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## PALLIATIVE CARE | RESEARCH ARTICLE

# Factors associated with the decision-making process in palliative sedation therapy. The experience of an Italian hospice struggling with balancing various individual autonomies

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**Abstract:** In this observational and retrospective study, the authors aimed to evaluate how the practice of palliative terminal sedation therapy (PST) in a hospice setting has changed in a given period of clinical activity and which psychosocial factors have influenced it. We considered the prevalence of palliative/terminal sedation therapy (PST) and the prevalence of some factors associated with the decision-making process in PST (awareness of death, impairment of cognitive function, discussion of sedation with physicians, etc.). Despite a downward trend in patients without awareness of death, the interlocutor of the decision-making process is always the caregiver (44 vs. 28% for the patient). Furthermore, the probability that conscious sedation preceded deep sedation was significantly reduced when the principal interlocutor in the decision-making process was the caregiver. The weight of the decision-making of the patient seems to be relative to an awareness of the death process and the families' responsibility is a relevant aspect in advanced care planning.

**Subjects:** Death and Dying; Medical Ethics; Palliative Medicine

**Keywords:** palliative sedation; end-of-life care; decision-making process; autonomy; death awareness; family coping; surrogate decision



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With the palliative care team she is interested to expand the knowledge of the phenomena related with the process of awareness of impending death and prognosis and is going to arrange a qualitative research project. With her group she has published two recent articles in *Body, Movement and Dance Psychotherapy Journal* about the use of dance movement therapy as instrument sustaining the awareness in the patient, family and health providers engaged in Hospice.

### PUBLIC INTEREST STATEMENT

This observational study has been conducted in an Italian hospice setting and concerns the attitudes toward end-of-life decisions. In particular the authors aimed to evaluate the influence of some factors associated with the decision-making process in the practice of palliative terminal sedation that is the pharmacological reduction of consciousness in patients faced on death.

Despite use of protocols and guidelines, it appears to be a complex treatment with a certain amount of conditioning (cultural, social, emotional, and ethical), as well as practical experience and professional competence. The quest for individual autonomy shifts forms of social inter-connectedness, so it is impossible to focus on individual preferences without a nuanced understanding of the family context. In the data the weight of the decision-making of the patient seems to be relative to an awareness of the death process and the families' responsibility.

## 1. Introduction

The use of palliative sedation therapy (PST) is carried out according to national guidelines (for example, Italian recommendations of the Italian Società Italiana di Cure Palliative [SICP], 2007) and international guidelines (with the framework of the European Association for Palliative Care, EAPC, 2009, or the National Hospice and Palliative Care Organization, NHPCO, Kirk & Mahon, 2010). The recommendations concern definitions, indications, methods, medications, risks and steps of the decision-making process. Claessens, Menten, Schotmans, and Broeckaert (2008) and Schildmann and Schildmann (2014) have published systematic and critical revisions of guidelines that are being compared regarding important aspects of PST: prevalence, type of sedation (mild or deep), survival, medication, food intake, fluid intake, decision-making, attitudes of physicians, family experience, efficacy, safety and important ethical issues consequent to the definition of refractoriness of symptoms, existential suffering, patient information, and family consent.

The picture drawn exhibits considerable variability regarding clinical as well as ethical aspects of indications, patient information and treatment decisions. For example, the prevalence of PST in palliative care units or hospice ranged between 3.1% (Menten, 2003) and 51% (Kohara, Ueoka, Takeyama, Murakami, & Morita, 2005) to 68% (Vitetta, Kenner, & Sali, 2005). This variability includes differences across countries (Miccinesi et al., 2005) and within the same country. In two Italian studies cited in Claessen's review, the prevalence varied between 52.5% (Ventafridda, Ripamonti, De Conno, Tamburini, & Cassileth, 1990) and 25% (Peruselli et al., 1999). This variability has not changed, at least not in the Italian scenery, as reported in a more recent review (Maltoni et al., 2012) with a range in the number of patients receiving sedation of 14.6–66.7%. Differences in case-mixes and different definitions of PST (Maltoni et al., 2012) could explain the wide variation in the prevalence of sedated patients. Regarding decision-making, the EAPC framework recommends family involvement but emphasizes that the family is not the decision-maker. The Japanese guideline requires consent from the family. The NHPCO recommends a family-centred approach for palliative care, but states that the needs of the patients have priority in the case of differences between family preferences and the best interests of the patients. To explain the different perspectives, the two reviews mentioned above emphasize the importance of cultural and country-specific aspects. Families also experienced high levels of emotional distress related to palliative sedation; the literature (Claessens et al., 2008) reports conflicts in the opinions between family members (15%), the patient and the family (7.6%), and the medical staff and the family (9.7%). Among the factors influencing the physician's decision to choose continuous deep sedation, Morita, Akeki, Sugawara, Chihara, and Uchitomi (2002) refers to the greater preference of symptomatic treatment or higher levels of emotional exhaustion. Therefore, PST appears to be a complex treatment with a certain amount of conditioning (cultural, social, emotional, and ethical), as well as practical experience and professional competence.

Therefore, we looked back at our experience with the aim to explore how much we were consistent or not with the procedural guidelines of PST, especially focusing on some indicators regarding the decision-making process. We were particularly careful in considering whether our clinical practice had changed over time and what the attitude was towards patients' autonomy and family involvement. In a prospective observational study in two Italian hospice settings (Maltoni et al., 2012), the family involvement in clinical decision-making regarding sedation was 100%, and patient involvement was significantly different (59.3% in Hospice B vs. 24.4% in Hospice A). The authors attribute this difference to different case-mixes but also to variable communicative behaviour perhaps for the physician's anxiety about the consequences of disclosing such delicate information to patients.

