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# **Reflection on Palliative Sedation for Existential Distress. It is Possible to Tolerate the Incomprehensible?**

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Cristina Endrizzi, Mirella Palella, Valeria Ghelleri and Roberta Bastita

Additional information is available at the end of the chapter

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## **Abstract**

The difficulty of making decisions in end of life is the subject of these reflections through two clinical cases. We considered the question of palliative sedation for existential distress through a phenomenological approach, focusing the relationship between a patient's clinical history and the reactions of the care team to the existential distress of the patients. We chose to introduce a concept, dynamic projective identifications, which is a powerful mechanism for communication between human beings. The hypothesis is that projective identification works as a powerful mechanism of emotional contagion between people facing death, families, and their health workers. In the cases, however, the use of this therapeutic tool is not oriented to provide psychotherapeutic methods of supporting dying patients but to sustain the awareness of the care team in the decision-making process. The psychological pressure on the care team may lead physicians to act considering "what you already know". Being aware of these mechanisms can help physicians to understand the phenomena that are happening. Even if palliative sedation is the best therapy, the care team must clarify the meaning of the projective identification and enter them into the flow of communication with the patients and their families.

**Keywords:** palliative sedation terminal, existential distress, end-of-life making decision, projective identifications, death

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## **1. Introduction**

The confrontation with impending death triggers emotional reactions (e.g., feelings of grief, sadness, despair, anxiety, loss and loneliness, etc.), some of which are adaptive responses to preparatory grief [1]. Many patients are able to achieve acceptance of their

illness and its prognosis, but each patient brings his/her own characteristic mode of coping and an array of strengths and vulnerabilities to the experience of a terminal illness. Systematic psychological assessment allows the clinician to support effective coping mechanisms and to identify persons at risk of experiencing high levels of difficulty during their illness [2]. Demoralization syndrome is an important clinical entity that is defined by the presence of pathological symptoms in the areas of mood, hope, and subjective competence. It is a personal experience of not coping with attacks on one's self efficacy and esteem [3]. In cancer patients, this process is sometimes described as "existential distress" [4], but it also occurs within the traditional psychiatric, and it is a risk factor for the manifestation of psychopathology. Demoralization is a spectrum that starts with subjective incompetence and non-pathological distress, and it can transition into helplessness, which sometimes grows into hopelessness. When it endures, it can be recognized as a syndrome that causes significant impairment in important areas of functioning [5]. Although some symptoms of demoralization are also expressed in existential distress at the end of life (feeling of apprehension, panic, threat, feeling of incompetence, of shame, impotence, aloneness, isolation, despair, etc.), existential distress manifests the experience of existential suffering in the context of an individual's confrontation with a specific stage of the dying process. Some people with certain personality traits, disadvantaged socioeconomic situations, or trauma histories in childhood might experience long-standing existential suffering (isolation, loss of dignity, meaninglessness, fear, etc.). Existential distress specifically develops as the result of facing one's impending death and is different from other reactions to end of life. In addition, existential distress must be distinguished from major depressive episodes, anxiety disorders, and delirium [6]. We refer to the definition article of Schuman-Olivier et al. ([7], p. 340) for definition and differential diagnosis from other psychiatric disorders. The authors have proposed a classification of existential distress based on the temporal context of the dying process: acute, subacute, and chronic are the general categories that focus on a person's proximity to likely death (imminent for acute and subacute, or <2 weeks, not imminent but life-threatening for chronic). We agree that the time available until death or loss functioning and a patient's baseline functional capacity to engage in the logistics of a therapeutic relationship are clear parameters to suggest therapeutic approaches (psychotherapy, psychopharmacological intervention up to palliative sedation) to clinicians and to help create a reliable decision-making language.

The questions of when and how to intervene with palliative sedation therapy (PST) are related to the concept of defining a refractory symptom [8]. Even if procedural guidelines for PST [9, 10] help physicians and care teams through the decision-making process and make them more comfortable to respond to physical suffering, when their patients experienced any psychological symptom, physicians more frequently reported an emotional pressure [11]. Individual clinician bias, emotional exhaustion, or burnout can influence the decision-making process [12] as well as cultural, social, and ethical conditioning [13].

