

## LAST 3 MONTHS OF LIFE IN HOME-VENTILATED PATIENTS: THE FAMILY PERCEPTION

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## **ABSTRACT (n° of words 198)**

**Purpose.** We studied the family's perception of care in patients under home mechanical ventilation during the last 3 months of life.

**Methods.** In 11 Respiratory Units, we submitted a 35-item questionnaire to relatives of 168 deceased patients exploring six domains: symptoms, awareness of disease, family burden, dying, medical and technical problems.

**Results.** Response rate was 98.8%. The majority of patients complained respiratory symptoms and were aware of the severity and prognosis of the disease. Family burden was high especially in relation to money need. During hospitalisation, 74.4% of patients were admitted to ICU. 78 patients died at home, 70 patients in a medical ward and 20 in ICU. 27% of patients received resuscitation manoeuvres. Hospitalisations and family economical burden were unrelated to diagnosis and mechanical ventilation. Families of the patients did not report major technical problems on the use of ventilators. In comparison with mechanical invasively ventilated patients, noninvasively ventilated patients were more aware of prognosis, used more respiratory drugs, changed ventilation time more frequently and died less frequently when under mechanical ventilation.

**Conclusions.** We have presented lights and shadows regarding end-of-life care in home mechanically ventilated patients. Noninvasive ventilation use and diagnosis have impact on this burden.

## **List of Abbreviations:**

COPD: Chronic Obstructive Pulmonary Disease

**ALS: amyotrophic lateral sclerosis**

CRF: Chronic Respiratory Failure

**CWD: chest wall diseases**

FEV1: Forced Expiratory Volume at First Second

GP: General Practitioner

**HCS: Health Care System**

HMV: Home Mechanical Ventilation

ICU: Intensive Care Units

NIV: Noninvasive Mechanical Ventilation

**NMD: neuromuscular diseases**

OR: Odds Ratios

PLS: Pre-Morbid Lifestyle

## **INTRODUCTION (Text body without references: 3266 words)**

Quality of end-of-life care and of quality of good dying are increasingly recognised as primary tasks for health care providers, both clinicians and institutions [1, 2]. A few studies have assessed the role of providers in these tasks, both from the perspective of patients [1] and their families [3-7]. The main reported problems were: identification of quality of end-of-life care, adequate management of pain and symptoms, emotional support, inappropriate prolongation of life, sense of awareness and control of the disease, relief of burden on family members, fair treatment and adequate communication with physicians. Some studies have assessed single components of end-of-life problems or care in patients with cancer or chronic progressive diseases [8-14]. Lack of surveillance, inadequate services and absence of palliative care have been also advocated in end stage of patients with chronic obstructive pulmonary disease (COPD) [15]. Patients with chronic respiratory failure (CRF) may receive life-support or life sustaining therapy in the terminal phase of their disease [16, 17], the quality of home services depending on specific geographical situations and often mainly relying only on the family or on the general practitioner (GP). A recent European survey [18] showed that approximately 6.6/100.000 patients are ventilated at home, many of these being managed in intensive care units (ICU) depending on the country. In these patients, underlying disease, level of dependency, hours spent under home mechanical ventilation (HMV), presence of tracheotomy, home distance from hospital and hospital accesses are the major burden care for families and Health Care System (HCS) [19]. Surprisingly, there are no studies that address the perceived quality of end-of-life care in this type of patients.

The aim of the current study was to determine – by the use of a specifically-designed questionnaire – the families' attitudes regarding end-of-life care in the last 3 months of life of patients on HMV delivered either invasively or non-invasively.

## **METHODS**

### *Patient Population*

This investigative multicenter protocol was approved by the Ethics Committees and review boards of the Institutions involved and it was conducted according to the declaration of Helsinki.

