

The terminal patient: practical aspects

Pereira de Moura*, Armindo Simões**, Sílvia Lopes*, Alberto Lourenço**, Políbio Serra e Silva***

Abstract

The authors present some reflections on the terminal patient. This topic was discussed at the First National Home Care Symposium, with a focus on the physical problems; the psychological aspects

were essentially discussed in edition no.8 of "Médice", and we believe that these two studies are complementary.

Key words: terminal patient, practical aspects.

Introduction

We present some reflections on the practical aspects of the supervision of terminal patients. This topic was the subject of debate at the "First National Medical Home Care Symposium" held in Coimbra, in January 1990. The article "The terminal patient: how to deal with ...", published in edition no. 8 of "Médice" magazine, focusing essentially on the psychological aspects of the problem, prompted us to offer some practical considerations on the difficulties faced by those whose task is to accompany these patients. We believe the two articles complement one another and, if the publication of this one serves to alleviate the physical and mental stress of the terminal patient, then the objectives that led us to write it have been well achieved.

As life and death are two inseparable realities inherent to every living being (who, being alive, will have to die one day), one would expect a profound knowledge of the phenomenon of death. It should be viewed as naturally as life, observed without fear and awaited without anxiety. However, death, due to its irreversible nature, has always generated fears, flights and taboos; rarely is this phenomenon a topic of conversation, whether in a group of friends or in scientific sessions. When it is addressed, it is almost always done so superficially, in the third person, and it is often trivialized, which merely serves to conceal

our unease. These considerations led us to believe that we do not know how to face our own death, or that of others.

As physicians, our principal mission is to defend life and to allow it to develop with the best quality possible; we are scientifically prepared to fight death, but, when this proves inevitable, we feel impotent and have a strong feeling that there is nothing more we can do. However, it is our obligation to accompany the patient in the terminal phase of their disease, alleviating their physical suffering, allaying their anxieties, and helping them to pass through the various stages of preparation for death (*Table 1*). In this study, we do not seek to address the psychological aspects of the terminal patient, which have been the subject of various studies by psychiatrists and psychologists^{1,2,3,4} but essentially, to review some of the problems that they come across as they accompany the final days of life of their patients, providing some suggestions that we deem useful.

It is essentially a palliative and preventive branch of Medicine that calls more than ever for frank and loyal collaboration and communication between the medical team, the patient and the family.

Each patient is always a particular case; the approach to their problems should not be fixed, but reviewed regularly, whenever necessary. The aim is to prolong life (but not at any cost), making it as meaningful as possible. Thus, the use of invasive methods, whether diagnostic or therapeutic, is generally inappropriate, and even simple gestures should take into consideration the patient's biological reserves, the purpose of each treatment, and the need to avoid prolonging the patient's agony. While allowing for the possibility of an improvement or unexpected cure, it is necessary, among the numerous terminal circumstances, to know how to recognize when the maintenance of life is essentially futile, letting nature take its course

*Temporary Hospital Assistant in Internal Medicine

**Hospital Assistant in Internal Medicine

***Director of the Medicine II Services of H.U.C. and Professor of the Faculty of Medicine of the University of Coimbra

Medicine Service II of the University of Coimbra Hospitals

TABLE I⁴

Kubler-Ross Stages

1 – Denial and Isolation Phase “It can't be happening to me”
2 – Anger Phase “Why me?”
3 – Bargaining Phase “Agreements with the physician, God...”
4 – Depression Phase “Yes, it is me; nothing else matters...”
5 – Acceptance Phase “My time has come and everything is alright”

in these situations, and giving “death a chance”. We must not confuse euthanasia – death upon request, compassionate homicide – with the responsible refusal of therapeutic obstinacy.

These days, a person is born and dies in hospital; while the first is one of the finest conquests of modern Medicine, for which physicians and the other health care staff, politicians and the population in general should fight, the second, although sometimes indispensable, is, in our opinion, used abusively. Indeed, for the patient that knows he is going to die, it is extremely distressing to spend the last days of his life far from family and friends, in the inevitably depersonalized environment of a hospital. This is why patients often express a desire to return to their family environment, and we should respect their wishes whenever possible; however, this implies the existence of socioeconomic conditions that are absent in the majority of our families. These conditions include the existence of a private room for the patient, which is spacious, quiet and well-ventilated; availability of materials and human carers, information and training of the family, regular medical home support to reassess the clinical and therapeutic situation and administering palliative and prophylactic care (control of pain, bedsores, inflammatory phenomena and depressive states).⁵ It is also vital to have a strong link between the medical homecare services and the supporting hospital, in order to ensure an agreement on the objectives and the methods by which they will be achieved. This collaboration includes temporary hospital readmission for the performance of therapeutic

and palliative techniques, such as a nerve block for pain control, or others that justify it.

