Supportive Care in Oncology

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By

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INTRODUCTION

Stating the reason for the preparation of such a complex and all-encompassing book is difficult for a person who is facing the stage of professional maturity. This is yet another effort, perhaps my last one, to provide an updated means of consultation to the doctors of our difficult discipline. I repeat difficult; difficult for its vast horizon that encompasses humanity, intuition, and science, and that unfortunately for years has been practiced as "good" medicine requiring no further refining of knowledge.

The text breathes a very familiar air, based above all on experience first domiciliary and then in hospitals in the field of cancer pain, palliative care, and supportive care, along an evolutionary journey parallel to changes in this discipline. Although the risk is that of self-referentiality, the book really wants to lead the reader along the lines of research being followed in these formidable years, the fruit of a scientific activity persistent in time in the various aspects of this discipline and confirmed by the attention of the scientific and academic world. Those who know these lines of research from following me over the years, know well how these actually reflect a clinical activity with primordial intuitions then confirmed by scientific data published in a wonderful virtuous circle of mutual reinforcement between clinical activity, renewed by research, inspired by clinical activity. The many visitors we have had at La Maddalena Cancer Center in recent years have been able to observe live as the protocols used, the obsession with a deep evaluation, and the need to individualize a treatment to find the most effective solution in the most difficult cases, in other words the life of the department, reflect exactly this plastic paradigm of the need to solve clinical problems, to form new ideas, and perform scientific demonstrations, with a curiosity that is very reminiscent of that phase of maximum mental openness that is typically found in childhood. Here, bringing out the child in us is probably the most daring aspect of this book, flattering the desire for Dante's knowledge, to run through the gardens of science, to admire the details of a painting, to tease their indomitable certainties, to train the movements so as not to accidentally injure yourself, to reassure while infusing doubts.

Palermo, June 2020
Sebastiano Mercadante

PART ONE:

GENERAL ASPECTS OF PALLIATIVE MEDICINE

CHAPTER ONE

PALLIATIVE CARE AND SUPPORTIVE CARE

Palliative care is central to public health for many reasons related to the aging of the population and the development of many degenerative diseases characterized by complex and chronic problems which require specific services and professional solutions. Palliative care is by nature multidisciplinary and requires knowledge of various types that include the physical, psychological, social, and spiritual needs of the patient, interposing in some cases with the etiological treatment of the disease after the point of diagnosis, as in the case of cancer.

Many models have been described for palliative care, often resulting from different national histories and cultures and the availability of public and private economic resources rather than homogeneous long-range planning dictated by incontrovertible epidemiological data (1).

In every country, therefore, palliative care has arisen on the emotional and emergency impulse, with the need, however, to satisfy an urgent need. Consequently, the distribution of services, the available economic resources, the organization, and the quality of care have been quite inhomogeneous across territories.

On the other hand, the observation that patients are living longer due to the improvement of the available therapies is unequivocal. However, the levels of quality of life are low enough for the persistence, moreover now longer lasting, of a symptom burden that requires considerable attention and a continuous care plan. The needs are therefore enormously increased and they sound a warning for organizational and structural reforms.

Yet, already many years ago, the World Health Organization had enunciated the definition of palliative care, through a rigorous examination by pioneering experts who had intuited primordial elements that should have been applied and adapted to changes in the years that followed. Many of these indications have been surprisingly disregarded in many countries, with the introduction of laws, apparently innovative but with unrealistic interpretations of the need for innovation, as a result of ignorance and political obstinacy.

> Palliative care is… applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

In previous years we have witnessed an expansion of palliative care programs, with widespread networks, generally in low-intensity facilities, such as hospices and at home, used to assist sick people mainly in the advanced stages of the disease and in the last weeks of life. In recent years, notable epidemiological and social changes, as well as relevant information from the scientific world, have subverted some traditionally consolidated organizational aspects. The need was therefore felt to further develop this activity beyond the boundaries of traditional structures. In particular, the need for early and simultaneous intervention in causal therapies, which mainly occur in hospitals, has been reimagined. To confirm this, the trajectory of many chronic degenerative diseases and cancer is to show a progressive loss of function with periods of acute crisis along the more or less rapid progress towards death.

Recent studies have affirmed that the use of early supportive therapies allows a clear improvement of the quality of life in terms of the prevention and treatment of physical and psychological symptoms, and in some cases also a prolongation of survival (2). The differences between the traditional pathway of care, with a clear sequential temporal pattern from oncology to palliative care, and the concept of simultaneous care, including early palliative care, are depicted in figures 1 and 2.