We agree with the perspective that the patient's role within decision-making processes depends on the extent to which he or she is able to or wants to take over the responsibility of his or her own choices (cultural and social issues) and on the ability of physicians to get away with emotional pressure at the intrapsychic and intersubjective levels (cultural issues and competence with a focus on communication skills and systematic analysis of clinical experiences) to balance the ethical tension among the different individual autonomies in the field, that is the effort to transform the cultural level of society and dominant opinions (social issues).

## 2. Setting

The study occurred in the hospice Il Gelso in Piedmont, Northern Italy. It has been a public health structure of the Alessandria Health Unit (ASL AL) since 2007. The costs of care are completely refunded by the regional health system with a daily charge that does not depend neither on the therapeutic intervention applied (complexity of intervention, costs of drugs, etc.) nor on the length of stay (up to four months of hospitalization is about 258 Euro, after this time the daily charge is reduced by 40%) (Regional Council of Piedmont, 2001). The province of Alessandria has a population of approximately 400,000 inhabitants. The 16-bed hospice Il Gelso admits an average of 300 patients per year and has an 80% mortality rate, with 20% of the patients discharged after a period of clinical stabilization or respite care for the family. These patients are followed by the palliative home care team. The average hospital stay is less than one month. The hospice team consists of 7 registered nurses, 12 nursing aides, 1 nursing coordinator, 1 chief medical officer, 1 psychologist specializing in psycho-oncology and 3 physicians with experience in palliative care. One of these is a psychotherapist with training in non-verbal therapies. The hospital statistical indicators are estimated as an average of annual indices<sup>1</sup> from 2007 to 2014 (on 2,096 patients admitted). The average length of stay (AVLS) is 12.7 days; the bed occupancy rate (BOR) is 71.5%; the bed turnover ratio (or rotation index) is 22.2; and the substitution interval (SI) is 4.9.

## 3. Aims

The principal aim was to evaluate how the practice of palliative terminal sedation therapy (PST) in a hospice setting has changed. We compared the differences in prevalence of some variables between three chosen years. Some indicators associated with the decision-making process were evaluated: awareness of death, impairment of cognitive function, communication skills when sedation was proposed, and who was the main interlocutor of the decision-making process in discussion of sedation with physicians).

## 4. Methods

This was a retrospective observational study that included all patients admitted in the first six months (from January 1st to June 30th) of each of three selected years (2010–2013–2014). The first year, 2010, was chosen because it was after at least three years of established clinical practice; then we compared it with 2013 (that is, after further three years of clinical practice). We added the first half of 2014 to run a further point of comparison by the first year. The collection and analysis of data began in second half of 2014. The comparison among the three years permitted us to show a trend in the factors considering a brief period (by year to year). We included in the analysis all patients suffering from hemato-oncological malignancies who died in hospice. Patients were excluded if they were discharged alive or their deaths were not due to cancer. The data were collected from medical records in which care teams noted talks with the patients and their families, the process of awareness of death and the steps of decision-making. The level of consciousness, depth of sedation and severity of suffering were routinely monitored. When the data regarding the variables examined were not noted, this was recorded as “not available” or “missing”. The data concerned clinical and demographic information: age of patients, sex, lengths of stay, performance status on the Karnofsky index, and prevision of prognosis with Palliative Prognostic Score (PaP score), (Maltoni et al., 1999). The reason for admission to hospice was specified in the medical records; for example, if the family needed a period of relief or if there was a clinical complexity difficult to treat at home. When the patients requested hospitalization to protect the family from the experience of death, we recorded this reason as “accompaniment to die”. We collected data on the relationship between the patient’s family/close people and the care team (for example, who provides assistance or who covered the role of surrogate for the decision-making process and what kind of alliance or conflict was established with the care team). We included the type of sedation (mild or deep sedation depending on the degree of loss of interactive functions), the doses and medicaments utilized, the reasons for mild and deep sedation and some variables of the decision-making process: awareness of death, cognitive impairment and capacity to express their own will (when PST was considered an appropriate treatment). In this study, we excluded intermittent or transient sedation (the injection of a bolus of medication for the temporary relief of a symptom) and decisions about life-sustaining treatments

(nutrition and hydration). We considered the day of hospitalization in which sedation was started and the time spent by the patient under sedation.

We performed a descriptive analysis of patients' characteristics and patterns of care over the period considered. A multiple logistic regression was used to study factors associated with PST, adjusting for age, sex, period, length of stay, mild sedation before, and awareness of death. ORs and their 85% confidence intervals (95% CI) were used as a measure of association.

#### **4.1. About the PST procedure**

The care team followed the procedural guidelines recommended by the EAPC (Cherny & Radbruch, 2009) and the national recommendations (SICP, 2007). In the medical records, we systematically adopted some instruments of evaluation for depth of sedation with Rudkin's scale (Rudkin, Osborne, & Curtin, 1991) compiled by nurses three times a day and a Numerical Rating Scale for monitoring the intensity of symptoms. Suffering or pain were also monitored in deep sedation with careful attention being paid to vocalization, facial expressions, body movements and non-verbal reactions to passive mobilization. The Abbey scale compiled by nurses was used for evaluation of pain in patients with non-verbal competence (Abbey et al., 2004).