Therefore, the goal, on one hand, is to understand the peculiar suffering of patients (and their families) and, on the other hand, to analyze the psychological responses of the care team toward the suffering of a particular patient.

Through two narratives, we propose the physicians' work to comprehend the context (the patient's clinical history) in which the phenomenon of existential distress appears and make an effort to be aware of the projective identifications ([14], pp. 37–74). We refer to mostly raw emotion, which is unfiltered by the reflective function of thought, or proto-emotional and sensory elements [15] that bridge the relationship between the patient and the care provider (family, physicians, and care team).

The purpose of this contagion is that one can feel and experience what another person experiences, even bodily sensations and perceptions (embodiment), through a total affective communication process. If a care team is not trained to contain the projective identifications or is overwhelmed by them, it will likely unconsciously react, adding another disturbance to the patient, in what has been termed "projective counter identification" (in [14] p. 43, [16]).

Two cases are presented of hospice patients who manifest symptoms of existential distress during the last days of life. Because of the rapid progression of their diseases, it was not possible to identify a therapeutic space for the patients to undergo routine psychotherapeutic and psychosocial approaches that are useful for patients with advanced life-threatening illness. Both patients experienced acute and subacute existential distress. In these clinical examples, we highlight the importance of clarifying the projective identifications and entering them into the flow of communication with the health care providers not to make hasty decisions and to tolerate the wait to ensure understanding of each incoherent or bizarre phenomenon before defining it as a symptom requiring treatment. Particularly in cases in which it is difficult to establish the refractoriness of a symptom, or when PST seemed to be appropriate for psychological distress, the care team is helped by a psychological team to reflect and recognize PST as a potential "counterphobic defense to treat."

The authors have adopted a phenomenological approach to study the case focusing on the relationship between the clinical history elements (symptoms, reaction to changes in therapy, biographical context, emotional, and behavioral relationships with significant others) and the countertransference reactions of care teams.

The countertransference refers in these cases to the use of emotions, images, thoughts, etc., within the care team, that are stimulated by what the patient and family live and feel [17, 18]. The survey method is qualitative and descriptive. Objective parameters (vital signs, pain and other symptoms, etc.) are noted in the diary, as well as the steps of the decision-making process, described in narrative form from the interviews with the patient and family.

The hospice team has a psychologist who specializes in psycho-oncology and three physicians with experience in palliative care. One of the physicians has also been a dance movement therapist since 2006 and a psychotherapist with training in expressive therapies. She is the narrator of the case histories reported here. The narrative approach is one method of revealing the intensity of end-of-life meetings and developing awareness reflection [19].

In these cases, the focus was on observing the events from a medical point of view, with precise job roles within the care team (i.e., observing from the perspective of "from the inside"), as well as observing through psychotherapy instruments and nonverbal language, thereby

stimulating the support and elaboration of the “*thinking functions*” ([20], pp. 61–79) “on the edge” of the team. These narratives are reported in the context of the work team, with the supervision of the psychologist, to discuss the suitability of PST.

## 2. Clinical cases

### 2.1. Albert

An anonymous patient referred to as “Albert” was a 56-year-old male, married with a young daughter and an adopted adult child from a previous marriage. He was described by friends as a brilliant, educated, and intelligent man who was a consummate reader. His wife told us that he referred to himself as rational and lacking affection, unable to handle emotions, with cultivated areas of rewarding personal interest not shared with his family. He was well informed of his terminally illness (a progression of prostatic cancer with secondary bone lesions) and was admitted to hospice after an episode of major depression and a suicide attempt.

At the time of admission, the patient had urinary incontinence, the inability to walk and postural instability. He became dependent for all daily activities. The patient was extremely anxious and frightened by the pain, as well as feeling like a burden to his family and losing control of his own autonomy. He said that he was worried that when he died, his wife would not be able to provide for his daughter “as she should.”