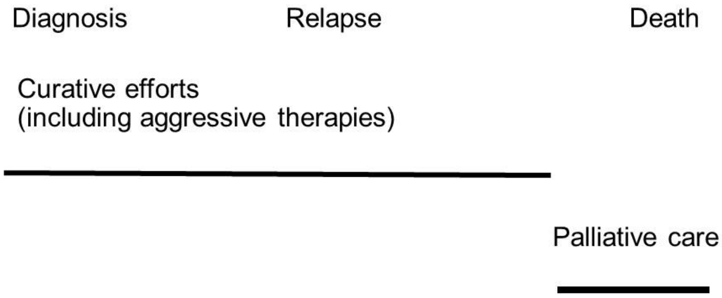

Figure 1. Conventional pathway from oncology to palliative care

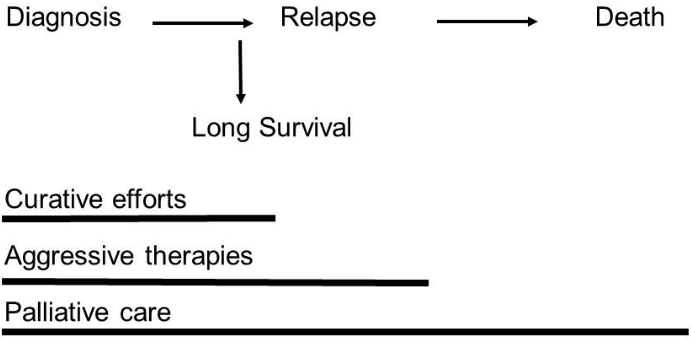

Figure 2. Modern pathway of simultaneous care

Thus, a network of palliative care should include various options with different characteristics, according to patients' needs, which are not interchangeable (table 1).

Care	primary	secondary	tertiary
Personnel	GP, other specialties	PC team	PC team
Setting team	home, hospital	home, hospice	PCU, mobile
Role	basic care	assistance, consultation	assistance, consultation

Table 1. Levels of care (GP = general practitioner, PC = palliative care, PCU = palliative care unit)

It should be more correctly pointed out that while it is understandable that the use of simultaneous supportive therapies can be of benefit during the active treatment of a disease such as cancer, the methodology by which to demonstrate this axiom remains very weak. In fact, in controlled studies to date the definition of "best supportive care" has always been very generic, as has that of the control arms, which obviously does not help us in being able to effectively treat a patient (3). The difference, if proved, continues to be based on the individual treatment of a doctor who follows a patient more or less conscientiously, rather than a well established system of integration.

Thanks to these scientific data, which have shown great advantages for patients, the interception of patients along all the phases of the disease, with the offer of a continuous and gradual service according to the needs, sometimes with more intensive spaces for the resolution of some more complex problems, has modified the traditional and unidirectional vision of palliative care, often recognized as end-of-life care. This underlines the need to provide in hospitals an integrated activity which foresees, alongside the treatment against the disease, the early intervention of a palliative care expert. Also from the terminological point of view there is the need for greater clarity regarding the available treatment modalities.

The complexity of some clinical situations often requires shelter to be provided in a protected environment in order to quickly achieve the control of symptoms, difficult to obtain in other environments (table 2). Consultancy services and units with beds available for high intensity care within a cancer department prefigure an indispensable support for the definition and resolution of the problems of these patients, redirecting the patient, according to a specific evaluation, towards a trajectory of care more suitable and proportionate to their conditions (figure 3). Therefore, in addition to supporting functions, these skills act as a filter and as moderators with respect to the aggressiveness and therapeutic futility observed in recent years. It is disarming to notice that chemotherapy treatments are continued well beyond the most optimistic expectations, with costs often unjustified from both an economic and financial point of view, and from the point of view of damage to the patient, considering that in some cases they cause early death by the toxicity inflicted on patients in precarious physical conditions (4-14). These centers are instead fundamental in the transition to more specific treatments, avoiding the clear-cut transition between so-called active and often disproportionate treatments and end-of-life care, a psychological phenomenon that is fatal for patients and family members, as active care and palliative treatment should be separated by a temporal space.