The patient's capacity to make a decision at the moment of palliative sedation was not specifically evaluated with standardized questionnaires about competence or cognitive function. We only distinguished between these circumstances: if the patient could express his/her own will; if the patient could not verbally express but could understand the relevant information; or if the patient could not understand and acknowledge the implication of her/his choices (not competent). Medication for PST was administered through an elastomeric pump for continued parenteral infusion. The doses were selected after trituration and modified with the aim to control a refractory symptom with the lowest level of sedation necessary to provide relief of suffering. Normally the sedation began as "conscious sedation" in which the ability to respond to verbal stimuli and interactive functions are retained. Deeper sedation should be used when mild sedation is ineffective. Before starting sedation, we excluded other possible causes of deterioration (in our experience, sepsis, reversible metabolic events, urinary retention, and gastrointestinal obstruction are the more frequent treatable complications). Delirium was treated more often with specific treatments (Keeley, 2007), and sometimes transient sedation was used with re-evaluation of patient after an agreed interval. Intermittent or transient sedation was also performed for temporary relief (for noxious procedures, insomnia, or psychological distress). If the patient is in the very terminal stage with an expected prognosis of hours or days at most, continuous deep sedation was also considered for existential distress (Schuman-Olivier, Brendel, Forstein, & Price, 2008). We are conscious of difficulties to establish refractoriness of a symptom, especially for psychological distress. In these cases, the care team discussed other palliative interventions and was careful to recognize the PST as a potential "counter phobic defence to treat" through systematic supervision with a psychology team. Multidisciplinary meetings (with an oncologist as well as nurse aides providing care at the bed side) help the care team to discuss and weigh the rationale of PST. We adopted for patients and members of staff programmes psychological support with the aid of the psychologist of the team, and with other interventions through non-verbal communications such as dance movement therapy (Endrizzi, Bastita, Palella, Cossino, D'Amico, 2014). Midazolam is the drug preferentially used. Morphine hydrochloride is often associated not to induce sedation but because it has been previously administered. We highlight that the degree of symptom control and not the level of consciousness determines the doses and combination of sedatives and the duration of treatment (Legemaate, Verkerk, van Wijlick, & de Graeff, 2007). We refer to pain as a physical as well as psychological, social and spiritual experience or "total pain" in which the patient may not be capable of expressing or even demonstrating an awareness of his or her own pain experience (Metha & Chan, 2008). The term was coined by Dame Cicely Saunders a key contributor to the modern hospice movement.

#### **5. Results**

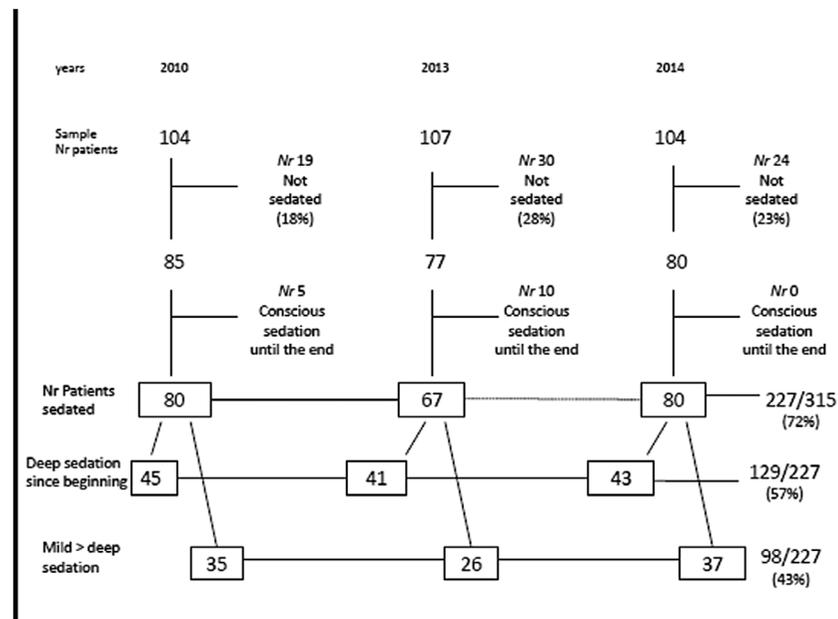
A sample of 315 patients who met the inclusion criteria was collected from years 2010 (104 of the total 273 admitted patients or 38%), 2013 (107/257 or 41.6%) and 2014 (104/274 or 37.9%). The

sample had metastatic cancer, impaired performance status, impaired levels of daily living activities (Karnofsky index lower than 30%) and poor prognosis at 30 days (66% of the sample had PaP score group C). In general, there were more males (56.8%) than females (43.2%) (Table 1). In 68% of patients, the reason for admission was monitoring the patient with a very terminal illness who was near death (or accompaniment to die); in 27% of patients, the reason for admission was stabilization of the clinical picture; and, in 3% of patients, the reason for admission was relief for the family. In 2% of patients, admission was necessary for patients with economic difficulties and social troubles. These variables were homogeneously distributed among the three years under review. However, we noticed an increasing trend in age (22.9% over 75 years old in 2010 vs. 45.1% in 2014) and length of stay, especially for recovery for more than 21 days (16.3% in 2010 vs. 21.2% in 2014), but the differences were not statistically significant (Table 1). Figure 1 shows how sedation was applied. In 15/315 (4.7%), “conscious sedation” was maintained until death (mainly used in patients with anguish or psychological distress). In these cases, death occurred without the need for deeper sedation. The prevalence of PST in the sample is 72% (227/315 patients); 57% of patients received deep sedation from the beginning and 43% of patients received mild sedation initially and then deep sedation over time.

