Supplementary materials

Table 1 supplementary material – Scenarios for dealing with missing data

Scenarios for dealing with missing data	Description
(i) Complete case scenario	No missing data tolerated
(ii) Best case scenario	One missing data for the whole scale tolerated and replaced with the value "zero"
(iii) Worst case scenario	One missing data for the scale tolerated and replaced with the value "four"
(iv) Total scale mean imputation	One missing data for the scale tolerated and replaced with the mean of the scale
(v) Total scale median imputation	One missing data for the scale tolerated and replaced with the median of the scale
(vi) Subscale mean imputation	One missing data per subscale tolerated and replaced with the mean of the subscale
(vii) Subscale median imputation	One missing data per subscale tolerated and replaced with the median of the subscale

Table 2 supplementary material – Participants' sociodemographic, medical characteristics, and setting

Age, years (mean ± SD)	68.8 ±12.9
Gender, men/women, n	81/92
Education, n (%)	
Compulsory	46 (27.5)
Vocational education	69 (41.3)
Highschool	12 (7.2)
University, University of applied sciences	40 (24.0)
Marital status, n (%)	
Single (never married)	14 (8.2)
Married/In partnership	89 (52.4)
Divorced/Separated	41 (24.1)
Widowed	26 (15.3)
Nationality, n (%)	
Swiss	146 (85.4)
Italian	9 (5.3)
Portuguese	4 (2.3)
Other	12 (7)
Main diagnosis, n (%)	
Oncologic disease	143 (85.1)
Advanced cardiac disease	5 (3.0)
Chronic obstructive pulmonary disease	4 (2.4)
ALS	3 (1.8)
Other	13 (7.7)
Existing anticipated decisions Y/N, n	67 (44.3) / 84 (55.7)
Patient setting	
Mobile, n (%)	31 (17.9)
PCU, n (%)	142 (82.1%)

ALS: Amyotrophic lateral sclerosis; PCU: palliative care unit; SD: Standard deviation

Table 3 supplementary material – MD at T1 and T2 per type of participant

Number of MD	T1 patient (n=173)	T1 staff (n=169)	T2 patient (n=108)	T2 staff (n=102)
no MD	135	117	86	74
1 MD	27	25	16	20
2 MD	4	17	2	5
3 or more MD	7	10	4	3

MD: missing data; T1= time 1; T2= time 2

Table 4 supplementary material – Frequency of MD at T1 per item and type of participant

Item number	Item	patient T1 n MD, (%)	staff T1 n MD, (%)
1	Pain	3 (1.7)	7 (4.1)
2	Shortness of breath	1 (0.6)	7 (4.1)
3	Weakness or lack of energy	2 (1.2)	10 (5.9)
4	Nausea	1 (0.6)	6 (3.5)
5	Vomiting	4 (2.3)	5 (2.9)
6	Poor appetite	3 (1.7)	7 (4.1)
7	Constipation	5 (2.9)	7 (4.1)
8	Sore or dry mouth	1 (.06)	6 (3.5)
9	Drowsiness	2 (1.2)	6 (3.5)
10	Poor mobility	1 (0.6)	8 (4.7)
11	Patient feeling anxious or worried about illness or treatment	2 (1.2)	6 (3.5)
12	Family or friends been anxious or worried about patient	15 (8.7)	34 (20.1)
13	Patient feeling depressed	4 (2.3)	8 (4.7)
14	Patient feeling at peace	6 (3.5)	7 (4.1)
15	Patient ability to share as much as wanted	4 (2.3)	24 (14.2)
16	Patient access to information	6 (3.5)	7 (4.1)
17	Practical problems	7 (4.0)	24 (14.2)
	Total participant n	173	169

Table 5 supplementary material – Factorial analysis with varimax rotation (extraction method: principal component analysis)

Total variance explained - patient						
	Initial Eigenvalues			Rotation Sums of Squared Loadings		
Factors	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
For patients						
1	3.1	17.9	17.9	2.3	13.7	13.7
2	2.1	12.2	30.1	2.1	12.6	26.3
3	1.8	10.4	40.5	1.9	10.9	37.3
4	1.3	7.4	47.9	1.5	9.0	46.3
5	1.3	7.4	55.3	1.4	8.2	54.4
6	1.0	6.0	61.4	1.2	6.9	61.3
For staff						
1	3.5	20.4	20.4	3.1	18.3	18.3
2	2.4	13.9	34.3	1.9	11.4	29.7
3	1.7	9.8	44.1	1.9	10.9	40.6
4	1.3	7.9	52.0	1.6	9.3	49.9
5	1.2	7.0	59.0	1.6	9.1	59.0

Table 6 supplementary material – Correlations between items of the patients and staff IPOS-Fr and the factors found by the principal component analysis with varimax rotation