- Interdisciplinary evaluation and identification of patients' needs
- Treatment of difficult clinical conditions
- Assessment and monitoring
- Oncological re-evaluation
- Constant education for professionals, patients, and relatives
- Bridge with other units facilitating transition to palliative care
- Informal behavior
- High opioid consumption
- Research
- Teaching and education
- Cultural pressure in other units
- Internal and external consultations
- Introduction to palliative care network (hospice, home care)

Table 2. Characteristics of the palliative/supportive care unit at the comprehensive cancer center La Maddalena

The low consumption or the delayed use of opioids, observed in some European countries, is probably linked to these discrepancies, rather than the availability of opioids now widely represented and marketed (15). It is also evident that these centers, having acquired great experience due to the high turnover of patients characterized by considerable criticality, are responsible for carrying out educational, didactic, academic, and research functions for other palliative care services, with an exchange of information and advice, thus allowing continuity of care in the territory (12). This system is also economically sustainable in terms of cost effectiveness, avoiding inappropriate admissions in non-specialist facilities that constitute a cost without providing adequate specialistic performance. In these circumstances, admissions to acute hospitals devoid of palliative care availability are often ineffective and expensive. The resolution of problems of a physical and psychological nature during a short and non-definitive stay during the course of a disease and, once the stabilization of the symptoms has been achieved, the continuation of treatment in a less intensive environment such as a hospice or the home, are an added bonus of services made available in a palliative care network. From this point of view, a specialist clinic is an important strength for the continuous assessment of these patients, who are often lost during the continuation of treatment and who often remain without a reference point (7).

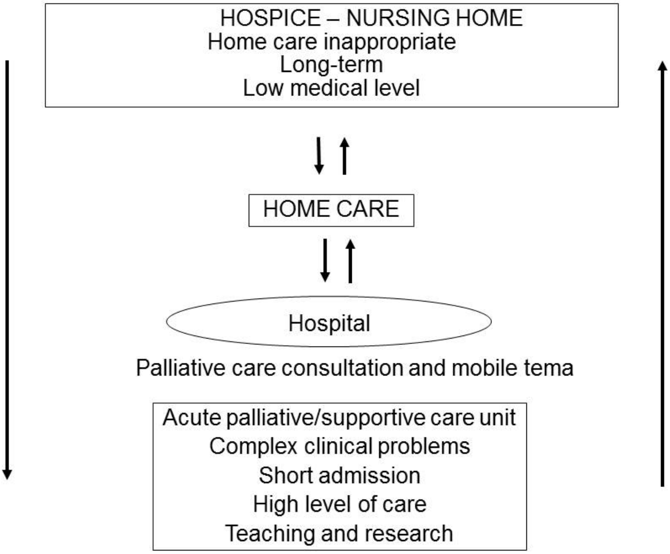

Figure 3.

These perspectives do not replace traditional services, which remain unavoidable, but add another element to a network of services that are not optional but essential for the providing of palliative care (figure 3). Also from the qualitative point of view it is possible to apply some differences in the field of a possible network, according to primary, secondary, and tertiary care, with an expansion of the offer according to intensity levels.

References

1. Centeno C, Lynch T, Garralda E, et al. Coverage and development of specialist palliative care services across the World Health Organization European Region (2005-2012): Results from a European Association for Palliative Care Task Force survey of 53 Countries. Palliat Med. 2015
2. Temel J, Greer J, Muzikansky A, Gallagher ER, Admane S et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Eng J Med 2010;363: 733-742.
3. Nipp RD, Currow DC, Cherny NI, et al. Best supportive care in clinical trials: review of the inconsistency in control arm design. Br J Cancer. 2015;113:6-11.