**Table 1. Socio-demographic variables (sex, age), length of stay (in days), reasons of admission in sample of 315 patients**

Variables N (%)	2010 (N = 104)	2013 (N = 107)	2014 (N = 104)	Total (N = 315)
Men	57 (54.8)	59 (55.1)	63 (60.6)	179 (56.8)
Females	47 (45.2)	48 (44.9)	41 (39.4)	136 (43.2)
<65 years	27 (26.0)	23 (21.5)	22 (21.2)	72 (22.9)
65–74 years	32 (30.8)	39 (36.4)	30 (28.8)	101 (32.1)
>75 years	45 (43.3)	45 (42.1)	52 (50.0)	142 (45.1)
1–3 days	26 (25.0)	28 (26.2)	17 (16.3)	71 (22.5)
>21 days	16 (15.4)	15 (14.0)	22 (21.2)	53 (16.8)
Relief to family	2 (2)	4 (4)	3 (3)	9 (3)
Accompaniment to die	63 (61)	79 (74)	72 (69)	214 (68)
Symptoms uncontrolled	39 (37)	19 (18)	28 (27)	86 (27)

**Figure 1. How sedation was applied.**



The duration of deep sedation was 2.3 days, and the beginning of PST was 11.2 days after admission (average values calculated across the three years). There appeared to be a trend to delay the start of sedation (in 2010, 12.5% of patients were sedated after 15 days and 52.5% within 2 days; in 2014, 30% of patients were sedated after 15 days and 17% within 2 days) as well as a trend in the reduction of patients who spent a period equal to or greater than 33% of the total duration of hospitalization in sedation (43.8% in 2010 vs. 32.1% in 2014); however, the data were not statistically significant (Table 2). Principal refractory symptoms were total pain (38%) and delirium (18%). We noted a significant decreasing trend for total pain as a refractory symptom ( $p$  value 0.001) compared with other symptoms (dyspnoea, vomiting, fatigue, convulsion, and haemorrhage). The average daily dose of Midazolam was 17 mg for mild sedation and 37.3 mg for deep sedation.

We mentioned that mostly conscious sedation for anguish has been observed in 6% of sedated patients and deep sedation was necessary in 12% because of the agonic phase onset of heart failure with pulmonary oedema. Regarding awareness of death, the variables were grouped as follows: (a) no awareness, (b) partial awareness (includes patients with consciousness of diagnosis but not prognosis; patients with consciousness of serious and terminal illness but death not impending; and patients informed of diagnosis and prognosis but with psychological defences such as denial or cognitive/emotional dissociation). We considered patients with awareness of death (c), the ones that knew they would die because of disease and the ones with presentiment of death without clear information about prognosis. The analysis (Table 3) included 261 patients (data was not available for 54 patients). We noted a trend in the reduction of patients without awareness (24.4% in 2010 vs. 16.1% in 2014), but this was not statistically significant. A total of 42.5% of patients in the sample was judged not competent at the beginning of PST with an increasing but not statistically significant trend over the three years (37.5% in 2010, 42% in 2013, 50% in 2014) (Table 3). In Figure 2, we noted that the dialogue for sedation was started in 254 patients, but only 242 patients were actually sedated because, in 12 cases, the sedation was refused or delayed at the request of family (for 6 cases) or patient (4). In two cases, the physician delayed PST while waiting for family members of patients who were not competent. Of 242 patients for whom the dialogue got to PST, 146 were not competent (60%).

**Table 2. Frequency of patient in SPT (mild and deep sedation)**

Variables N (%)	2010 (N = 104)	2013 (N = 107)	2014 (N = 104)	Total (N = 315)
Not sedated	19/104 (18)	30/107 (28)	25/104 (24)	74/315 (23)
Mild (or conscious) sedation (Ms)	40 (39)	36 (34)	36 (35)	112 (36)
Deep sedation (Ds)	45 (43)	41 (53)	43 (54)	129 (41)
Palliative terminal sedation	80 (77)	67(63)	80 (77)	227 (72)
Starting Ms. after 0–2 days	21/40 (52.5)	10/36 (28)	6/36 (17)	37/112 (33)
3–14 days	14 (35)	19 (53)	19 (53)	52 (46)
≥15 days	5 (12.5)	7 (19)	11 (30)	23 (21)
<15% of all days of stay in Ds	25/80 (31.3)	21/67 (31.3)	28/80 (35.8)	74/227 (33)
16–32% of all days of stay in Ds	20 (25)	23 (34.3)	23 (34.3)	66 (30)
≥33% of all days of stay in Ds	35 (43.8)	23 (34.3)	26 (32.1)	84 (37)
Total pain*	41 (51.3)	24 (35.8)	22 (27.2)	87/227
OR (95% CI)	1	0.53	0.34	(38)
Delirium	12 (15.0)	14 (20.9)	14 (17.3)	40 (18)
Other symptoms**	27 (33.8)	29 (43.3)	45 (55.6)	101 (44)
OR (95% CI)	1	1.76 (0.91–3.38)	2.18 (1.14–4.16)	

Notes: Categories by days of stay before SPT (starting of SPT), duration of sedation (as proportion of days in which the patient is sedated) and refractory symptoms.

\*Decreasing trend  $p$  value = 0.001.

\*\*Increasing trend with  $p$  value = 0.004 (other symptoms were dyspnea, vomiting, fatigue, convulsion, hemorrhage).