Between 1<sup>st</sup> April 2000 and 30<sup>th</sup> September 2005, the main caregiver among family members of all consecutive patients died after following a HMV programme in 11 Italian Respiratory Units was contacted. He/she was provided with a questionnaire investigating the last 3 months of his/her relative's life. No patients were excluded for non-identified familiar caregivers or because resident in a nursing home. The cause of patient's death was retrieved either from the hospital record or from death certificate to exclude hypothetical accidental deaths. Underlying diagnosis was identified according to the Eurovent classification and definition [18]. Modalities of ventilation were also recorded from clinical reports. No dedicated or structured palliative home care services for respiratory patients were available during the study.

### *Other Measures*

We took into consideration the following: i) number of chronic comorbidities as assessed by hospitals' discharge registers (including peripheral vascular, cerebrovascular, coronary artery, acquired immunodeficiency syndrome, hepatic cirrhosis, or diabetes), ii) pre-morbid lifestyle (PLS) score (from bedridden to active) [20], iii) years of MV, iv) number of tracheotomised patients with invasive MV, type of tracheotomy cannula used, type of mask for noninvasive MV (NIV), daily hours of MV, type of ventilation and percentage of patients under long-term oxygen therapy were considered.

### *Setting*

Usually, the public HCS funds the care package, the ultimate responsible for general and palliative care being the GPs. However, the responsibility for ventilator malfunction depends on the

respiratory teams. Moreover, the outreach nurses care availability is unstructured and varies from region to region.

### Questionnaire

The Steering Committee of the study, composed by a panel of medical doctors, psychologists, nurses, respiratory therapists, patients with respiratory end-stage diseases and caregivers, developed and approved the questionnaire. The development of this questionnaire was based on: i) data already published in the literature [1-7] and ii) a conceptual framework of end-of-life care based on “clinical and emotional” perspective or interviews with patients and families. The preliminary draft of the questionnaire was tested to assess readability and clarity with a focus group of external specialists including a clinical ethicist, nurses and palliative care specialists. We have also submitted it to the evaluation of 10 patients and their families who met the inclusion criteria in order to identify unclear questions. They were asked to make comments, changes and suggestions to improve the quality of the questionnaire, and to point out those questions that could be uncomfortable or embarrassing.

The final 35-binary item questionnaire is shown in the Appendix. Briefly, it is composed of six specific domains, four directly dealing with end-of-life care: 1) control of symptoms [1-7], 2) awareness and control of disease [1], 3) family burden [1-7] (assistance burden as time spent for care or requested to a private member and financial burden as direct costs of drugs and equipment, indirect costs such as loss of employment, time off work for caregivers), 4) the process of dying 5) medical (visits and hospitalisations) and 6) technical (ventilator-related) problems. The questionnaire was explained by the medical staff to a family member of the patients who died within 1-3 months. The face-to-face interview was performed by a physician not directly involved in the patient care. All data were coded and kept strictly confidential.

### Statistical Analysis

Patient population was classified in four subgroups according to main diagnosis of COPD or No-COPD, and use of NIV or MV via tracheotomy. Statistical analysis was performed using SPSS 13.2 software (\*www.spss.com\* <http://www.spss.com/>). Summary results are expressed as percent of informant positive (=yes) responses. A descriptive analysis was performed for each of the 35 binary questions cross-tabulated in 2x4 tables by using Logistic Regression modelling to identify differences among subgroups. The *t*-test (=parameter/standard error) was used to analyse the logistic regression odds ratios (OR) of conditional, and interaction effects of diagnosis, and HMV mode on the binary responses. A 2-side p-value <0.05 was considered statistically significant.



## RESULTS

### *Patient Population*

The entry criteria differed among the involved units in view of the different number of HMV patients in the single unit. This was due to the different years of involvement in this field, different local management and plan/organisation of community ventilatory care of HMV patients, and general management of end-stage respiratory disease.

930 patients [73% under NIV and presenting the following diseases: 36 % COPD, 16% amyotrophic lateral sclerosis (ALS), 16% neuromuscular diseases (NMD), 18% chest wall diseases (CWD) and 13% others] were cared at home during the study period. 168 questionnaires were filled-in out of 170 dead patients (98.8%). Only two family members refused to participate in the study.