4. Haun MW, Estel S, Rücker G, et al. Early palliative care for adults with advanced cancer. Cochrane Database Syst Rev. 2017 Jun 12;6:CD011129. 5. Elsayem A, Swint K, Fisch MJ et al. Palliative care inpatient service in a comprehensive cancer center: clinical and financial outcomes. J Clin Oncol 2004;22:2008-14.
6. Hui D, Elsayem A, De la Cruz M, et al. Availability and integration of palliative care at US cancer centers. JAMA 2010;303:1054-61.
7. Yennurajalingam S, Atkinson B, Masterson J et al. The impact of an outpatient palliative care consultation on symptom burden in advanced prostate cancer patients. J Palliat Med 2012;15:20-4.
8. Hui D, De la Cruz M, Mori M et al. Concepts and definitions for "supportive care", best supportive care", "palliative care" and "hospice care" in the published literature, dictionaries, and textbooks. Support Care Cancer 2013;21:659-85.
9. Murray SA, Kebdall M, Boyd K, Sheikh A. Illness trajectories and palliative care. Clinical review. BMJ 2005;330:1007-11.
10. Boyd K, Murray SA. Recognizing and managing key transitions in the end of life. BMJ 2010;341:649-52.
11. Bruera E, Hui D. Palliative care units: the best option for the most distressed. Arch Intern Med. 2011; 171:1601
12. Mercadante S, Villari P, Ferrera P. A model of acute symptom control unit: Pain Relief and Palliative Care Unit of La Maddalena Cancer Center. Support Care Cancer. 2003;11:114-9
13. Mercadante S. For a modern concept of palliative care. J Palliat Care Med 2012;2:e105.
14. Mercadante S, Intravaia G, Villari P, et al. Clinical and financial analysis of an acute palliative care unit in an oncological department. Palliat Med. 2008;22:760-7.
15. Mercadante S. The low opioid consumption in Italy depends on late palliative care. Ann Oncol. 2013;24:558

CHAPTER TWO

BIOETHICS

Bioethics in medicine is a fundamental resource in undertaking difficult decisions in certain contexts. In the field of palliative care, it assumes a peculiar role regarding the social, cultural, philosophical, and spiritual connotations. The burden of physical and psychological suffering, the approach to the end of existence, and the need for difficult decisions in the various stages of an incurable disease, particularly in the last days of life, require the knowledge of bioethical aspects (1). In order not to remain a sterile subject of abstract rules, it is necessary that the principles that regulate bioethics should be considered in a determined clinical context where all information needs to be known. A basic knowledge of different concepts and principles is the common language with which professionals can identify practical solutions. The recourse to the systematization of the ethical analysis of cases in which it is difficult to undertake a decision is fundamental; such decision making must be according to some orderly steps that allow the following of an intelligible path to reach the best possible solution (2).

Analysis

A first consideration concerns the ethical analysis, that is, the identification of the current problem for the formalization of an adequate response. An operational definition of an ethical analysis, albeit within limits, is given by the challenge of resolving a case for which simple clinical and technical information cannot resolve the issue and for which it is necessary to turn to the ethical principles that indicate a solution, often in contrast with the possible technical aspects. A typical example would be: is it acceptable for family members to require of a clinician not to communicate the diagnosis and prognosis to their loved one? Is there an overriding right of the family members or of the patient in this sense? Once the question has been identified, it is necessary to evaluate the principle to be invoked according to the priorities for that individual patient.

Information

Clinical information is essential for the formalizing of an appropriate ethical analysis. A lack of technical information on the diagnosis and prognosis, the therapeutic options, and their risks, benefits, and symptom loading often results in abstract and meaningless bioethical statements.

Individual values and preferences

Exploring the values of life and individual preferences is fundamental in making decisions. Respect for dignity, freedom, and the patient's own thinking, at least in the competent patient, is fundamental. Therefore, the first point is to establish the patient's cognitive and affective level, which requires a professional technical evaluation. In cases where the patient is unable to express these values, a surrogate must be identified. There are profoundly different cultures which envisage conflicting attitudes concerning for example the implicit delegation of decision-making powers to family members, as happens in the Latin world. A lack of knowledge of these details risks severely disrupting the relationship with the patient and family members. On the other hand, in globalized societies, treatment has always been more centered on the patient rather than on the different cultural and traditional values of family members. Therefore, a further effort should be made to differentiate patients according to an individual or parental style, thus respecting their autonomy of thought.

Evaluation of possible alternatives

Beyond the possible therapeutic actions already considered, there are also alternatives on how to pose an ethical question. For example, if the problem concerns the lawfulness of communicating or not the diagnosis to the patient at the request of the family members, we can highlight alternatives to the problem – for example, how to follow the wishes of the family, communicate the truth against the opinion of the family, or review patient preferences.

Formulation of the ethical solution

Having analyzed all the technical and ethical data, one is in the best condition to respond to an ethical question. In making such a decision it is essential not only to explain the reasons that lead to a conclusion, but also to suggest how to facilitate the application of these principles, or to specify the circumstances of the action to be undertaken according to a typically journalistic scheme (who, how, where, when).

Re-evaluation

Each decision-making experience must be re-evaluated with an accurate reflection on the results obtained in each individual case in which an ethical evaluation of an emerging problem has been expressed. This aspect of concreteness, guided by the value of prudence, makes it possible to direct future actions and acquire greater wisdom.