**Table 3. Frequency by awareness and competence**

Awareness N (%)	2010 (N = 82)	2013 (N = 92)	2014 (N = 87)	Total (N = 261)
Not awareness*	20/82 (24.4)	18/92 (19.6)	14/87 (16.1)	52/261 (20)
Awareness of death	14 (17.1)	32 (34.8)	27 (31.0)	73/261 (28)
Partial awareness*	48 (58.5)	42 (45.7)	46 (52.9)	136/261 (52)
Competence N (%)	2010 (N = 104)	2013 (N = 107)	2014 (N = 104)	Total (N = 315)
Verbal or non-verbal skill present	65/104 (62.5)	62/107 (58)	54/104 (50)	181/315 (57.5)
Not competent	39 (37.5)	45 (42.0)	50 (50.0)	134 (42.5)

Notes: Categories by awareness of death (includes patients that know they will die because of disease and patients with presentiment of death without clear information about prognosis); partial awareness (includes patients with consciousness of diagnosis but not prognosis; patients with consciousness of serious and terminal illness but death not impending; patients informed of the diagnosis and prognosis but with psychological defense like denial or cognitive/emotional dissociation); no awareness of death. The data missing was 17% (54/315). Categories by competence includes patient not competent and patient competent (including the ones with no verbal skill to express him/herself).

\*Decreasing trend  $p$  value = 0.179.

**Figure 2. Principal interlocutor of SPT.**

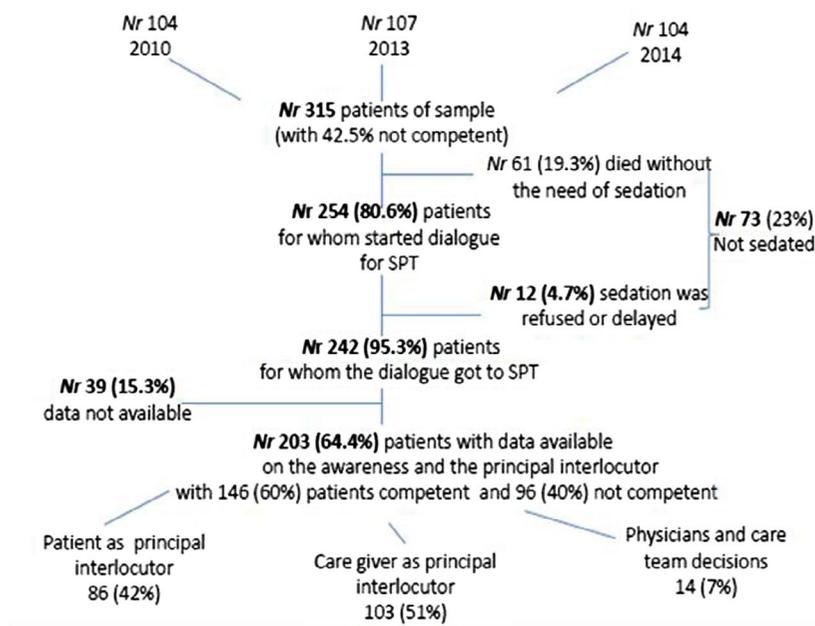


Table 4 and Figure 2 show the relationship between awareness of death in patients and the principal interlocutor in the decision-making process. Data analysis included 203 patients with available data (data missing for 16% of patients). In this analysis, a surrogate for the patient (within the family) was involved in 103/203 decisions (51%); the patient was involved in 42% of cases (86/203). The decision was made by the physician and the care team in 7% of cases (14/203). From Table 4, we noted that, when the patient was not aware, his/her involvement in the decision-making process was lower (11%) than when there was awareness (45%), and vice versa the caregiver involvement was much higher when the patient was not aware (24%) or was partially aware (57%). We noted that the physician's decision occurred with patients who were not aware or were partially aware, but never with patients who were aware of death. We considered the weight of the caregiver's decision by comparing two groups of patients: those who were sedated with deep sedation from the beginning and those who had mild sedation first. When the principal interlocutor in the decision-making process was the caregiver, the probability that conscious sedation preceded deep sedation was reduced to 34.9 vs. 62.8% in the cases in which the patient was involved (OR: 0.32, 95% CI 0.16–0.61).

**Table 4. Relation between awareness of death of patient and who is the principal interlocutor in decision-making process.**

<b>Patient as principal interlocutor (%)</b>	<b>2010 (N = 26)</b>	<b>2013 (N = 32)</b>	<b>2014 (N = 28)</b>	<b>Total (N = 86)</b>
But not awareness of death	3 (12)	5 (16)	1 (4)	9 (11)
With awareness of death	9 (35)	15 (47)	14 (50)	38 (44)
With partial awareness of death	14 (54)	12 (37)	13 (46)	39 (45)
<b>Caregiver as principal interlocutor (%)</b>	<b>2010 (N = 35)</b>	<b>2013 (N = 33)</b>	<b>2014 (N = 35)</b>	<b>Total (N = 103)</b>
With patient not aware	9 (26)	9 (27)	7 (20)	25 (24)
With patient aware	4 (11)	8 (24)	7 (20)	19 (19)
With patient partially aware	22 (63)	16 (49)	21 (60)	59 (57)
<b>Physician as principal interlocutor (%)</b>	<b>2010 (N = 6)</b>	<b>2013 (N = 3)</b>	<b>2014 (N = 5)</b>	<b>Total (N = 14)</b>
With patient not aware	2 (33)	2 (67)	0	4 (28.5)
With patient aware	0	0	0	0
With patient partially aware	4 (67)	1 (33)	5 (100)	10 (71.5)

Note: Data not available in 39 patients (16%).

