Medical and Research Publications
International Open Access

Review Article **Journal of MAR Oncology (Volume 3 Issue 3)**

Palliative Care and Quality of Life

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Received Date: March 14, 2022

Published Date: April 01, 2022

Introduction

The reform of health care, promoted worldwide in the sector, has placed ethics at the epicenter of the transformation of medicine and its conceptual renewal. Reasons for this are, on the one hand, the fact that in the last decade the political-health debate has moved from the ideological to the moral field; and on the other, the evolution during that same time of biomedical ethics towards a clinical ethics -oriented to cases- that allows a multidisciplinary reflection on the new realities of medical praxis.

This is certainly tangible in the moral dilemmas referred to the end of life, where, faced with the false options concerning both euthanasia, such as therapeutic cruelty (dysphasia) or the complete abandonment of the terminal patient (myasthenia), palliative care arises as an ethical and efficient scientific alternative.

Since Hippocratic medicine (4th century BC) the need to relieve symptoms in patients whose illness became incurable has been raised, being a duty of the doctor, the care and attention of the suffering being. Already in the first centuries of the Middle Ages, the principle of Christian charity entailed the adaptation of many monasteries into true hospices or hospitals for assistance to the "poor of charity", deprived of the home care typical of the wealthy classes. In the modern age and with a strong impulse since the mid-nineteenth century, the traditional scientific-natural medical model, while producing a true miracle in the science and technology of diagnosis and treatment of diseases, seemed to forget one of the oldest aphorisms on the activity of the doctor: "sometimes to cure, often relieve, always console."

The segment of patients framed within what secularized society has marginalized as a "medical failure", that is, the elderly and the chronically and terminally ill, have seen from bioethics a resizing of their meaning. In the case of oncology, the commendable techno-scientific attitude of achieving curative achievements and constant improvements in survival, unfortunately, has not always had a correlation with the necessary scientific attitude and humanistic aptitude regarding the terminally ill patient and their familiar surroundings.

It was only in the middle of the 20th century, when under the innovative impulse of Cicely Saunders, an English doctor and founder of Saint Christopher's Hospice in 1967, that palliative care or the hospice movement found its modern meaning. In 1987, palliative medicine is recognized as a specialty in England and Australia, achieving equal recognition in Canada in 1991. In Argentina, in 1992 the Association of Medicine and Palliative Care was created, developing the first congress of the specialty in that same year. Currently in our country, despite the difficulties for funding and support, both public and private, there are around a hundred palliative care teams.

According to the World Health Organization (WHO 1990), “palliative care consists of comprehensive and comprehensive care for people with advanced, progressive and incurable disease and their families”.

Let us see in Table 1 the differences between curative and palliative medicine.

Box 1

CURATIVE MEDICINE

PALLIATIVE MEDICINE

Focus

Action

place of assistance

Type of assistance

Evaluation of results Disease

Cure

Hospital

Maximum specialization

Sick Person Survival

Look after

Patient's address

Multidisciplinary team

Quality of life

Patients who for medical or social reasons cannot be cared for at home must be institutionalized with a totally different approach from the acute, critical, or convalescent patient. In general terms, the traditional hospital has a curative and short-stay support scheme, while the long-stay patients we are referring to need a warmer and more familiar environment, since their needs are more about care and support psycho-spiritual. The presence of the different socio-sanitary resources in a sector allows it to adapt to the changing needs of users and define the ideal resource for each one of them.

Importance of palliative care in oncology

As a brief analysis, we distinguish within the Palliative Care programs, basic premises, objectives, and specific tasks.

1-Basic premises

There are three premises of the team: humanitarian attitude towards the patient in the terminal stage, scientific aptitude in the control of pain and other symptoms, and time available for the needs of these patients.

2-Priority objectives of a Palliative Care program.

- Adequate control of symptoms (to relieve the patient and make it easier for them to d play a leading role even in the terminal stage, integrated into their reference group).

- emotional accompaniment and spiritual support for the sick person, according to their demands and with absolute respect for their beliefs.