Traditional principles of bioethics

Benevolence and non-malevolence are traditionally the underlying ethical principles, also called "of reason" – in other words, doing well and avoiding evil. With the evolution of society and culture, the importance of autonomy and justice has been underlined. These four elements represent the typical set of ethical principles that should guide medical decisions. In general, none of these principles has a moral priority over any others (3).

a) Autonomy is defined as the ability to act freely according to one's choices in an unconditional way without interference and limitations. This concept expresses intentionality, understanding of the problem, and lack of external influences. Respect for the autonomy of a patient can be expressed with a negative obligation (for external influences, for example), or positive (respect for individual rights), as long as they do not cause damage to others.
b) Non-malevolence supports the obligation not to determine to cause damage to others. This concept is not always absolute and should be reasonably balanced, since in some cases there are reasons that can justify an intervention that does not intentionally, but may well, lead to a shortening of life, as in the case of the double effect doctrine.
c) Benevolence corresponds to the need to provide a contribution to individual well-being. Positive benevolence compels us to help others, even if this is balanced with utility, or rather the need to balance the benefits and drawbacks, and possibly even costs, of an action. The use of *quality-adjusted life years* is a typical example of the application of the utility principle.
d) Various theories of justice have been proposed, based on concepts of equality and health costs. It could be defined as the right to use health

services in the context of available resources and incorporates utility and equality – in other words, a distributive justice.

Personalistic bioethics

The principles of bioethics have also been dealt with according to different views. Personalist bioethics involves the defense of life and death, the therapeutic principle, freedom and responsibility, and sociality and subsidiarity – points based on concepts of phenomenological philosophy that rest on an anthropological basis. Respect for human life and dignity are the fundamental moral values of our society and a precondition of the common good (3).

The first point provides that life, not necessarily the state of health, is an indispensable asset and an ethical imperative. On the other hand, it supports the dignity of death as a fundamental value that justifies, for example, interventions that involuntarily can accelerate death (double effect doctrine). In fact, experiences in terms of terminal sedation have made it possible to exclude the possibility of an anticipated death, using specific protocols and adequate monitoring and above all with highly professional management, even if there is a risk, observed in some countries, of deliberately accelerating the death, in prevalently unprepared environments, albeit in a context of imminent death (see chapter 26). On the other hand, the same doctrine of double effect, accepted by the Catholic world, could be misleading because it would allow us to glimpse the doubt that sedation can actually accelerate death,

- The therapeutic principle of totality specifies the conditions by which a medical intervention must be legitimized from the ethical point of view. It is more specific than the bland concept of benevolence. The intervention must:

a) protect the life and well-being of the patient
b) be directed to the cause of the disease
c) have no alternatives
d) be expected to be better than or equal to the risk
e) be carried out with informed consent.

This principle therefore affirms the moral obligation to use the therapeutic means available to preserve life or restore health. In this case it does not solve the dilemma of a patient who refuses an intervention despite the potential benefits or who accepts high-risk interventions. The limit of moral obligations to ensure health is evident. The principle of therapeutic proportionality makes a distinction in this sense, adding a non-irrelevant element (4). It is argued that there is an obligation to offer the best possible treatments that ensure a reasonable hope of preserving life or restoring a state of health or otherwise that there is no obligation for interventions that do not offer reasonable possibilities. This principle makes a distinction between ordinary intervention, in which traditional treatments are used, and extraordinary intervention (5). Therefore, in order to verify whether a given intervention is compulsory, it is necessary to judge the usefulness of an intervention in a specific circumstance. The concept of utility and futility must therefore be placed in a dynamic context rather than circumscribed at the time, and the final judgment cannot be the result of a simple cost-benefit equation (6).