**Table 1** shows the demographic and clinical characteristics of the population. Most respondents (62%) were either the spouses or the partners of the deceased; the remaining was a different relative. There was a small prevalence (55%) of invasive MV in comparison with NIV being the choice between the two performed by the caring physicians according to clinical parameters and by patient's desires. 69 patients had COPD as diagnostic category, while the remaining had no-COPD diagnosis as ALS, NMD and others. Patients were aged, had multiple comorbidities with poor PLS, have been used HMV since 2 years with a high daily compliance. No-COPD patients used more frequently volume preset in comparison with COPD patients.

**Table 2** shows the frequency distributions (percentage of "yes" responses) of each question per each domain across the whole group, and the OR estimate by Logistic Regression among the four subgroups studied (no-COPD vs. COPD, and NIV vs. tracheotomy users) in relation to 1-6 domain.

### Domain 1: Control of Symptoms

The majority of patients complained of respiratory symptoms while other symptoms (i.e. neuropsychological or abdominal) were present only in a small percentage. Few patients added and/or increased the drugs prescribed at the time of a previous hospital admission or visit, meaning that symptoms control was obtained only in about 50% of the patients. Sedatives and opiates prescription was very low (15.5%) being patients with ALS using these drugs more frequently (19%). The specialists were marginally (36%) involved in the drugs' "adjustment". The presence of neuropsychological symptoms was 0.66 times lower for patients with COPD than for no-COPD. In details, caregivers of patients with ALS described depression, anxiety and sleeping disturbances in 24%, 12% and 8 % of the cases, respectively. NIV users were more likely (OR=2.36) to get more respiratory drugs compared to those patients under invasive MV since they complained more respiratory symptoms (OR=2.94).

### Domain 2: Awareness of the Disease

The majority of the patients seem to be well aware of the severity and prognosis of their disease: they could feel the progression of the disease mainly because their doctors explained to them the clinical status and disease expectations. NIV users were less likely (OR=0.46) to be conscious of their disease and they reported a higher feeling of progressive worsening (OR=3.15) compared to those under invasive MV.

### Domain 3: Family Burden

Once the patients were at home, overall the family burden was high, since they received very little help from the national HCS, and from other forms of private or voluntary assistance (patients with ALS were cared by private assistance in the 26% of the cases). Financial burden was reported to be excessively high in 17.3% of the cases. However, in those patients receiving NIV compared to

those undergoing invasive MV, the costs due to the ventilation itself was reported to be considerably lower (OR=0.26).

#### Domain 4: The Process of Dying

78 patients died at home. The remaining 90 patients were hospitalised due to the last exacerbation before death. Within this subgroup, 40 patients (44%) were admitted to ICU where patients with COPD were more likely (OR=1.54) to be admitted than no-COPD. However, only 20 out of 40 hospitalised patients (22% of the whole group and 50% of the ICU group) died in the ICU, a part of them after withdrawing ventilatory assistance.

Interestingly, few patients received a resuscitation manoeuvre. NIV users were less likely to die under MV (OR=0.26) or during sleep (OR=0.79) compared to the invasively ventilated patients. In details, patients with ALS died at home, received resuscitation manoeuvres and called emergency in 78%, 14% and 30% of the cases, respectively.

#### Domain 5: Medical Problems

The use of health care resources in the last 3 months was very high, since at least one hospital admission was necessary in 121 patients (72% of the cases). When in hospital, 74.4% of patients (n=90) were admitted to ICU; GPs and specialist's visits were very frequent. No significant differences were observed between the different modes of ventilation and types of pathology. A borderline statistically significant increase in the number of hospital admissions due to respiratory reasons (p=0.055) was observed in the group of patients with COPD vs. no-COPD (OR=0.79), irrespectively of the ventilation modality. When hospitalised, all patients with ALS needed respiratory assistance and only 12% of cases were admitted to ICU.