We started specific therapy to address his pain and antidepressants, with some initial benefit. However, the episodes of pain occurred more frequently, as did his anxiety, despite changes to the therapy (**Figure 1**).

The patient was in despair, and he wished to die. Facing refractory pain and anguish, we spoke with him about “conscious” or mild palliative sedation and the option of receiving additional doses of sedatives (intermittent sedation) when he desired to sleep. This proposal seemed to reassure him, perhaps returning to the patient the opportunity to regain some control by managing his symptoms. His wife took part in this conversation. She remained still and silent, sitting in the middle of a chair away from her husband's bed. Outside the room, she told us that the patient had repeatedly asked for euthanasia and that she disagreed with the mild or conscious sedation, as this option would not have protected her husband from the awareness of death. Confronted with oscillating sedation, in which the patient retained moments of awareness or reacted to surrounding stimuli, she showed apprehension and insisted that the sedation should be continuous and deep.

The patient spent nearly 20 days starting to again read and receive friends. He ate with an appetite and agreed to mobilize in a wheelchair, even going out for small trips. To the staff, he seemed to be sensitive and empathetic; however, his behavior with his wife seemed distant and not affectionate. I met him every day for visits with conversations about his tales of life.

Recovery days	Symptoms	Drugs (dosage/day)	Follow-up
Prehospitalization	Major depression	Duloxetine 60 mg Olanzapine 15 mg (in three divided doses) Alprazolam 0.75 mg (in three divided doses)	Antidepressant therapy was not changed until the week before his death
	Neuropathic pain from spinal metastases	Naropin 150 mg + Morphine hydrochloride 6 mg for peridural by elastomeric infusion device Naropin peridural bolus 5 mg as needed Transmucosal fentanyl (tm) 400 µg need to be administered Morphine hydrochloride 10 mg for subcutaneously injection)	Necessary amendments to pain killers
First 3 days	Neuropathic pain Numerical Rating Scale (NRS) 6/7 More than three episodes/day with NRS > 8	Naropin 150 mg + Morphine hydrochloride 6 mg for peridural by elastomeric infusion device More than 800 micr Fentanyl tm At least 10 mg Morphine hydrochloride for subcutaneous injection At least 20 mg of Naropin for peridural catheter divided into four boluses	Episodes of intense pain; effectively addressed by parenteral morphine (NRS from 10 to 4) Changes in sensation and voluntary movement of the lower limbs
	Crisis of anxiety associated with pain, insomnia, and agitation	Midazolam 10 mg for subcutaneous injection as needed (at least two doses during the night)	When awake thoughts are fixed on the pain with an anticipatory anxious attitude
From 4 to 24 days	Neuropathic pain Side effects of an overdose of anesthetic via epidural The patient spoke of problems in life and expressed a wish to die; returning to thoughts of suicide Asked to be euthanized Faced the possibility of a palliative sedation with the addition of a benzodiazepine (Midazolam) by continuous infusion at doses that do not induce awareness reduction Patient managed his sedation "on demand"	Added dexamethasone 8 mg for intravenous infusion Elastomer suspended by epidural; small amount of naropine by epidural (from 150 to 80 mg) with four boluses of 20 mg every 12 h during the day Elastomer device intravenous (Morphine hydrochloride 50 mg + 15 mg Midazolam) Midazolam 20 mg in 250 ml saline at 20 ml/hour for hypnotic purposes	The patient returned to reading, receiving friends, resting all night, eating at the table, and walking about the room Pain control requires periodic adjustments of doses of intravenously infused drugs