- The proportionality of an intervention depends on the individual clinical situation and therefore the decision does not concern the individual medical intervention but rather the general context. The need to assess the weight of an intervention in its wider meaning is clear and includes the physical, psychological, spiritual, family, social, cultural, and financial aspects of the context. Therefore, once again a professional knowledge of the most technical aspects is fundamental for a moral judgment on the obligation of an intervention. From the clinical point of view the necessary elements are constituted by the certainty of a diagnosis, the relationship between the utility and futility of the intervention under discussion, the risks and the adverse effects of the possible alternatives, and the accuracy of the prognosis. The moral relevance of the concept of proportionality is based on the possibility of distinguishing between the moral obligation of an intervention, the possible options, and the illicit intervention. The lack of observation of this principle corresponds to a malpractice, such as the omission of a lawful intervention or, on the contrary extreme, an intervention that is disproportionate to the circumstances. Many good or seemingly charitable treatments actually result in an aggressiveness or futility of intervention and would therefore be worthy of bioethical evaluation (7).
- Respect for dignity is a fundamental ethical principle in the personalistic conception. This concept is expressed by respect for human life and by the principle of freedom and responsibility. It is therefore presumed that a subject is able to operate freely, but according to a rational scheme, that is, to realize a responsible exercise of his freedom. A violation of this right corresponds to an act of malevolence. With respect to the concept of autonomy already mentioned, the positive dimension of freedom is

emphasized rather than the negative one, i.e., the capacity for self-determination towards one's own good, and therefore concerning one's own structure, rather than the mere possibility of choice without illegitimate obligations, and therefore an external condition. The connection between freedom and responsibility is underlined. For a free and self-determined decision it is necessary to know the appropriate information. Therefore, the communication of a truth, for example a diagnosis, is not simply the opposite of a lie, but a manifestation of mutual respect (8). Deception, on the other hand, is contrary to this principle, since it contravenes the right to know the truth. In palliative medicine, the problem of communicating the diagnosis or the nefarious prognosis is certainly one of the most complex. The reluctance to share clinical data is often associated with family pressures, particularly in Mediterranean countries, according to a culture that predicts that knowledge of the truth can be detrimental to the patient's psychology, increasing anxiety and depression. It has been observed instead that the sharing of truth can have initial negative effects but limited in time, while with limited information the psychological effects persist for a long time due to the isolation and silence that prevent the sharing of one's own fears, anxiety, and other personal problems (9).

- The principle of sociality and subsidiarity describes the value of an individual as part of a community and therefore the obligation to contribute to the common good and to provide assistance to others, especially the most fragile. The dying patient is an example of vulnerability and requires the respect and competence to preserve his life (or his death) and dignity (10).

These different modes of thought are often complementary and not necessarily incompatible. All lead back to a common thread, or to the habit of using these arguments in making a difficult decision in a specific case encountered in the clinic, although there are many commonalities between the personalistic approach and the philosophy of palliative care: the affirmation of life and respect for death as a natural process, without accelerating or delaying its event. The dying person has the right to receive competent assistance by the addressing of the different components of global suffering with compassion and unconditional respect for life and dignity. In clinical practice three elements are therefore needed: clinical competence, compassion, and respect for human dignity, especially in conditions of extreme vulnerability. These elements are closely connected. The term compassion is often confused with pity. Rather, it should be considered the ability to understand and share the suffering of others, and at the same time the desire, and therefore the better ability, to alleviate it.

References

1. Singer P. Practical ethics. Cambridge University Press, 2011.
2. Calman K. Ethical issues. In Doyle D, Hanks GW, Cherny N, Calman K eds. Oxford textbook of palliative care, Oxford 2004;55-7.
3. Sgreccia E, Lafitte J. Alongside the incurably sick and the dying person: ethical and practical aspects. Libreria Editrice Vaticana 2009
4. Calipari M. The principle of proportionality in therapy: foundations and applications criteria. Neurorehabilitation 2004;19:391-7.
5. Sullivan S. The development and nature of the ordinary/extraordinary means distinction in the Roman Catholic tradition. Bioethics 2007;21:386-97.
6. Calipari M. The principle of proportionality in therapy: foundations and applications criteria. Neurorehabilitation 2004;19:391-7.
7. Taboada P. Bioethical principles in palliative care. In Bruera E, Higginson I, von Gunten C, Morita T. 2015:105-18.
8. Sudore RL, Fried TR. Redefining the planning in advance care planning: preparing for end of life decision making. Ann Inter Med 2010;153:256-61.
9. Tulsky JA. Ethics in the practice of palliative care. In Bruera E, Higginson I, von Gunten C, Morita T. 2015:92-108.
10. Tulsky JA. Beyond advance directive: importance of communication skills at the end of life. JAMA 2005;294:359-65.