### Domain 6: Technical Problems

Overall, the patients did not experience severe technical problems with the ventilator that was changed in about 1/3 of the population mainly for maintenance reasons. Ventilation parameters had to be modified in <50% of the patients during the last 3 months and this was almost equally decided by either the specialist or GP. Patients undergoing NIV had a higher chance of having changed their time on ventilation (OR=3.12) compared to the patients undergoing invasive MV. This was frequently decided by the specialist (OR=2.23). These technical problems were 2.59 (p=0.046) times higher in no-COPD-NIV patients vs. COPD-tracheotomy ventilated ones [the only significant interaction (not reported in Table 2)]. In NIV patients, technical problems were mainly related to changes in masks as patients became more ventilator-dependent. Patients with ALS frequently presented troubles under HMV (24%) and ventilator change (43%) while change in time spent under HMV was less frequent (23%).

## DISCUSSION

The main findings of the current study present lights and shadows regarding end-of-life care of HMV patients: overall, patients were aware of their prognosis and disease severity since well informed by their doctors. 50% of the caregivers reported symptoms control in their relatives but the relief of the respiratory symptoms was not easily achieved despite the use of drugs and sedatives. Family burden and hospitalisation access were high. Deaths were equally distributed between home and hospital. NIV use and diagnosis may have influenced this familial reporting.

This is the first study assessing the families' view and attitudes of quality of care in the last 3 months of life of patients with CRF and receiving long-term HMV. As reported in other studies [18,31] on HMV in European countries, we found differences between i) data collected from different centres (range: 6-40 patients/centre), ii) number of patients discharged at home, iii) diagnosis and iv) number of patients under NIV referred centres. Conversely, the percentage of patients under invasive ventilation, obstructed or with ALS was much higher in the dead patients in our study due to the higher risk mortality.

The last few months of life of patients with CRF are characterised by poor control of pain and severe dyspnoea [11, 21, 22]. As shown in previous studies, most of these patients, like those with COPD, are confined to their home and/or wheelchair [11]. HMV is not necessarily associated with relief of dyspnoea. Indeed, it might be perceived as uncomfortable due to hyperinflation, bronchospasm and, most of all, difficulty in achieving a fair patient-to-ventilator interaction. Opiates for palliative care were poorly used and this may be explained both by the occurrence of side effects (mainly, unacceptable drowsiness) and the poor confidence and knowledge of GP vs palliative drugs and protocols.

Doctor-to-patient communication is one of the major challenges in everyday clinical practice [21, 23]. Most of the patients with chronic progressive disorders want to be informed about their diagnosis and prognosis, but this does not necessarily mean that they are ready to afford this

psychological burden [24, 25]. The awareness of their clinical status may help patients to achieve a sense of control, and possibly help them to decide against inappropriate prolongation of life. According to their families, >80% of the patients were informed about the time course and severity of their disease by a physician, and were aware of their prognosis. Families often feel frustrated by the difficulty of relieving pain and other symptoms in the final stages of the disease, and most of them also experience major financial burdens [3, 4, 6, 26]. Common ways to deal with these problems are either to receive external financial or caregiver support at home [4] or to admit the patient to the hospital [27]. Patients getting free assistance (that is only for few hours/day) were also helped by private assistants with no specific training and sporadically by a religious organisation providing support.

Most elderly and seriously ill patients die in an acute care hospital setting or in-patient hospice, nursing home, or assisted living, so that only a very small percentage of them die at home [28]. Our survey indicates that in Italy, half of the ventilated patients die at home probably due to lack of hospice and nursing homes dedicated to HMV patients and due to the good acceptability of the home care programme proposed to the family. A great number of patients died in hospital and this event may be considered a “failure” of end-of-life care protocol. This is not a contradictory result considering the increased difficulty in predicting non-cancer deaths (such in patients with COPD) in perceiving if a relapse is the “last” one. For this reason, the majority of patients and families requested to our care staff the “final” hospital admission both for palliative and for sophisticated MV care. In our Country, there is no specific law about advanced directives, so that admission to the hospital was mainly based on subjective judgment and/or request by the patient, the family or GPs.

Early identification and acknowledgment of end-of-life care choices may heavily influence the quality of life of patients during the dying process [29]. Thus, resuscitation manoeuvres, which are performed “only” in <30% of patients, are unrelated to patient desires, but rather based on the physician’s judgment.