Recovery days	Symptoms	Drugs (dosage/day)	Follow-up
From 24 to 33 days	Leakage of the epidural catheter and accentuation of pain Neurological side effects increasing opioid and benzodiazepine (concentration deficits, ideomotor slowdown, and impairment of concentration)	Increased dosage of morphine hydrochloride in 90 and 60 mg of midazolam in elastomeric device intravenous Dexamethasone was reduced from 8 to 4 mg	Ideomotor slowdown with lucid and coherent; ataxia with postural instability in standing position. Able to receive visits, talk, listen to music but finds it impossible to read A week before death reported having seen <i>Out of body experience</i>
From 34 to 39 days	Total pain with a prevalence of existential pain Reported desperation because the contact with reality was slipping The patient was reassured not to be afraid of his dreams and imagination In the end, we proposed a continuous sedation	Morphine hydrochloride 120 mg and midazolam 90 and 100 mg chlorpromazine into elastomer device intravenously Haloperidol 6 mg divided into three doses	Sedation oscillated at times the patient responds to verbal stimuli or to the presence of people, and when he awakens takes water and/or semi-soft food Refers to hearing death approaching

Figure 1.

Once, we used expressive therapy to represent his emotions and thoughts. I invited his wife to stay, but she preferred to leave.

I felt discomfort between the couple, although I did not understand why. I think that his wife left out of respect for his privacy perhaps as she used to. Albert insinuated that his wife did not want to participate because he had always demonstrated little emotion with her. He seemed sorry for this situation, and I thought that there was a sense of unworthiness and mortification, as it had appeared after the interview with the psychologist.

We drew on the same sheet, just like playing chess, his favorite game. We noted the difference in our traces. His was rigorous and linear, crossing the sheet directly. My trace ran under his and sometimes outlined a colorful space.

He said: "It's wonderful that you colour inside my lines." He found that one of the colored spaces seemed like Fonzie's hair tuft. We joked about this because Albert was left bald after chemotherapy. I thought that an element of narcissistic gratification could have been present. Despite the tone, the dialogue was lighter and less desperate. Albert talked about his own death and his wish to die (WTD). To end was no longer seen as an affront or undignified, and he no longer experienced the loss of control in making decisions. He would have shown his family how one can die, as a way of instructing them and giving them time to deal with the loss.

By the 18th day of hospitalization, Albert reported proprioceptive changes before waking up (e.g., one leg was larger than the other, his mouth was smaller, or one-half of the body slid diagonally in space). He spoke about these phenomena as an attentive witness. He understood

his detachment from reality as a sign of impending death. The patient did not ask for a reduction of consciousness, even when he was in despair. Despite oscillating between drowsiness and wakefulness, he retained an awareness of death and dying until a few days before his death, when continued palliative sedation was initiated at his request. After Albert's death, I talked with his wife once again to ask permission to report this story. On that occasion, I had the opportunity to make my unease at the request for euthanasia known to her and told her that the mild and respite sedation had given Albert an opportunity to be together with his family and friends. Laconically, turning her head slightly sideways and with a smile she said something that I do not remember exactly but it could sound something like, "I would have preferred euthanasia."

## 2.2. Discussion of Albert's case

In this case, the care team is involved in different perspectives.

From the psychological point of view, the care team felt a sense of inadequacy and impotence toward the patient's wife, who insistently demanded deep sedation. Health workers were conflicted by the emotional pressure of his wife's, although the pharmacological treatment had ameliorated the quality of life of the patient, that started to eat, to receive friends, to read again and he agreed to mobilize in a wheelchair, with a sort of resilience, nonetheless in a difficult condition. Albert talked about his own death and his wish to die in a way less desperately. It seemed to emerge a new significance of his death, with a sort of project brought out: he would have shown his family how one could die, as a way of instructing them and giving them time to deal with the loss. The care team felt inspired from image behind the expression "You colour inside my lines" that Albert said at the end of expressive encounter with artistic material supporting the verbal dialogue. Albert manifested a capacity to be ironic about the changes of body image that is intrinsically linked to identity and the meaning of dignity [21]. Through the pharmacological treatment, the attention and the listening, the care team had returned to Albert the control of his end-of-life decision, prevented by burdening of symptom's disease and psychological distress.