CHAPTER THREE

COMMUNICATION

Communication is one of the most important aspects in palliative care for patients with a progressive disease such as cancer because of the fear and uncertainty that add a strong emotional element in the interaction with clinicians. It reflects the ability to exchange ideas, information, and thoughts. This process can be considered as a form of the application of ethical principles in relation to the exchange of information with the patient, especially in some topical conditions, such as diagnosis, prognosis, continuation of treatment, suspension, transition of care, artificial nutrition, the approach to death, and the need for sedation. Communication, which should be carried out continuously to improve its effectiveness, is often limited to the essential, often as solely a formal and legal fulfillment, rather than being empathically oriented to the well-being of the patient and the family. In medical practice, apart from experience and good individual attitudes, there are mandatory steps to communicating effectively (1).

a) Information

It is essential to acquire information on the reasons for a consultation. In addition to knowing the clinical conditions in detail, it is necessary to know how patients have previously learned about the disease, any problems in the relationship between the patient and family members, and what has been reported in relation to a consultation with a palliative care doctor. Therefore, it is advisable to contact the referring physician for an update on these aspects.

b) Environment

A fundamental requirement is the creation of an atmosphere in which the patient is at ease and feels to be considered as a person, compared to any previous paths that have not been always positive. A good doctor-patient relationship that includes trust, respect, empathy, and complicity is the main requirement for good communication. The use of the gaze, contact, and position, for example sitting at the patient’s bed, showing interest and respect, are non-verbal expressions that can help in the beginning of a relationship. Often the expression of a good mood and a smile, which is not exaggerated or out of place, is a good way to continue the interview because it inspires trust and dispels the commonplace notion of the gloomy and circumspect doctor.

c) Identification

The explicit presentation of oneself as a palliative care physician, even if apparently it could evoke the fear of death and the loss of hope, has instead a overriding characteristic: to start the building of a relationship, avoiding misunderstandings. An explanation of the intent, not necessarily the end of life care, can favor this approach. It is necessary to emphasize that the interview does not represent a therapeutic abandonment and to introduce the elements that can be positive for the patient, such as continuity of care and therapeutic collaboration not conditional upon the clinical conditions , multidisciplinarity, and attention to specific aspects. Aspects related to the need to introduce a palliative care consultation early when the patient continues active care fit precisely in this sense, because these aspects favor a smooth and painless transition.

d) Facilitation

Before communicating any information, it is necessary to elicit the patient’s problems, to induce him to speak, to listen to the perceptions and reactions in everyday life. This will allow the patient to relax and be more forthcoming. Some patients may be reluctant to open up or be particularly pessimistic about opportunities for improvement. In these cases it will be necessary to encourage him by trying to solicit the emerging problems that concern him. The patient should not be interrupted, but rather encouraged to continue if a break is granted. Finally, it will be important to show that you understand the problems of the patient by summarizing a set scale of priorities for any problems that have emerged. It is important not to close the interview without setting a new appointment, showing availability at the new meeting.

e) Empathy

Expressions of empathy regarding the emotions shown by the patient and the family allow a reduction of the levels of anxiety, through our asking, for example, his opinion on the arguments discussed so far. This will allow the patient to feel at the center of our attention and understand that his opinion is important. Respect moments of silence (2).

Normalize a strong expression
Understand what kind of emotion
Give a name to the emotion
Make non-verbal gestures of understanding
Encourage to keep talking
Make synthesis and reformulation of emotion
Foment an appreciation of the manner in which care was taken
Embrace silence

Table 1. Strategies for coping with emotions during a consultation

Discussion regarding the diagnosis and prognosis with the patient and the family is a topical moment and is crucial in the planning of decisions, objectives, and priorities, and eventually in preparing for the end of life, if one thinks it is the right time, respecting the feeling of the patient (3). From an ethical point of view, it means respecting the principle of autonomy and self-determination. Moreover, communication is a pillar of informed consent. Most patients want to know all the information possible by which to cooperate and it is the doctor’s duty to answer the questions and problems posed about the clinical conditions, the prognosis, and the treatment options. There are good reasons to inform the patient, as good information provides a better collaboration in future choices, creates less anxiety, and also engenders a certain complicity and confidence. Nevertheless, there are often doubts over completeness. In some cases the doctors, for example, feel that they do not have to underline the toxicity of a new treatment because of the fear that the patient will be terrified, and generally try to maintain an optimistic attitude.