Surprisingly, home nurse public assistance was requested/offered in the minority of the cases (14%) in contrast with the high request of medical assistance (57% for pulmonologist and 72% for GP). The use of HMV is often associated with technical problems [30, 31]. In our survey, most interventions on the ventilator were for scheduled maintenance rather than for malfunctions. The majority of these interventions were performed by a respiratory specialist since most general physicians do not receive specific training in HMV.

As expected [19], patients with ALS resulted in high burden to their families in particular for respiratory encumbrance and ventilator troubles; this burden was partially reduced by a higher private assistance request. The poor prognosis of ALS justifies the limited admissions in ICU and use of cardiopulmonary resuscitation, thus resulting in patients remaining at home to die.

The results of our study are strengthened by the high rate of participation (168/170) with observations based on home families rather than in-hospital view. This unusual response rate may be explained by the strict and well conducted follow-up programmes proposed by the sanitary staffs to these frail patients and families. Although organisation of home care varies from country to country, we believe that some findings can be generalised and applicable to most of the personnel involved in the home care field. The findings are likely to lead to genuine debate and improvements to the care of these patients.

### **Limitations of the Study**

Our research also presents some flaws that deserve careful evaluation. First, the current study only addresses the relatives' view and we do not know if this really reflects the real situation of the patients during the last months of their life. Secondly, the questionnaire was retrospectively filled in, and we do not know if this really reflects all the real situation of the last months of the patient. It is noteworthy that the majority of domains could be filled-in only after the patient's death. Moreover, the binary questionnaire that we used has not been validated and especially religious questions or data on health care support and medical supply might be different among countries. The questionnaire was proposed from a team who provided ventilatory care to the

patients: therefore, the families might have not wished to sound ungrateful while answering. Although the questionnaire was administered by a doctor not involved in HMV prescription and followed-up to avoid or minimise the bias, it is possible that a “special” emotional link was probably built between the hospital teams and the caregivers. However, it is also true that the large majority of the questions were focused on “objective” items, so that the emotional factor, if any, was of marginal importance. Another limitation is that a long stay in hospital during the last three months may have influenced the family burden thus resulting lower, especially in the financial aspects, when compared to patients with short or no hospitalization. Furthermore, differences between patients receiving invasive ventilation and NIV are interesting. However, the type of ventilatory support was likely dependent on disease severity and category and other individual factors. Since this was not a controlled trial, conclusions of these two entities should be performed with caution.

## **Conclusions**

Our study presents lights and shadows regarding end-of-life care in HMV patients. Noninvasive ventilation use and diagnosis have impact on this burden. Due to the complex topic addressed, we believe that we cannot provide any strong conclusion or generalisation of results on this important area. Recommendation for further studies should be undertaken to better characterise the specific deficiencies of care and determine how quality of end-of-life care can be improved.



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**TABLE 1. Demographic and Clinical Characteristics of Patients in the Study**

	<b>Whole Group</b>	<b>COPD</b>	<b>No-COPD</b>
<b>Patients, n</b>	<b>168</b>	<b>69</b>	<b>99</b>
<i>ALS, n</i>	/	/	42
<i>CWD, n</i>	/	/	34
<i>NMD, n</i>	/	/	19
<i>Others, n</i>	/	/	4
<b>Age, yr</b>	68±8	74±7	65±14
<b>Sex (M/F), n</b>	116/52	80/32	36/20
<b>Patients' caregivers, n (%)</b>			
spouse or partner	104 (62)	47 (68)	57 (56)
children	47 (28)	22 (32)	25 (25)
parents	17 (10)	0 (0)	17 (19)
<b>Comorbidities, n/patient</b>	1.7±1.4	2.1±1.6	1.4±1.0
<b>PLS</b>	2.5±0.9	2.6±1	2.4±0.7
<b>Duration of ventilation, y</b>	2.8±2.0	2.7±1.2	2.9 ± 1.9
<b>Tracheotomy, n (%)</b>	92 (55)	27 (39)	65 (66)
<b>NIV, n (%)</b>	76 (45)	42 (61)	34 (34)
Nasal mask, n (%)	61 (80)	39 (93)	22 (64)
Facial mask, n (%)	15 (20)	3 (7)	12 (36)
<b>Daily Average time of ventilation use, h</b>	14±5	12±6	18±4
<b>Type of ventilation, n (%)</b>			
Pressure present, n (%)	96 (57)	57 (83)	39 (39 )
Volume present, n (%)	72 (43)	12 (17)	60 (61)
<b>Long-term O<sub>2</sub> supply, n (%)</b>	109 (65)	69 (100)	40 (40)