- Interaction with family members, clarifying situations and providing guidance (in the stage before or after the death of the loved one).

- Primarily home care (the palliative care team is a real link between the hospital and the home).

- Care of the “caregivers” (to optimize the functions of the treating team and prevent complications due to the emotional impact of the task).

3-Specific tasks

Palliative Care Programs are provided by interdisciplinary teams of expert professionals in the field, with accredited training, whose task is not intended to interfere but rather complement that of the family doctor or specialist in the different branches of oncology.

- Symptom control: pain and a set of disabling symptoms appear with marked frequency in these patients: their appropriate relief is one of the main functions of the program, improving symptoms and activity level.

- Accompaniment: this is the tactic and technique of psychological and spiritual care that, with absolute respect for the personality and beliefs of patients and their families, facilitates the level of adaptation to the present situation and helps to prevent avoidable complications (e.g..: claudication in the family, disorders in children, pathological mourning, impossibility of finding a personalized meaning to the ailment.

- Treatment at home: traditional medical care and its financing are based on institutional models, while in palliative therapy the home is the main setting for treatment. Institutions are considered supporting resources rather than building blocks of the program.

- Day Center: it is a service that is offered to patients who are at home, to provide them with a recreational activity and supervision of their health for a few hours, also providing family members with a short break in the care they provide on a daily basis. .

- Consultation service: intended to provide care to outpatients or inpatients in hospitals, clinics, or sanatoriums (experience in our country shows that the need for hospitalization for these patients does not reach 20% of cases when care is provided appropriate.

- Assistance during the period of grief: some people need additional support to cope with the stage of grief, which is achieved through the care provided by trained professionals.

However, palliative treatment does not only include a host of specialized services, but palliative care is also a concept: while some of the basic components mentioned may be useful, they are not always essential for the provision of appropriate palliative care. It is cost-effective, simple to apply, and feasible to deliver at home when delivered by a properly trained and experienced interdisciplinary team.

We focus in this chapter on two fundamental areas: symptom control and home care.

Control Of Symptoms

Until recent years, doctors did not have clear regulations that typified the analgesic ladder that should be applied to patients, nor did they have sufficient information on how to control other symptoms. It was tradition to medicate as little as possible because the final futility of that effort was recognized in advance. Frequently, sedation of the patient was resorted to to silence his pain, clouding the conscience of a patient who was already becoming annoying even for his own family. These confusions delayed the advent of one of the privileged lines of action in the field of terminal care: symptom control.

With this name is called a set of strategies that allow pain relief in more than eighty percent of patients, as well as adequate control of other disabling symptoms.

The experiences published by centers in the country and the; outside, show that each patient with an advanced stage neoplasm suffers from an average of 9 symptoms, including among them (ranked according to frequency):

In more than 75% of patients:

SOFT SPOT

PAIN

HYPOREXIA

In 50-75% of patients:

NAUSEA and VOMITING

CONSTIPATION

DRY MOUTH

In 25-50% of patients:

DYSPNOEA

DROWSINESS

COUGH

ANXIETY

INSOMNIA

The global strategy for symptom control encompasses, generically, a sequence of stages (mnemonic rule: EMA):

1. Evaluation of the causes and characteristics of cad to symptom.

2. Simple explanation both to the patient and to his relatives.

3. Pharmacological and non-pharmacological therapeutic methods.

4. Prescription monitoring, to control both the level of relief achieved and the appearance of toxicity or new symptoms.

5. Attention to detail, a combination of science and art that facilitate symptomatic relief for each patient.

We analyze this strategy taking pain as an example:

Symptom assessment

1. Consider for each symptom (70% of patients suffer from two or more symptoms):

Probable cause: remember that the symptom can be due to four categories of causes:

- Caused by the disease itself. Examples: pain due to bone metastasis in a patient with metastatic breast carcinoma; Dyspnea due to tumor progression in a patient with lung cancer.
- Associated with the disease (but not caused by it). Examples: generalized muscle pain in a patient with neoplastic cachexia; constipation in debilitated patients.
- Caused by the treatment. Examples: actinic brachial plexopathy in a patient who received radiotherapy as antineoplastic therapy; Itching or skin discomfort due to cytostatic extravasation.
- Concurrent etiology (not provoked or associated with the underlying disease or treatment). Examples: pain from osteoarthritic degenerative disc disease in an elderly patient with cancer; Neuritic pain of diabetic etiology in a patient with endometrial cancer.