**Table 5. Role of caregiver: Aide in the assistance or surrogate in medical decision in total sample of 315 patients**

<b>Variables N (%)</b>	<b>Caregiver (aide in assistance)</b>	<b>Caregiver (surrogate in decision)</b>
	<b>(N = 315)</b>	<b>(N = 315)</b>
Consort	126 (40)	78 (25)
Offspring	119 (38)	175 (55)
Friends	4 (1)	4 (1)
Brothers and sisters	25 (8)	26 (8)
Other relatives	23 (7)	24 (8)
Private health professionals	10 (3)	1 (0)
Other figures	1 (1)	2 (1)
Not caregiver	7 (2)	5 (2)

In Table 5 we summarized the role of caregiver as aid in the assistance as well as surrogate in medical decision. Alliance with the family regarding sedation was reached in 69% of cases. A total of 3% of families were not involved at the patient's request. There was conflict with families that threatened the alliance in 10% of cases, and this was overcome by offering more time listening or a psychotherapeutic approach. A total of 8% of these families had a critical setting (emotional outburst of one's family members, economic problems, social break down, history of drug abuse, violence or psychological trauma).

## 6. Discussion

This research has many important limits (selection bias, low sample size, missing data, instruments not validated for detection of competence, etc.). Nevertheless, we have identified some elements for reflection that could be better investigated in the future with a prospective study. The multivariate analysis (Table 6) shows that the probability of PST is related to the length of stay (it increases by three times if the length of hospitalization is prolonged beyond a week) and to age (it decreases by 74% in patients over 74 years old), and it is 3.7 times more likely if the patient had previous mild sedation.

**Table 6. Multivariate analysis in Nr 261 patients with SPT and data on awareness available, adjusted for age, sex, period, length of stay, mild sedation before, and awareness of death (CI 95%)**

<b>Variables (%)</b>	<b>OR</b>	<b>95% confidence limits</b>	
Men	1		
Women	0.838	0.449	1.564
<65 years	1		
65–74 years	0.565	0.211	1.511
≥75 years	0.261	0.105	0.649
2010	1		
2013	0.714	0.337	1.512
2014	1.395	0.615	3.165
<8 days of stay	1		
>7 days of stay	3.315	1.790	6.140
Mild sedation before	1		
Not mild sedation before	3.707	1.803	7.620
Not aware of death	1		
Aware of death	0.808	0.337	1.935

The first point can be explained by the relationship between length of stay and the threat of imminent death. Most serious patients who came into hospice in a state of unconsciousness caused by severe illness died within hours or days without the need for PST. The patients who stayed longer are the ones who mostly lived in hospice during their progressive decline in which the PST could become a planned or expected treatment option. The second point is applicable to very elderly patients. It could be explained with a senile marasmus over cachexia that produces a lowering of a certain level of consciousness with spontaneous sedation. The third point confirms the approach to start the PST as conscious sedation.

In the sample, we noticed an increasing trend in age (especially over 75 years old) and in the length of stay (more than 21 days) in admission to Hospice. It is possible that economic changes and health policies contribute to a wider range of patients eligible for admission, including those patients who previously would have been admitted to long-term care or nursing homes. The recovery in hospice is completely refunded by the regional health system, whereas funding cuts have penalized the reimbursement for long-term care or nursing homes. Even if we have only 2% of recovery for social disadvantages (or people known to social services), we experience the impoverishment of families and their collapse every day.

The dying process is situated within a social, economic and cultural process.

Intergenerational relationships have changed over the last few decades, and families and careers carry significant burdens in the context of end-of-life.

In fact, hospice is a viable alternative when there are no criteria to ensure home care.

The admission to hospice was partially a product of the families' inability to manage complex symptoms at home, and individual preference or the patient's ideal were situated within a consideration of the desires of their families. Sometimes there is a tension between individual wishes and family needs that cannot be negotiated at home.

The hospice become a place of negotiation between traditional social influences that continue to provide routine ontological security and individualization with the cultural pressure for individual autonomy to maintain their own biography based on personal choices rather than structural forces (Broom & Kirby, 2012). Obviously there was no singular family dynamic or expected interaction indicative of the near-death family experience, but it is possible that the dying process may be shaped by intergenerational shifts, potentially raising questions about a perceived lack of sense of intergenerational responsibility.

In the sample, the role of caregiver (Table 5) in aide of assistance is performed by a consort in 40% of cases and by offspring in 38% of cases; however, in the decision-making process the weight of the consorts falls to 25% compared to that of the offspring (55%), and the role of sons tends to grow during the years examined (from 45% in 2010 to 61% in 2014). It is likely that sons have a protective attitude towards their parents (patients and caregivers) that tends to exclude them from the discussion of end-of-life decisions. We aim to highlight that the quest for individual autonomy shifts forms of social inter-connectedness, so the family dynamics strongly influence individual experiences near death. It is impossible to focus on individual preferences without a nuanced understanding of the family context.

The third point is that conscious sedation preceded deep sedation but the data also reflected that, when the principal interlocutor in the decision-making process was the caregiver, the probability that conscious sedation preceded deep sedation was reduced to 34.9% (vs. 62,8% in the cases in which there was the patient involvement). Probably the unconsciousness is perceived as the “best way out” when a family resignedly accepts the poor prognosis of one of its members. This theme seems to be accepted for example also in a traditional Spanish culture (Núñez Olarte & Guillén, 2001). The Authors discuss typical characteristics of the Spanish conceptual approach to palliative care, which might be relevant in an ever larger Latin palliative care context (like the role played by the families of terminal patients or the high percentage of sedation due to psychological and/or family distress). Social and family links and the traditional Catholic approach seems relevant to explaining southern European perspectives (Meñaca et al., 2012).

Relatives are involved during the whole end-of-life care process: caring for the patient at home, accompanying the patient most of time in the hospital, worrying about the patients’ pain and participating disclosure. Catholic traditions have influenced the medical paternalism, pro-life positions, negative attitude towards withholding and withdrawal of treatment, acceptance of pain relief to the point of sedation. We have not consider the people views on religion and spirituality among the variables detected, but in the sample were not professed Protestant, Muslim, Jewish or other religion at the time of admission in Hospice, therefore we are likely consistent with the principal findings of the literature. In a Italian study the end of life preferences in advanced cancer patient were explored through a questionnaire specifically constructed to support the physician-patient communication, the End of Life Preferences Interview (ELPI) (Borreani et al., 2008).