The care team struggled with the request of euthanasia; therefore, the second point of analysis has been from this perspective. Albert represented cases in which a wish to die (WTD) persists even if pain is treated in a palliative care model [22]. A desire to hasten death is associated with functional impairment related to pain, and, moreover, it is a measure of pain severity in some studies [23]. Therefore, the significant decline in pain intensity levels was not predictive of an improvement in the desire to hasten death, particularly in patients in the last days of life, for whom other symptoms may also be associated with psychological distress, such as depression with insecure attachment, low self-esteem, and younger age [24]. Probably for these reasons, the patient's wife insisted with the therapy addressed to the abolition of consciousness (instead of the euthanasia, not legally performed in Italy). The care team, in line with the emotions and embarrassment expressed in the narrative explicit above and experienced by the physician in the encounters with the patient, referred the sense of unworthiness and mortification felt in the room when the wife was into a low self-esteem relationship or to reactualization in the couple of an insecure attachment. We have no other data on past to support this analysis,



but the possibility “*to colour the lines inside of mine,*” recalled a new chance for Albert to experience himself in the relationship with the care team, instead of a crystallized, fixed and “black and white” defenses.

After all, WTD is a complex subjective and social phenomenon, a process rather than a mental state, in which it is important to explore not only the reasons or triggering factors, which can be treated, but also how a WTD makes sense for the patients [25]. Caregivers have a great responsibility because the WTD can be influenced by conversations about them. Then, to cultivate the skill of active listening, to reflect on their own ideas and fears about death, and to facilitate the patient’s inner dialogue and discussion of his/her wishes about life and dying are the tasks required to assist patients in formulating their connection to their personal values and perspectives [26].

At this point, the care team had clarified that the request of the patient’s wife could not be accepted as a surrogate decision, and the woman must be helped to tolerate the process of awareness of patient in front of his death. Nevertheless, the care team needed to tolerate the insistent demand of the wife, highlighting the ability of Albert to be the main interlocutor of end-of-life decisions and understanding that the psychological pressure experienced by the care team (that is the result of a projective identification) was attuned with the anxiety of the woman overwhelmed by the proximity of the death (in the context of the psychological and relational dynamics experienced in the couple, understood only partially). The PST could be the best chance, but the way and the time should be arranged with the patient.

Now we face with the third perspective of analysis. How should we interpret the proprioceptive impairment that occurred near the death? Was it a sign of delirium? If this hypothesis was correct, how we should consider the patient, competent or not competent?

The patient had, as we have shown in **Figure 1**, a complex drug therapy and a high-dose of neuroleptic drugs. There are insufficient clinical studies that allow one to clearly determine whether certain patient expressions that could be considered bizarre or incoherent are attributable to drugs with known neurological side effects or to impairment of thought function (e.g., delirium at the end of life) or whether they belong to a degree of consciousness that is part of the process of preparing for death.

The recent information available on proprioception suggests the role of small-diameter sensory cortical fibers representing each body part. For example, immediate distortion of body size with local anesthesia has been linked to loss of input from small-diameter fibers [27]. Findings in cardiac arrest survivors suggest that central hypercapnia and peripheral hypoxia, secondary to cerebral ischemia, cause a cortical hyper-activation that helps to explain the phenomenon of increased awareness in these patients in the absence of cerebral activity [28]. On the other hand, the cerebral ischemia is responsible for metabolic alterations also involved in nociceptive synaptic transmission, such as the inhibition of the production of nitric oxide, a free radical that regulates the cerebral phenomena of apoptosis. It would seem that it was implicated in the long-term potentiation (LTP), which supports the reinforcement of the synaptic transmission of spinal neurons and in fact represents an expression of a memory of the nociceptive stimuli [29, 30]. It is also known that pharmacological interventions can change

the function of nociceptive neurons by transforming them into broad spectrum neurons of potential action (wide dynamic range or WDR) that receive impulses not only from the nociceptive system but also through the sense of touch and heat, which leads one to assume a link between nociception and proprioception, particularly in situations of peripheral or central hypersensitivity [31].