Therefore the decision on whether to keep the terminal patient in hospital or to send him home is, in our view, a choice that should be made by the patient, the family and the patient's own physician; this resolution would be supported by a multidisciplinary team ideally formed by the physician, nurse, physiotherapist, psychologist and social worker.⁵

The physician and the nurse are the first to see the problems that gradually arise over the course of evolution of the disease; therefore they must be informed and aware of this role, and have sufficient time available to address the complexity of these situations; one example is the fact that the physician and nurse should listen to and inform the patient, gradually and at a pace that matches the patient's questions, replying to them in a clear, simple way. Their informative role should be extended to the family, so that they can accompany the patient in the best possible way. Problems like food, hygiene and positioning should be discussed with the family and the patient himself.

The psychologist is responsible for following the progress of the patient and the family, helping them to accept the disease, its consequences and evolution through to death, and to deal with the mourning process.

The physiotherapist should act essentially to maintain and restore the patient's autonomy in day-to-day movements.

The social worker, as a vehicle of support to society, should provide the family with the means of assuming the terminal patient daily care.

Terminal patient does not necessarily mean death is imminent in a short period of time; the process may drag on for weeks, months or even years. Throughout this period, it is necessary to ensure that the patient has the best quality of life possible. Therefore, if heroic maneuvers and therapeutic approaches to resuscitation are generally contraindicated in the terminal patient, every effort should be geared towards proper health care.^{7,8,9,4}

Of the problems that most frequently affect the patient in this situation we will emphasize those related to the respiratory, gastrointestinal and genitourinary systems, the central nervous system, and the skin. For each of these, we will suggest some steps that can be taken to lessen the patient's suffering. Finally,

we deal with the problem of pain, which is almost constant in terminal situations, particularly neoplastic conditions.

One of the most common respiratory symptoms is dyspnea. The terminal patient, particularly when bedridden, presents various limitations relating to the ventilatory mechanics; loss of the cough reflex, exhaustion of the respiratory muscles, dehydration and prolonged immobility, all of which contribute to the retention of secretions with inevitable obstruction of the airways.¹⁰ Adequate hydration is recommended in these cases, with aspiration of the secretions, respiratory kinesitherapy, frequently changing the patient's position, oxygen therapy and, when there is an underlying bronchospastic component, administration of salbutamol or atropine (0.6 to 1.2 mg i.m.).¹⁰ Morphine is sometimes indicated in the control of dyspnea as it reduces the respiratory rate to a compatible level. The respiratory difficulty can be exacerbated by the existence of cardiac insufficiency. In these cases, the use of diuretics and tonicardiacs will be indicated in the minimum effective doses. Also concomitant extensive malignant pleural effusion impairs the ventilatory mechanics. It must therefore be drained, and if it is recurrent, chemical sclerosis carried out.¹⁰ All these problems can be aggravated by the existence of anemia, which often accompanies terminal situations, particularly in oncological patients.¹⁰ We should resist the temptation to "maintain good hemoglobin levels", for which reason transfusions are rarely indicated.¹⁰ Pneumonias, often called "merciful" by the voices of our ancestors, are nowadays often treated, in desperation, with broad spectrum antibiotics, when these are rarely indicated, as their use merely prolongs the patient's suffering.¹⁰

Nausea and vomiting are other problems that afflict the terminal patient, and may be related to an iatrogenic disorder, since many of these patients are under multiple medications, particularly with digitalis drugs, diuretics, morphine and other medications.¹⁰ Whenever possible, we should suspend or reduce suspect medications, correct any electrolytic disorders - hypokalemia, hypercalcemia (associated, for example, with bone metastases) - and teach hygienic and dietetic norms, such as recommending more frequent meals with smaller portions, and respecting the patient's preferences.¹¹ If the vomiting persists, we can resort to the use of certain medications such as metoclopramide, in doses of 10 mg 3 i.d. and, in

patients with significant anxiety, better results may be obtained with prochlorperazine, 5 mg 3 i.d., or chlorpromazine.^{10,11} When the cause of the vomiting is central, one option is cyclizine, in doses of 50 to 100 mg 3 i.d., as this medication acts on the center of vomiting.^{10,11} Just one word for the situation in which metastatic dissemination, but without hypercalcemia, is accompanied by vomiting which, because it responds to the administration of corticosteroids, is designated, by some authors, as "vomiting responsive to corticoids".¹⁰