We must also consider the different impact that each symptomatology implies, not only in its physical or biological considerations, but also in its meaning for the patient and her family. Example: low back pain due to bone metastases in a young woman with resected gastric carcinoma (possible for radiotherapy, implication of disease relapse and poor prognosis) versus low back pain due to non-malignant arthritic disc disease (with obviously different therapeutic approach and evolutionary implication... For To define the probable cause, one must inquire about the past or present history of cancer, as well as recognizing the usual evolutionary pattern of the underlying disease.

Beyond the importance of a detailed and adjusted search for the symptom and the efficacy of its relief (in chapter 55 the subject of pain is addressed in detail), from the philosophy of palliative care it is a priority to take into account in each patient their characteristics emotional and psychological (hopelessness, exhaustion, helplessness); information received (adequate or not) and socio-family factors.

Physical pain is usually the visible part of the iceberg (although for many it remains outside the visual clinical field): its appropriate relief implies consideration of the other dimensions of suffering (the concept of "total pain" established thirty years ago by Dr. Cecily Saunders, see figure)

Physical

Other symptoms

Adverse effects of treatment

Chronic fatigue and insomnia

Social Psychological

Anger over delayed diagnosis Worry about family and finances

Anger over treatment failures Loss of job, prestige and income

Changes in body image Loss of social position

Fear of pain and/or death Feeling of abandonment hopelessness isolation

Spiritual

Why did it touch me?

Why does God allow this suffering?

What all this for?

Does life make sense?

How will I get forgiveness for my past faults?

Explanation

The first therapeutic intervention is established with the attitude of the professional during the interview, including, once the evaluation has been carried out, a simple and clear explanation of the cause and underlying mechanism of the symptom, adapted to the personality characteristics of the patient.

Attention to details!

The only worthwhile result in the symptom control strategy is to achieve a level of relief that is appropriate for the quality of life of patients. This implies not only the necessary scientific knowledge but also a set of skills and ethical foundations, among which we mention:

- Evaluate physical pain in the context of total pain, recognizing how different aspects (mood, expectations, personality, frustrations, etc.) modulate the perception of pain.
- Provide a clear explanation to the patient and his relatives, including written advice (indication booklet).
- Prescribe the appropriate analgesics, without forgetting the recommendation of complementary measures to avoid toxicity (eg, prescription of laxatives in patients receiving morphine).
- Work as a team, to facilitate the appropriate approach to the different needs of the sick person and their environment.
- Avoid unnecessary diagnostic studies that do not add anything to symptom control but conspire against the desired well-being and comfort of the patient and family (for example, laboratory routines or invasive studies).

Other Common Symptoms

Dyspnea

It is defined as the subjective sensation of respiratory difficulty or "thirst for air" (Claude Bernard). It is probably one of the symptoms that causes the greatest discomfort to the patient and that most often distresses family members. Anxiety in the patient and the environment around her can lead, if not handled properly, to panic attacks and emotional loss of control. Dyspnea in a cancer patient is multifactorial, and the primary objective from the symptomatic point of view is to reduce the patient's perception of respiratory distress. The drug of choice is morphine, in doses similar to pain treatment (5 to 10 mg subcutaneously every 4 hours). If the patient is already receiving opioids, the dose should be increased by 50% initially, and if dyspnea is accompanied by symptoms of anxiety, supplement with diazepam (10 to 20 mg subcutaneously). In the event of a crisis of respiratory distress that does not respond to the basic medication, it is feasible to increase the doses of morphine and diazepam subcutaneously.

As non-pharmacological measures, the supply of oxygen is only recommended in cases of manifest hypoxia and not permanently. If possible, it is recommended that the patient exercise relaxation techniques with permanent family and professional accompaniment, always showing understanding and affection.