Therefore, the care team pointed out some questions: this phenomenon should be understood in the context of the peripheral desensitization induced by drugs that act on mu receptors and GABA receptors (such as the association opioids and benzodiazepines) or as a cortical hyperactivation that occurs in the phenomena of near-death experience? Was it possible that Morphine and Midazolam hydrochloride in high doses act like a block anesthetic causing distortions in body size (like the proprioceptive alteration of Albert)? What was the relationship between the cortical areas of expansion representing the body parts and more complex alteration of body image in people who are dying taking neuroleptic drugs?

Thus, it was difficult to conclude whether the described phenomenon of depersonalization could be understood in the context of existential distress or if it has been caused by a pharmacological effect or a more complex alteration of body image in people who are dying. Some authors believe that the process of dying may consist of the translation of a progressive withdrawal of psychic energy in the neurological and peripheral nervous systems [32, 33]. The importance of defining this phenomenon was related to determining a strategy to treat it (pharmacological treatment up to palliative terminal sedation, or other approaches as psychotherapy, touch therapy, etc.).

Eventually, we regarded to this proprioceptive impairment like a sign of the disorder of the "body-container" [34] that could be a cause of anguish and could also explain the manifestation of proprioceptive reactions that often occur in a seriously ill patient [35]. Clinging to objects, fear during passive mobilization in bed, increased muscle tension, motor restlessness secondary to the loss of bowel control or failure to deplete the elimination organs such as the bladder and rectum, and the lack of perception of body parts could be an expression of primitive anguish. In the case of Albert, changes in proprioception had been integrated with vestibular afferents and condensed in the content of "dream-thought" in the form of imagination, visions, and hallucinations. Although drugs administered may account for a cognitive dysfunction, it is interesting to note that hallucinations were concomitant to the general decay of the patient and were present close to death after a relatively long period of therapy, which still ensured a good quality of life. What was interesting in this case was that the presumed hallucinations of the patient were only of a kinesthetic nature, and this aspect was contextualized in the attitude of a person with difficulties making body contact.

We considered Albert competent and aware of the death impending, therefore we accepted his ability to let us know the proper time to start unconsciousness sedation.

### 2.3. Edy

Edy was an anonymous name for a 73-year-old married woman, with two sons and a husband. She suffered from dilated cardiomyopathy. For many years, Edy faced her cancer diagnosis

and chemotherapy with a type of awareness that was obscured by an unjustified expectation of healing. Cancer of the rectum was already in an advanced stage, with liver metastases and infiltration of the uterus—at the time of diagnosis, 6 years to our knowledge. Edy had faced surgery and chemotherapy, apparently delegating her husband to receive information about the evolution of the clinical oncology. In fact, Edy unconsciously led her husband to believe what she wanted to believe, thereby causing him to downplay or cast doubt on the information received. Her husband had some type of dissociation from the information that he received. He seemed to be aware, though he had an emotional reaction of denial or devaluation (the same reaction demonstrated by his wife). Therefore, in terms of communication, the couple seemed to function as a unique individual.

Within a year, there were sub-occlusive symptoms, with two hospitalizations for nausea, vomiting, and lack of canalization of the intestine, which appeared to show peritoneal carcinomatosis.

We met Edy at her home, after she had started palliative home care on the advice of her oncologist, who intended to reduce hospital admissions for clinical symptoms by utilizing only symptomatic treatment. The husband was visibly fatigued and short of breath, but he was bustling around his wife and received us in the living room.