	Factors					
Patients						
	1	2	3	4	5	6
Item 1	-.044	.184	.047	-.082	**.768**	.016
Item 2	.208	-.064	-.143	.298	-.198	**.700**
Item 3	**.717**	.107	.181	.083	-.029	.092
Item 4	.127	.015	**.897**	.058	-.026	.040
Item 5	.020	-.004	**.855**	.025	.129	-.118
Item 6	**.542**	-.030	.392	.040	.248	.122
Item 7	.164	-.063	.081	.192	**.655**	-.089
Item 8	**.631**	-.086	-.108	.058	.305	.151
Item 9	**.689**	.030	.122	.027	-.070	.026
Item 10	**.705**	.206	-.172	-.127	-.022	-.168
Item 11	-.029	**.710**	.105	.138	.022	.160
Item 12	-.043	.450	.118	-.199	.222	**.608**
Item 13	.232	**.832**	-.005	.101	-.063	-.138
Item 14	.051	**.746**	-.138	.242	.169	.036
Item 15	-.002	.109	.013	**.748**	.026	.068
Item 16	-.007	.112	.118	**.621**	.254	-.349
Item 17	.056	.231	.019	**.542**	-.060	.218
Staff						
	1	2	3	4	5	
Item 1	.153	-.066	-.022	.178	**.789**	
Item 2	.020	-.106	-.129	**.484**	-.434	
Item 3	.095	**.809**	-.028	.102	.022	
Item 4	.115	.117	**.907**	.110	.017	
Item 5	.005	.065	**.916**	.068	.133	

Item 6	-.016	**.535**	.243	.420	-.126
Item 7	.027	.051	.243	**.630**	.208
Item 8	.087	**.360**	.117	.097	.093
Item 9	-.010	**.822**	-.007	-.093	.018
Item 10	-.057	.336	.057	**.540**	-.025
Item 11	**.771**	.084	-.041	.219	.138
Item 12	**.550**	.072	-.038	.445	.057
Item 13	**.778**	.164	.046	.198	.184
Item 14	**.847**	.017	.107	-.039	.007
Item 15	**.578**	-.014	.083	-.261	.090
Item 16	.011	.101	.113	-.070	**.718**
Item 17	**.704**	-.029	-.008	-.220	-.269

Table 7 supplementary material – Cronbach's alpha for factors

	Patients		Staff	
	Items	Cronbach's alpha	Items	Cronbach's alpha
Factor 1	3, 6, 8, 9, 10	.70	11, 12, 13, 14, 15, 17	.80
Factor 2	11, 13, 14	.74	3, 6, 8, 9	.61
Factor 3	4, 5	.78	4, 5	.85
Factor 4	15, 16, 17	.44	2, 7, 10	.30
Factor 5	1, 7	.33	2, 7, 10	.42
Factor 6	2, 12	.05		

Table 8 supplementary material – Cronbach's alpha for original subscales

		Patients	Staff
	Items	Cronbach's alpha	Cronbach's alpha
Physical subscale	1 - 10	.64	.60
Emotional subscale	11 - 14	.70	.81
Communication and problems subscale	15 - 17	.44	.34

Table 9 supplementary material – Intra-class correlations between patient and staff scores for items and subscales

	Intra-class correlation	95% confidence interval (average measures)	
	Average measures	Lower Bound	Upper Bound
Item 1	.721	.622	.794
Item 2	.765	.681	.827
Item 3	.605	.464	.709
Item 4	.665	.546	.753
Item 5	.733	.638	.803
Item 6	.534	.367	.656
Item 7	.538	.372	.659
Item 8	.397	.181	.556
Item 9	.535	.368	.657
Item 10	.650	.525	.742
Item 11	.542	.377	.662
Item 12	.380	.158	.543
Item 13	.548	.386	.667
Item 14	.579	.428	.690
Item 15	.342	.102	.519
Item 16	.195	-.095	.409
Item 17	.516	.338	.646
Physical subscale	.673	.556	.759
Emotional subscale	.642	.514	.737
Communication and problems subscale	.511	.331	.643

Table 10 supplementary material – Pearson's correlations between patient IPOS-Fr and MQOL-R items and subscales

	Time of evaluation	Pearson's correlation (sig.)
IPOS total score and MQOL-R	T1	-.623*
total score	T2	-.628*
IPOS physical subscale and	T1	-.461*
MQOL-R physical subscale	T2	-.463*
IPOS item 11 and MQOL-R	T1	-.601*
psychological subscale	T2	-.630*
IPOS item 13 and MQOL-R	T1	-.633*
psychological subscale	T2	-.799*
IPOS item 14 and MQOL-R	T1	-.331*
existential subscale	T2	-.459*
IPOS item 12 and MQOL-R	T1	-.007
social subscale	T2	-.119
IPOS item 15 and MQOL-R	T1	-.511*
social subscale	T2	-.372*

MQOL-R: McGill Quality of Life-Revised questionnaire; *p=.000

Table 11 supplementary material – Sensitivity to change between T1 and T2 based on IPOS-Fr total score

	Mean T1 (SD)	Mean T2 (SD)	z	p
No change (n=26)	22.8 (7.4)	21.2 (8.7)	-1.467	.142
Improvement (n=41)	22.2 (8.8)	19.5 (7.1)	-2.326	.020
Worsening (n=36)	21.8 (7.8)	22.8 (7.8)	-.947	.344