However, in some cases it is legitimate to profess optimism for some patients, generally of low cultural profile especially in some geographical cultures, as patients may not understand well or delegate family members. On the other hand, the same principle of autonomy states that the patient may have the right not to know (4). In different cultures, therefore, personal autonomy has different meanings. The doctor should prepare to identify the level at which the patient or family members wish to be informed about the situation and possible options, to face the emotional impact and help to make the right decision. Knowing the previous level of information a patient holds, and even more understanding what the patient would like to know, are essential before starting such a topic. While in the Anglo-Saxon and North-European world patients prefer to be duly informed about diagnosis, prognosis, and therapeutic options, in Latin-Mediterranean culture patients do not want such complete information, with a clear conflict between the need to know and the fear of learning the truth or of the confirmation of a suspicion held in balance by hope. In many cases, the family is delegated to acquire information, especially in the less developed social levels and in the elderly.

Patients with a good level of culture and young people tend to request complete information. Some patients wish to have less information with the progression of the disease, and psychologically prefer to distance this type of discussion, while family members require more information, perhaps even on the expected survival (5). Even if prognostic factors have been identified (see chapter 4), it is advisable not to be precise when defining exact times that could be disregarded, except in cases where a verticalization of clinical conditions is sufficiently evident. However, it is not always possible to reason on the basis of geographical, social or epidemiological data, and therefore it is necessary to clarify for that given family group what are the attitudes and preferences regarding important information according to the individual characteristics. Advance directives (living will) represent the process by which patients, informed about some basic clinical data, articulate their future preferences (6). This implies an extreme determination and autonomy of the patient, which is not always observable in many cultures. In the United States, these directives are particularly promoted. This is confirmed by legal procedures to which physicians and family members can refer, when the patient will no longer be able to decide and family members take legal responsability for their loved one. This moment can be an occasion for reflection for the patient due to the numerous problems at the end of life. The reinsurance that has been planned to take place automatically is generally favorable and improves trust in the care team (7). On the other hand, many conflicts between family members, emerging in chaotic hours full of emotion, can be prevented. Some doctors are reluctant to start a discussion of this type, due to a lack of time, stress in dealing with patients and family, and the fear that the patient will interpret it as a sense of abandonment. In some cases, advance directives do not provide for the exact course of events and new needs remain uncovered from the point of view of the indications. In others, the necessary documents are unavailable at the culminating moment.

There are some rules in discussing end-of-life decisions with the patient or family (8):

a) Ensure that the patient or family members are ready to discuss these matters. While the pro-activity of the doctor is indisputable, it is useful to understand whether one is ready to do the same or wants to postpone the moment. As mentioned, some patients prefer to delegate family members. The effectiveness of the discussion seems to be better when all the actors are present.

b) Know the patient's values and priorities, expectations, and concerns.
c) Structure the discussion on end-of-life care goals and patient wishes and concerns.
d) In the Anglo-Saxon countries the discussion of some end-of-life options (non-resuscitation order) is very frequent. In this case it is necessary to offer one's own opinion, avoiding, however, inappropriate counter-questions such as asking "what would you do in case of cardiac arrest", harbingers of an inappropriate emotional load. If the patient comes to a decision, assure him that everything possible will be done to satisfy his wishes.

The discussion should take place early, progressively, and across several sessions to dilute the emotional load, although generally these issues are not appropriately addressed with the right timing. The palliative care physician is often demanded or otherwise forced to deal with these sensitive issues. Therefore the acquisition of the empathic skills needed in this field requires considerable experience and continuous and inevitable exercise in coping with difficult situations. Avoiding these responsibilities is a source of serious professional distress, which results in burn-out (9).

Patients may be furious, even if not visibly. The facial grimace, the tone and the volume of the voice, and gesticulations can testify to a strong emotion that requires listening and help. The patient may insist on the same topic with increasing intensity. Such frustration requires he be given the help that he feels has been denied. A fearful attitude and an unsolicited attempt to justify the ineffectiveness of one's intervention or, on the contrary, a reaction of anger, are avoidable errors. Understanding anger and mitigating it is the first step to a subsequent moment of reasonableness in which the patient will be able to express the causes of his anger. In the re-articulation of the question on which one is insisting it is a delicate matter to make the patient perceive that we understand the problem and their hopes and that we are not disengaging from solving the problem. However, a trap to avoid is getting stuck in trying to support the patient in a simplistic way, arousing new hope and becoming enclosed in a dead end without solution. Concretely, it should be explained that all possible help will be provided in a realistic way, in successive steps that will be explained. In some cases the anxiety is such that it dominates the discussion. In these cases, once again, the re-articulation of the request is the most appropriate response, acknowledging the serious concerns that