Severe obstipation frequently accompanies the long-term bedridden patient.¹⁰ We should avoid the abusive use of laxatives that will, on one hand, provoke abdominal cramps and, on the other, frequent dejections with inevitable discomfort for both patient and family. The use of enemas and the ingestion of low residue diets are often sufficient to resolve this problem. Whenever it is necessary to administer opiates, laxatives should be used in association, to counter their constipating effect.^{10,11}

Another common situation, particularly in the elderly, is urinary incontinence. Moreover, in this situation we should exclude iatrogenic disorder (diuretics), decompensated diabetes or hypercalcemia.¹⁰ The involuntary loss of urine by the patient is a considerably inconvenient situation, not only for the family (requiring multiple changes of clothing) but, particularly for the patient, causing discomfort and exacerbating skin maceration; the easiest way to overcome this situation is permanent vesical catheterization.¹⁰ Septic problems associated with catheterization are infrequent; however, when a catheterized patient reports pain in the hypogastric region or becomes more agitated, we should consider a urinary infection,¹⁰ perform a urine analysis and, if the suspicion is confirmed, perform a simple vesical lavage, with an antiseptic product, which is generally sufficient. The use of antibiotics is rarely indicated.¹⁰

The terminal patient, particularly the elderly, often appears disoriented and agitated, particularly when placed in a strange environment.¹⁰ The return to the family environment, regular contact with loved ones, and receiving answers to their questions and concerns, is often sufficient to pacify the patient.¹⁰ If, despite all this care, the agitation persists, we can resort to the use of certain medications such as thioridazine, 10 mg 3 i.d., promazine, 12.5 to 50 mg 3 i.d. or fluphenazine decanoate, 12.5 to 25 mg i.m.,

in the first week, repeated in the following week, and afterwards, once every 2 or 4 weeks.^{10,11} In patients who are particularly aggressive we can use chlorpromazine, in doses of 50 to 100 mg i.m.¹¹ With the use of these medications, we should always be careful not to sedate the patient excessively, enabling him to maintain contact with his surroundings.¹¹

Pressure ulcers (bedsores) are one of the problems that cause most discomfort for bedridden patients and generate the most anguish in those caring for them. Immobility, hypoalbuminemia, fecal and urinary incontinence and the presence of fractures are factors that exacerbate the appearance of bedsores.⁷ The best weapon against bedsores is prevention.¹² The observation, in animal experiments, that prolonged pressure (1 or 2 hours) leads to muscle necrosis enabling to come to the conclusion that it is necessary to move the bedridden patient into a different position at least every two hours.⁷ The patient should be repositioned successively on his right side, back and left side. Furthermore, for the same reason, patients should not be allowed to remain seated, in bed or in an armchair, for more than two hours without having their position changed. The widespread use of cushions with a central cavity should be discouraged, as this hinders blood circulation in the area without support. The use of articulated beds, special mattresses and cushioned wheelchairs are a considerable aid for the prevention of bedsores.⁷ Despite taking all the due precautions, it is not always possible to avoid the appearance of pressure ulcers. When this happens, they should be treated quickly, according to the size and appearance of the bed sore, as well as its location. Surrounding erythema, the presence of purulent secretions and a fetid odor indicate the presence of infection; the existence of necrotized tissue generally requires debridement to allow healing.^{6,7} Since all cutaneous wounds are contaminated with bacteria, cultures are not indicated, unless there is evidence of infectious complications that require systemic antibiotherapy, as is the case with cellulitis, sepsis or osteomyelitis.⁷ Local measures alone are indicated in most situations, with special emphasis on the use of antibiotics and topical antiseptics and avoiding pressure on the affected area. Frequent washing with saline solution and the application of topical antibiotics, such as gentamicin and sulphadiazine, frequently lead to the healing of the bed sore.^{7,10} Antiseptics such as iodized polyvidone, hydrogen peroxide and sodium hypochlorite

proved cytotoxic in cultures of human fibroblasts, and may delay healing.⁷ The use of hydrophilic substances, such as crystallized sugar, facilitates the cure of bedsores with abundant secretions.⁷

We will now present some considerations on pain and the methods for its control. According to the majority of studies, 60% to 80% of cancer patients in the terminal phase have moderate or severe pain. However, fast and effective relief of pain symptomatology should constitute a priority for any physician monitoring these patients.^{6,13} In most situations, the concern with the appearance of tolerance and habituation to the most potent analgesics (opiates), which should be used whenever indicated, is unfounded.^{6,13} Pain results from the perception of a nociceptive sensation and the emotional reaction that accompanies it; the more traumatizing the patient's past experiences of pain, the more intense the emotional reaction will be. Neglected pain invariably reduces the patient's threshold of perception, generating anguish and depression which, in turn, contribute toward an even greater reduction of the pain threshold; thus a vicious cycle is created that can only be interrupted by a personalized, regularly reviewed analgesia.^{6,10,13}