**Legend:** COPD=chronic obstructive pulmonary disease; ALS= amyotrophic lateral sclerosis; CWD=chest wall disease; NMD= neuromuscular disease; PLS= premorbidity lifestyle score (ref 21); NIV= noninvasive mechanical ventilation.

**TABLE 2. Frequency Distributions (percentage of “yes” responses of the whole sample), and ML (maximum likelihood) Odds Ratios Estimates the Effect of Diagnosis (no-COPD vs. COPD) and the Effect of Users (NIV vs. tracheotomy ventilation) of Each Question per Each Domain**

		OVERALL COHORT	ODDS RATIOS	
		(n=168)	Effect of diagnosis	Effect of users
		Expressed in percent	(no-COPD vs. COPD)	(NIV vs. tracheotomy)
<b>DOMAIN 1: control of symptoms</b>				
Q 1	Presence of respiratory symptoms	81	1.01	2.94 (p=0.024)
Q 2	Presence of neurological symptoms	31	0.66 (p=0.017)	1.10
Q 3	Presence of abdominal pain	10.7	0.89	0.41
Q 4	Respiratory drugs increase	17.9	0.88	2.36 (p=0.037)
Q 5	Sedatives use	15.5	0.64	0.59
Q 6	Symptoms control	58.9	1.17	0.65
Q 7	Was the pulmonologist the main figure who changed therapy	36.3	0.75	1.27
<b>DOMAIN 2: awareness of the disease</b>				
Q 8	Aware of the gravity	86.9	0.81	1.31
Q 9	Aware of the prognosis	75.6	0.76	0.46 (p=0.038)
Q 10	Anyone (doctor) explained gravity and prognosis	69.6	0.89	0.58
Q 11	Feel a progressive disease worsening	83.9	0.90	3.15 (p=0.019)
<b>DOMAIN 3: family burden</b>				
Q 12	Free public home nursing service	38.7	1.10	1.29
Q 13	Private home assistant	6	0.95	1.22
Q 14	Additional spiritual support from a religious organisation	19.6	0.98	0.65
Q 15	Friends and/or voluntary service	22.6	1.17	0.54
Q 16	Higher financial burden for HMV	10.7	0.68	0.26 (p=0.030)
Q 17	Higher financial burden for care	17.3	0.86	0.78
<b>DOMAIN 4: the process of dying</b>				
Q 18	Died at home	46.4	0.89	0.58
Q 19	Died in ICU	22	1.54 (p=0.012)	1.21
Q 20	Called anyone before death	48.8	0.96	0.63
Q 21	Called emergency number	27.4	1.14	1.46
Q 22	Death during sleep	34.5	1.38	0.79 (p=0.033)

Q 23	Death during HMV	55.4	1.05	0.26 (p<0.001)
Q 24	Resuscitation manoeuvres	27.4	1.29	1.58
<b>DOMAIN 5: Medical problems</b>				
Q 25	Hospital admissions within last 3 months	72	0.81	1.13
Q 26	Respiratory reasons for admissions	78	0.79 (p=0.055)	1.98
Q 27	When hospitalised admitted in ICU	74.4	0.86	1.21
Q 28	GP examination in the last 3 months	72.6	0.96	1.04
Q 29	Home nurse public assistance in the last 3 months	13.7	0.97	1.14
Q 30	Respiratory specialist visit in the last 3 months	57.7	0.93	1.13
<b>DOMAIN 6: Technical problems</b>				
Q 31	Problems for MV	14.9	0.78	1.50
Q 32	MV changed	32.1	0.89	0.93
Q 33	MV parameters changed	22	0.90	0.88
Q 34	Time spent under MV changed	38.09	0.91	3.12 (p=0.001)
Q 35	Pulmonologist/Intensivist changed MV time and setting	43.5	0.76	2.23 (p=0.015)