The logistical setting did not seem to function well for their needs. The bedroom was likely located on the top floor of the house, which was accessed through a staircase, with no hand-rail. In the room, there were two leather sofas. It resembled a showroom (visible but not touchable). The husband offered us two chairs in front of Edy, who was sitting at the dining table. The chairs were solid wood and uncomfortable. It was difficult to imagine that Edy could remain sitting there for very long. The conversation was dry. The symptoms that we were supposed to be treating were discussed openly, but we were warned that many good, reliable doctors (whose advice, we thought, could not be discussed) were attending to the family, including the family doctor, physical therapist, and cardiologist (who treated Edy's husband, as well as Edy's atrial fibrillation). Indeed, it seemed that only the cardiological therapy was the most important, because it was "life-saving." The examination of the patient did not indicate an acute phase diagnosis, although there was diarrhea indicative of a sub-occlusion, but the treatments that we had prescribed were stopped by the patient with advice of her family, as soon as we left the house.

A few days later, we received a phone call notifying us that the patient had been admitted to Oncology Department again. Another 15 days passed, and the patient was then transferred to hospice. Edy then appeared to be depressed and tired; however, her sons insisted on moving their mother to an armchair. When Edy refused food, they urged her to eat. Edy's husband was taciturn and present only when one of the sons was with him; he never asked us for information, and sometimes, he did not visit his wife for an entire day. Edy seemed to have chosen him as the subject toward whom to express her anger.

She also showed a certain level of contempt toward us. She snapped bitterly at the health workers who helped her with her basic needs. With her husband, she would let loose. However, this behavior did not seem to disturb the family.

There was a tendency to "normalize" everything in the family and not interpret Edy's unfriendly and rejecting manners as an aspect of her anger and mortification.

Her adult children refused to accept the recommended psychological support. However, it finally emerged through the sons that there was a possibility that Edy felt betrayed by her family because they had given up on bringing her home. This admission in hospice provided a way for Edy of dealing with topics, such as disappointment, the rupture that she sensed with the world, and the likelihood that her autonomy was irretrievably lost.

We had already prescribed antidepressants. We were witnesses to not only the physical decay of her body but also a particular manner of rejecting the world and preparing for death, which was also a source of anxiety for the team.

Edy became silent, without conditions or compromises. We tried various relational approaches, but there was no longer a productive relationship for an alliance with the patient regarding her decisions and desires. We tried to talk to her about the possibility of using a sedative type rescue dose, to discontinue the "passive" waking moments, but the patient, with her eyes closed, denied us even eye contact, saying, "I sleep enough already." We felt cornered, closed in and somehow gagged. When performing hygienic care in the morning, providing treatment or administering medication, some of the team members felt crushed by the silence and the passivity of the patient. The health care professionals were competing to stimulate or to induce Edy to answer merely yes or no.

We seemed to have become lost in the same trap that her sons were in: trying to please her, to stimulate her, or to talk to her in the belief that she could hear. It was strange that in front of her motionless body and her calm breathing, as if sleeping, with her muscle tone flabby from passive mobilization, that no one would think that she might have been in a state of coma. Everyone continued in the belief that she could understand what we were saying but that she wanted to punish us with her silence. We examined her again, excluding a state of coma. The feelings of alienation, depersonalization, and derealization that we felt when facing Edy not only excluded us from her world but also effaced us. From this perspective, we understood the reactions of the family members when faced with the proposal of respite sedation: "No, because it would extinguish her completely."

Clearly, it was a fact with which we did not agree; however, we could not overlook it. We did not have the support of the patient or her family members. In some last words spoken by Edy in the 15 days before her death, she told a nurse, "Here I am committing suicide." The tense used in the sentence referred to an action that was in progress, so the nurse thought she was dreaming in real time. However, following questions by the nurse, Edy replied, "I'm not dreaming, it is precisely what is happening; see, I'm committing suicide."