For practical reasons, and bearing in mind the therapeutic goals, pain is classified, generally speaking, in terms of its intensity (slight, moderate, intense) and type (*Table II*). It is necessary to use a so-called ladder approach, that is, to initially use the less potent drugs, in the minimum effective doses, then gradually and successively increase the doses and possible associations, keeping the most potent drugs and surgical methods for last.^{10,14} This does not mean that one should prolong this ascent out of fear of tolerance or habituation, in which that is mandatory - if necessary, one can and should begin with the most powerful weapons.^{13,14} The final objective, whatever the situation, is to relieve the pain as quickly and safely as possible. Slight or moderate pain can be controlled with non-opioid drugs, such as acetylsalicylic acid (A.A.S.), paracetamol and non-steroid anti-inflammatory drugs.^{10,13,14} Therefore in bone pain, which is often resistant to opioids, A.A.S. is usually effective in doses from 900 to 1200 mg every 4 hours; paracetamol, at a dose of 1g every 4 hours, is mainly indicated for pain of the soft tissues; in mixed pain (bone and soft tissues), we can use an association of 300 mg of A.A.S with 250 mg of paracetamol.^{10,13,14} The control of severe pain requires

TABLE II¹⁴

Type of Pain

Type	Organs	Characteristics	Causes
Somatic	cutaneous	deaf	bone metastases
	tissues	profound	musculoskeletal
Visceral	abdominal	"pressure"	metastases
	viscera	"poorly located"	bone
	thoracic	"referred"	neoplasia pancreas
Nerve	peripheral n.	burn	plexopathies
		severe paroxysm	neuropathy Cytostatic

the use of opiate medications. Also known as central analgesics, these drugs can be divided into morphine agonists, presenting the same pharmacological effects, and into agonists-antagonists, with activity similar to that of morphine when administered separately, but that inhibit the action of the latter when administered in association with it.¹³ Consequently, associations of drugs from the two categories should not be used.¹³ A rule to follow, when using this and any type of analgesic, is the rigidity of the administration schedule: it is essential to know the half-life of the drug used and its administration "at the right times", even if this entails waking the patient.^{10,13,14} Pain should never appear, at least not with intensity, hence their use is discouraged in "S.O.S".^{10,13,14} In very anxious patients who are skeptical about the possibility of controlling their pain, it is sometimes preferable to immediately suppress the symptomatology, introducing treatment with high doses and reducing them afterwards, until the effective dose is reached.^{13,14} The standard medication continues to be morphine; in its chlorhydrate form it is absorbed orally; it presents bioavailability of 30% to 40%; and its analgesic effect lasts approximately 4 hours.^{6,12,13,14} It is recommendable to start its administration in the doses of 5 mg 6 i.d., which can be progressively increased (10, 15, 20, 30, 40,100 mg) until effective analgesia is obtained without sedation.^{10,13,14} In the Portuguese market we also have access to "retard" (delayed action) pills, with doses ranging from 10 to 100 mg and that enable only two

daily doses to be administered.⁶ Morphine is faster acting via intramuscular route, but its effects last for a shorter time; the intravenous route is only indicated in patients who need to be perfused for other reasons, allowing the maintenance of constant levels of morphine if it is administered in continuous perfusion.^{6,13} As secondary effects, we can expect sedation, obstipation, nausea and vomiting, which sometimes require symptomatic therapy.^{6,13,14} Respiratory depression, the potentially most severe effect, should not occur if the treatment follows the proposed norms; however, if this does happen, it will be corrected by the administration of intravenous naloxone.¹³ Diamorphine, which is not yet available in our market, presents better