Religion was mainly considered helpful not only in leaving life easily (75% of the responders) and finding meaning (53%), but also in healing (34%). In the sample 63% of responders stated that dying sedated by drugs would be preferable to dying in a state of consciousness. Furthermore believers were less likely to prefer dying unconscious, with a significant association between a preference for not dying in a state of unconsciousness and the belief in life after death (Miccinesi, Bianchi, Brunelli, & Borreani, 2012).

Communication also was considered to be influenced by the Catholic tradition of gradual truth giving. Finally non-disclosure in Italy was also understood as a way to maintain hope and continuity of social life (Toscani & Farsides, 2006). Therefore, the problem is how to inform a patient who is not willing to be informed, knowing that the first moral duty in these social contexts is to comfort patients, not to inform them about their prognosis. In the Italian context the practice of giving complete information on diagnosis and prognosis in the oncology field is still in usual (Costantini et al., 2006).

A high proportion of Italian physicians (Grassi et al., 2000) persist in the belief that patients “never want to know the truth”, and, at the same time, the families usually prefer that their ill relative is not informed of the diagnosis. While the EAPC, the International and the Canadian guidelines explicitly emphasize the need for awareness of cultural diversity and appropriate culture-sensitive care at the end of life, some authors (Schildmann & Schildmann, 2014) raise the question of whether and to what extent value-oriented behaviour in the context of PST should be adapted according to moral views held in a specific community. The problem is more complex due to the fact that providing the physicians with guidelines is not sufficient to modify their behaviour permanently, as Grassi et al. suggest. We advise that the process of making end-of-life decisions should be applied in a way that promotes a trust-based relationship and the role of the family as desired by the patient. McCabe, Wood, and Goldberg (2010) outline some of the steps of this process: (1) spend time developing an understanding of the family’s point of view; (2) understand the patient’s true preferences for receiving information; (3) take an incremental approach to resolving requests for non-disclosure; and (4) continue to work with and include the family at key time points. “Accompanying prognostic implication may require a gradual sharing of information in a way that allows the family to adapt and meet cultural obligations and, at the same time, permits the physician to live up to his or her professional obligations” (McCabe et al., 2010, quoted in page 95).

It seems clear enough that autonomy has to be seen as a relational construct as it depends on cooperation with doctors (implementation of decisions) and relatives to promote and not restrict one’s own needs. However, to be self-confident in decision-making requires the ability to understand and to rate an issue without being influenced by others. To acknowledge the autonomy of one person may undermine the autonomy of another person. In their studies, Marx, Owusu Boakye, Jung, and Nauck (2014) present different ways to experience the progression of a disease from the perspectives of patients and their relatives. In the context of progressed life-threatening diseases, the patient’s autonomy is ambivalently constituted because of the structural asymmetry of knowledge between the patients and healthcare professionals and because of the shared history in the familial context. Therefore, the trust between patients and their families often has a stronger constitution than the trust between patients and doctors. Certainly, one of the key points suggested by Marx et al. is that the interaction of patients and relatives depends on the degree of their acceptance of the diagnosis, the physical visibility of the disease and the acceptance of its incurability, as well as internalized action patterns of the relationship.

Therefore, the degree of awareness of death influences the possibility of directly involving the patient in decision-making, which some Italian research has demonstrated (Fortis, Brembilla, Mogni, & Cossolini, 2011). A previous prospective and multicentric study (Orsi et al., 2010) analysed a sample of 81 patients who died in home care with PST (17.5% of the total deaths). The awareness of illness (that is diagnoses and prognosis) was complete in 58% of the terminally ill patients, with over or underestimation in 25% and uncertainty in 13%. Interestingly, the study demonstrates that a large number of the terminally patients were sufficiently capable of making their own decisions (62%) during the period in which the decision-making process was taking place (that is, before starting PST), and 47.5% of the patients were involved in the dialogue for PST. The competence in the group of patients involved in the decision-making process was reduced at the moment of starting PST, with 45% who were not competent anymore.

In our data of 242 patients for whom the dialogue got to PST, 40% were not competent during the decision-making process. In the whole sample of 315 patients, 42.5% were not competent at admission; 61/315 (19%) died without the need for PST, whereas 3.8% refused sedation. The beginning of PST was 11.2 days after admission with a trend to delay the start of sedation (12.5% of patients were sedated after 15 days in 2010 vs. 30% in 2014).

These results regarding competence at the beginning of the process seem to be comparable to those of Orsi et al. (62% competent and 38% not competent); however, we consider the competence at the moment in which the sedation became the only treatment of choice and not the competence

at the admission to hospice. This difference in methodology leads to the question when is the right time to begin the dialogue for PST. The impairment of cognitive functions with the global decline of patients would require us to address this issue as soon as possible (Cherny & Radbruch, 2009; Schildmann & Schildmann, 2014).

Moreover, our experience demonstrates a difficulty in talking about palliative sedation at admission when the degree of awareness of the patient and the value system of the family are not yet clear. Also, the psychological work on defences, such as denial and dissociation, would require more time than there is given in hospice. Ideally, this work would have already been started during the assessments by oncology specialists; however, in our context, this is considerably delayed. We know to raise a problem that is not just local.