## **2.4. Discussion of Edy's case**

In this case, the burden on the family in end-of-life decisions is clear, as was how little attention is still given to the process of awareness of the disease and poor prognosis before arriving at the point of palliative care [36]. The demand for information is not uniform in our society, and



the role played by the families of terminally patients and in the attitude of physicians toward information disclosure clearly differs from the Northern European or Anglo-Saxon model [37]. Sometimes, the problem is how to inform a patient who is not willing to be informed. The culturally established *modus operandi* obliges the health care professional to be discrete when discussing cancer [38]. Moreover, the patient is free to use their autonomy even to delegate. The patient must decide how much autonomy he or she wishes to exercise, and this amount likely varies from culture to culture. In addition, many families are opposed to inform the patients of their conditions [39] as demonstrated by the second case, such cases can evolve and become difficult to treat. It is obvious that these are situations in which the team feels guilty about a shortcoming, something that could have been done or that they were not doing. As care providers, we are not satisfied with these cases, but we have to accept that this individual had long eluded her diagnosis and had experienced the disease as if it concerned another person, forcing those around her to feel that her anger was directed precisely toward herself, and she wanted the world to experience a sense of guilt. It may be possible that in cases in which a person is alienated from the awareness of death, there must be an extreme effort of self-denial and self-punishment to break away from the body, as in the case of Edy. In addition, in the conflict between family and care providers, palliative sedation for existential distress, even if appropriate, could not have been of benefit because it could cause further distress. Therefore, the dramatic sentence repeated to the nurse by Edy “I’m committing suicide” talks about not an intention but probably resumed the psychic dynamics in the relational field.

With her mutism, Edy elicited in the caregivers (care team and family) a feeling of impotence; with the refuse to eat elicited a sense of guilty; when she was acting out a state of coma, caregivers thought that she could understand what we were saying but that she wanted to punish us with her silence. With this passive attitude, the care team was obliged to feel her alienation and depersonalization. But like her family, the care team did not understand this powerful mechanism of psychic contamination; in front of anger, fear, and anguish of the patient, it could not find a way to deal with the subject of the imminent death and so doing, was allied to the defense mechanisms of the family (untruth, avoidance, and the complaisance, trying to please her or to stimulate her).

The care team countertransference seemed to be that it was expressed by the family when PST was proposed “the feeling that the doctors killed a loved one.” The sentence of Edy about committing suicide reverses the roles, attributing to herself the damaging action (that caregivers attribute to themselves). In this sentence, Edy became in certain way assertive again and self-determined (in the sentences she is able to act), while the care team, with regret, could see mirrored its inability to propose their active role (the dialogue for truth, the support to the patient’s role in end-of-life decision).

### 3. Conclusion

Sometimes troubled relationships that are full of emotions will short-circuit between the patient, family, and care team when they are inexorably facing the possibility of death and, sometimes,



sudden death, during the process of a rapidly advancing, progressive, serious illness. The knowledge of some powerful mechanisms of communication, such as projective identifications, can explain the intensity of emotional involvement and the difficulty in making important decisions. Knowledge of this mechanism can become an instrument (as in psychodynamic psychotherapy and psychoanalysis) to understand what happens to a person who is living an end-of-life experience and to help health care professionals tolerate conflicts that overshadow important clinical decisions. In such cases, the guidelines that establish the decision-making process in these areas of care, although useful, are not sufficient to guide choices and decisions shared between the team and family. Both cases are suitable for PST, but in the first case, the problem was tolerating the wife's requests for deep sedation, which did not align with the patient's dissociative phenomena and persistent WTD; in the second case, the PST that seemed to be appropriate (because of the existential distress that was strongly expressed) was not achieved due to the family conflicts and poor auto-determination of the patient, who was not cognitively impaired. The care team, who had to share and develop intense feelings of frustration and doubt, also had to, at minimum, not surrender to an analysis based on "what you already know." It is known that in care team, this psychological pressure might result in physicians acting inappropriately [40, 41] before considering the need to understand the meaning of what is being observed. We agree that more training needs to be provided to physicians and palliative care teams [42].

## Author details

Cristina Endrizzi\*, Mirella Palella, Valeria Ghelleri and Roberta Bastita

\*Address all correspondence to: [c.endrix@alice.it](mailto:c.endrix@alice.it)

Hospice Il Gelso, ASL AI, Piedmont, Italy

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