gastrointestinal absorption, greater solubility (less solvent in parenteral administrations) and fewer side effects than morphine; it is effective in doses of 2.5 to 5 mg 6 i.d.^{13,14} Buprenorphine, another opioid, has the advantage that it is absorbed by sublingual route. Its duration of action is around 6 to 8 hours, and each individual dose is from 0.2 to 0.4 mg; it does not cause constipation, but exhibits a "plateau" effect, from which the increase of doses does not entail greater analgesia.^{6,13} One morphine agonist is pethidine, a medication of low potency that does not have good oral absorption, therefore it is not recommended for the treatment of chronic pain.^{6,13} Pentazocine, which has weaker analgesic strength than morphine, has a dysphoric effect, causing frequent hallucinations even in low doses, which is why its use is not recommended.^{6,13,14} Methadone, a potent analgesic only available in hospitals, has the dosage convenience of two daily administrations of 5 to 10 mg, to be subsequently adjusted.¹⁴ In the treatment of severe pain, people sometimes resort to the association of opiates with other drugs, seeking to boost their analgesic action and, at the same time, lessen their side effects.^{6,13,14} One example is the association of anticonvulsants such as phenytoin and carbamazepine for the control of paroxysmal nerve pain, dramatic in trigeminal neuralgia; the initial dose of carbamazepine is 100 mg, administered orally, to be initiated and suspended progressively.^{6,13,14} The phenothiazines, with antiemetic and anxiolytic properties, should be associated

TABLE III¹⁴

Nerve Block

Celiac Plexus Block	Neoplasm: - liver - pancreas - stomach - intestine
Paravertebral Block	chest pains
Intrathecal Block (lumbosacral region)	perineal pains

with the opiates in somatic and visceral pain, while methotrimeprazine is proposed in doses of 5 to 10 mg i.m.^{6,13,14} for cases of nausea and vomiting. The antidepressants amitriptyline and imipramine are particularly indicated for neuropathic pain and in sleep disorders, used in initial oral doses of 10 mg.¹³ Finally, corticosteroids, particularly dexamethasone, are indicated in cases of inflammatory bone pain, nerve compression – reflex sympathetic dystrophy and plexopathies - and when there is intracranial hypertension.^{6,10,13,14}

We should pay attention to the particular metabolism of the terminal patient when using all these medications, seeking to avoid iatrogenic disorders whenever possible.

Although outside the scope of this study, as they require specialized techniques, we would nevertheless like to make brief mention of other analgesic therapies, such as radiotherapy and nerve blocks.^{13,14} The first is used mainly in bone metastases, where a single dose of radiation is usually sufficient in the case of the long bones and ribs, but where four or five sessions are frequently necessary in lesions located in the pelvic bones and vertebrae. The analgesic effect is not immediate, reaching its peak at between two and four weeks.¹³

The nerve block constitutes an option for the treatment of pain that resists other kinds of therapeutic approach, and its effects may be temporary or permanent, depending on the drugs used.^{1,13,14} A temporary block is obtained through the use of anesthetics, acting essentially as a means of diagnosis. In permanent blocks, substances (phenol and alcohol)

and techniques (freezing) are used that bring about the irreversible destruction of the nerve.^{1,3} As a point of interest, we indicate the most prevalent nerve blocks and their indications in *Table III*.

We have sought, in these brief considerations, to address some of the problems that most frequently affect not only the terminal patient, but those who care for them. Although we should never forget that we are physicians, we should mainly be aware of the fact that these patients look to us for human support, as much as for our technical knowledge. ■

References

- Bernardo S. Cuidados a ter com os moribundos. *Arquivos de Medicina*. 1989; 2: 317-321
- Guerra M. Algumas considerações sobre a Psicologia da Doença. *Arquivos de Medicina*. 1991; 4: 366-373.
- Milheiro J. Psicologia do Estado Terminal. *Arquivos de Medicina*. 1988; 2: 89-93.
- Vale L. O doente terminal: Como lidar...*Médice*, 1991: 12-15.
- Abiven M. Pour la pratique ... on retiendra ... *Rev. Pract* 1986; 36: 508-513
- Twycross R. In *Terapêutica em Cancer Terminal*. Edit Artes Médicas. Porto Alegre, 1991: 24-44
- Allman R. Pressure Ulcers Among the Elderly. *N Engl J Med* 1989; 320:850-853.
- Boisvert M. Que sont les soins palliatifs terminaux ? *Rev Pract* 1986 : 36 :455-456.
- Rakel R. Care of the Dying Patient. *Principles of Family Medicine*. 1987; 118-133.
- Livesley B. The management of the Dying Patient. In *Principles and Practice of Geriatric Medicine*. 1986.
- Twycross R. Prévention de tous les troubles du mourant. *Rev. Pract* 1986 ; 36 : 473-478.
- Tavernier M. Soins Palliatifs à domicile. *Rev Pract* 1986 : 36 : 501-507
- Salamagne M. Douleur physique. Souffrance globale à la phase ultime d'une maladie cancéreuse. *Rev Pract* 1986 : 36 : 457-469.
- Foley, M. Management of Cancer Pain. In *Principles and Practice of Oncology*. Edited by Vincent T. de Vita Jr. M.D. 3rd Ed. 1989; 2046-2086.