist center	prescription: mean 120 (3–420) * days prior death; in contact: mean 30 (3–75) * days prior death
<i>n</i> = 7	SOPC team, home visits; prescribed by other actors	in contact: mean 45 (14–240) * days prior death
<i>n</i> = 3	SOPC team, home visits	no further details available
<i>n</i> = 1	SOPC team, nursing home visits	first contact 14 months prior death, regularly since 4 months prior death
<i>n</i> = 1	Hospice last 6 months	plus sporadic SOPC contact before
<i>n</i> = 1	Hospice last 5 days	-
<i>n</i> = 1	Hospice last 4 days	plus sporadic SOPC contact during last two years before

* Median (range); SOPC; specialized outpatient palliative care.

Table S2. Characteristics of disease and wellbeing in different care settings; *n* = 49.

	Family Care (<i>n</i> = 16)	Family Care and Nursing Service (<i>n</i> = 20)	Inpatient Care Setting (<i>n</i> = 13)	<i>p</i>
BSFC-S (<i>n</i> = 46) ^a	9.5 ± 6.6	10.2 ± 6.3	15.1 ± 7.2	0.069 *
ALSFRS-R prior death ^a	18.3 ± 6.4	12.0 ± 8.7	11.3 ± 8.4	0.032 *
Patients' age (years) ^a	68.6 ± 9.4	70.4 ± 7.9	74.9 ± 7.5	0.129 ×
Duration MND diagnosis to death (months) ^a	26.8 ± 37.6	30.1 ± 28.1	26.9 ± 29.6	0.936 ×
Gender caregivers m:f ^b	7:9 (44:56)	7:13 (35:65)	5:8 (38:62)	0.866 °
SPC yes:no ^b	7:9 (44:56)	11:9 (55:45)	4:9 (31:69)	0.390 °
Time spent for care (hours per week) ^a	78.1 ± 47.8	50.7 ± 42.7	0.9 ± 3.0	<0.0001 ×
Time spent together, excluding care (hours per week) ^a	28.6 ± 21.4	25.9 ± 28.0	8.3 ± 7.0	0.012 ×

^a Data are presented as mean ± standard deviations; ^b data are presented as n (%); * ANOVA; × Kruskal–Wallis test; ° chi²; ALSFRS-R, Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised; BSFC-s, Burden Scale for Family Caregivers short version; SPC, specialized palliative care; The bold means *p*-values reached significance.