In 2014, Medscape physician members and non-members from the United States and Europe were invited to participate in an online survey (Kane, 2014, Medscape report). Conflict with a patient's family is not uncommon. Honesty is valued in ethical medical treatment, and there is no doubt that legal threat is part of the equation. Therefore, 76% of the physicians interviewed declare to be completely truthful about diagnoses. However, many doctors (21%) also believe that a patient's positive attitude can help her/his physical condition and that grim news could destroy hope; they respond by softening the news in the communication of terminal diagnoses (46% of physicians in Europe).

Physicians are occasionally asked to withhold information from a patient for various reasons. Sometimes the request makes sense, but physicians also say that sometimes they are troubled by the family's motives or decision. In the context of an European collaborative research project (EURELD), a study on attitudes towards medical end-of-life decisions was conducted among physicians in some European countries and Australia (Miccinesi et al., 2005) using a written questionnaire with structured questions that was sent to practicing physicians from specialties frequently involved in the care of dying patients. In the results, there were large differences between countries for "non-treatment decision and alleviation of pain and symptoms"; Italy gave the least support for this kind of end-of-life decision and was the most supportive (with Sweden) for preserving life. We refer to the study for all the results and conclusions, among which we highlight that country and religious beliefs are the strongest determinants of attitudes towards end-of-life decisions, confirming what had already been suggested regarding the effect of cultural and social factors. In addition to differences by country, the study identified physician characteristics that were associated with attitudes towards end-of-life decisions. For example, the authors found a stronger opposition to the "use of lethal drugs" and more support for "life preserving" among physicians working in geriatrics and oncology. On the other hand, physicians working in anaesthesiology had the lowest score for "life preserving". The authors attributed these results to the specific patient/doctor relationship of each specialty.

Perhaps, regarding this argument, we would consider that the patients can benefit today from more lines of chemotherapy and target drugs, which introduce the concept of "palliative chemotherapy". Therefore, the confusion generated by the significance of the information received is because communication of a poor prognosis by oncologists cannot coincide with the information of illness facing to death.

In the results of our study, we noted a trend in the reduction of patients "not awareness" over the years analysed. As we expected, when the patient is not aware, his/her involvement in the decision-making process is lower (11%) than when there is awareness (45%); and vice versa the caregiver involvement is much higher when the patient is not aware (24%) or is partially aware (57%). The condition of partial awareness is due to psychological defences and to difficulty

processing the information received, which is often ambivalent and not clear just because many opportunities to cure cancer are addressed in patients with advanced or terminal illness. We also recall that decisions by the physician and the care team for PST (7%) never occurred when patients were aware of death.

In the Table 4 of the article of Borreani et al. (2012), the Authors summarized the factors hindering communication when ELPI was not considered feasible, related to the patient (when the patient is not aware, is withdrawn, is emotionally frail), related to family (when the family interferes) and related to physicians (when physicians identifies himself/herself with the patient, or feels the need to protect himself/herself emotionally, or feels powerless and when there is poor communication among the staff). Therefore in the group of ELPI responders (Miccinesi et al., 2012) and concerning information, 42% of the sample did not want to be constantly informed, 8% preferred to delegate decisions to the medical staff, 16% did not want to receive detailed information about the drugs administered and 23% were not ready to discuss the deterioration of their conditions. These findings indicate that there are a number of patient who prefer information to remain in the hands of trusted health professional.

Obviously the situations in which the patient is unable to take responsibility for their choices are the ones in which the responsibility, and autonomy, of relatives and health care professionals is greater. In a recent article, Roeland et al. (2014) discuss the theme of paternalism, considered as the antithesis of autonomy, restoring the points of the strength of this concept, especially in the case of advanced disease and maladaptive coping, to reduce confusion and suffering by avoiding non-beneficial care.

The authors start from the observation that truth telling occurs between medical colleagues and not between the clinicians and the patient, and the lack of truth telling with the patient may lead to requests for non-beneficial interventions. “The hurried pace within the hospital create many obstacles to effective communication. Consequently, specialists use patients as communication conduits with other specialists, asking patients what other specialist services have told them” (Roeland et al., 2014, quoted in page 417).

## 7. Conclusion

The conclusion is that attitude of physicians and families’ responsibility is a relevant aspect in advanced care planning, as it determines the role that family members will accept with respect to end-of-life decision-making. Probably more studies are needed to investigate this complex phenomenon.

The task of the physician and care team is to adapt the communication of therapeutic choices to the level of autonomy possible in each family context and to adapt the communication to the coping styles of the patient and their family, if necessary with a moderate paternalism approach. Despite stressing the concept that family members or surrogates must base their decisions on the presumed will of the patient, the difficulty for the palliative care team is knowing that the results of their own work will have to be balanced between the ideal degree of patient autonomy and realistic awareness of dealing with patients and families with whom there is much work to do and little time to do it. We think that more work needs to be done in acknowledge in this area, because the ethical constructs change with the change in the cultural frame, that is developed by continuously collecting and analysing the experiences in front of death. In this way the organizations of palliative care can contribute to transform the cultural level of society and dominant opinions.

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### Note

1. The AVLS is an indicator of the time the patient is retained in the hospital (or the number of calendar days from admission of the patient to discharge). The BOR, or occupancy rate, is the percentage of official beds occupied by hospital inpatients for a given period of time; it is a measure of productivity of hospital beds: greater productivity is indicated by higher values. Bed turnover ratio is a measure of hospital utilization and includes the number of times each hospital bed changes occupants. SI is an index of turnover, it refers to the average vacancy time of official beds. When SI is higher, efficiency of the hospital is lower. (See also Basic statistical data used in acute care facilities. Jones and Bartlett Publisher [www.jblearning.com/samples/0763750344/45561\\_CH01.pdf](http://www.jblearning.com/samples/0763750344/45561_CH01.pdf))

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