## **Appendix: QUESTIONNAIRE**

### **Domain 1: ADEQUATE PAIN AND SYMPTOMS MANAGEMENT**

**1. Did the patients present respiratory symptoms (dyspnoea, thorax pain, secretions) in the last three months of life?**

1) YES

2) NO

**2. Did the patients present neuropsychological symptoms (sleep, headache, confusion, anxiety, and depression) in the last three months of life?**

1) YES

2) NO

**3. Did the patients present abdominal symptoms in the last three months of life?**

1) YES

2) NO

**4. Did the patients increase the use of respiratory drugs compared to last hospital prescription?**

1) YES

2) NO

**5. Did the patients increase the use of sedative drugs – including morphine – compared to last hospital prescription?**

1) YES

2) NO

**6. Did the use of drug control the symptoms?**

A) Yes

B) NO

**7. Who decided modification and/or addition of drugs?**

A) Pulmonologist

B) GP

### **Domain 2: ACHIEVING A SENSE OF CONTROL**

**8. Do you think the patient was conscious about the gravity of his illness?**

A) YES

B) NO

**9. Do you think the patient was always conscious about the prognosis of his/her illness?**

A) YES

B) NO

**10. Has anyone (doctor) explained to the patient the prognosis of the illness?**

A) YES

B) NO

**11. Did the patient feel a progressive worsening of the disease?**

A) YES

B) NO

**Domain 3: RELIEVING BURDEN**

**12. Did the family receive free public home nursing service help?**

A) YES

B) NO

**13. Did the family pay for private home assistant help?**

A) YES

B) NO

**14. Did you receive spiritual religious additional support at home during the last period of time before death?**

A) YES

B) NO

**15. Did you receive friends and/or voluntary service association as additional support during the last period of time before death?**

A) YES

B) NO

**16. Did you have a higher economical burden for equipments and material for mechanical ventilation?**

A) YES

B) NO

**17. Did you have a higher economical burden for sanitary care?**

A) YES

B) NO



**Domain 4: AVOIDING INAPPROPRIATE PROLONGATION of DYING**

**18. Did the patient die at home?**

A) YES

B) NO

**19. If admitted to the hospital, did the patient die in ICU?**

A) YES

B) NO

**20. In the moment of the “final” worsening, did you call anyone?**

A) YES

B) NO

**21. In the moment of the “final” worsening, did you call emergency number?**

A) YES

B) NO

**22. Did the death happen during sleep?**

A) YES

B) NO

**23. Did the death happen under HMV?**

A) YES

B) NO

**24. Was a resuscitation manoeuvre performed at home or in the hospital?**

A) YES

B) NO

**Domain 5: MEDICAL PROBLEMS**

**25. During the last three months, was the patient admitted to a hospital?**

A) YES

B) NO

**26. Were respiratory problems responsible for hospital admission?**

A) YES

B) NO

**27. Was the patient admitted to the ICU?**

A) YES

B) NO

**28. During the last three months, was an at home examination of the general practitioner necessary?**

A) YES

B) NO

**29. During the last three months, has the frequency of the home nurse public assistance been intensified?**

A) YES

B) NO

**30. During the last three months, was an examination of a respiratory specialist necessary?**

A) YES

B) NO

**Domain 6: TECHNICAL PROBLEMS**

**31. Were there any problems for the use of mechanical ventilation in the last three months before death?**

A) YES

B) NO

**32. Have you changed mechanical ventilation in your possession?**

A) YES

B) NO

**33. Was it necessary to change parameters of mechanical ventilation in the last three months?**

A) YES

B) NO

**34. Was time spent modified under mechanical ventilation in the last three months?**

A) YES

B) NO

**35. Was the setting and time modifications ever decided and performed by pulmonologist/intensivist?**

A) YES

B) NO