Nausea and Vomiting

They constitute a multicausal antiperistalsis process, which causes an intensely unpleasant sensation in the patient. This complex process is regulated by two brain areas: the vomiting center and the emesis chemoreceptor. Various neurotransmitters are involved in the central and peripheral activation of emesis (dopamine, serotonin, substance P, etc). Before deciding on a therapeutic strategy, an etiological orientation through anamnesis and complete examination is essential, as well as in certain cases resorting to complementary diagnostic methods. Treatment, in general terms, is aimed at depressing the brain centers of vomiting and favoring gastrointestinal kinetics. The most used centrally acting drugs (generally administered subcutaneously or intramuscularly) are chlorpromazine (25-50 mg every 6 hours), haloperidol (2 to 5 mg every 6 hours) and ondansetron (8 mg every 8 hours). Of more eminently peripheral action, in our experience we recommend metoclopramide (10-20 mg every 6 hours), dexamethasone (1-4 mg every 6 hours), domperidone (15 mg every 6 hours) and hyoscine (10 to 20 mg every 6 hours) . Generally, centrally acting medications should be associated with those of peripheral predominance.

Anxiety and sleep disorders

It is estimated that a third of terminal cancer patients develop some degree of adjustment disorder with an anxious or depressive reaction, hence the need for a correct diagnosis within the clinical and family context. Ultimately, the decision to start a specific therapy is based on the patient's subjective perception. Complications of neoplastic disease such as hypoxia, sepsis, pulmonary embolism, dehydration and confusional syndrome must be ruled out a priori. It should be noted that insomnia disorders are direct enhancers of the patient's anxiety and psychophysical discomfort, hence the urgent need for a joint clinical and pharmacological approach. The most used medications are benzodiazepines, neuroleptics, antihistamines, antidepressants, and opioids. About the former, (by far the most used), those with a shorter half-life (lorazepam, alprazolam) are recommended. Lorazepam (0.5-2 mg every 8 hours orally or sublingually) is the drug of choice in situations of liver failure, while alprazolam (0.25-1 mg every 8 hours orally) and diazepam (5-10 mg oral or subcutaneous) are suggested in panic attacks. Midazolam, in doses of 15 to 60 mg, is recommended for use as a sleep inducer.

Constipation

It is one of the symptoms most associated not only with the clinical picture of the cancer patient and n terminal phase, but because of the opiate treatment started. Prostration, lack of intake or dehydration are factors to consider, but what is involved at this stage is to use pharmacological measures that tend to prevent and eventually alleviate this symptom. It is recommended, in case of constipation, after a detailed examination, proceed to a digital rectal examination and request a standing abdominal X-ray, to visualize the presence of feces in the colon. About laxatives, given the presence of numerous active ingredients, I think it is convenient to attempt a classification according to their mechanism of action:

a- mass formers: they increase the volume of feces, requiring an abundant intake of water. Since they take several days to start acting, they are not recommended in palliative medicine. The most used are methylcellulose and wheat bran.

b- Peristalsis stimulants. They increase colonic motility and intestinal secretion of water, they are suitable for short periods (not in chronic constipation) and in the prophylaxis of constipation associated with the use of opioids. We mention in this category bisacodyl, sodium Pico sulfate and sennosides.

c- Osmotic: they cause a retention of the fecal liquid content, starting its effectiveness in 24-48 hours. The most used laxatives of this group are lactulose, mannitol, sorbitol, and magnesium salts.

d- Local action: we highlight the use of glycerin or bisacodyl suppositories and phosphate or sodium citrate enemas.

Home Care

…” I don't want any more experiments; I know I'm going to die, and I'd like to be at home with my wife and daughters”.

Carlos was 48 years old and had advanced pancreatic cancer that caused him intense pain and uncertainty because, faced with this situation, some doctors who were treating him "disappeared" (abandoned) and others "tried" treatments that deteriorated him even more (therapeutic relentlessness).

When the physical pain was relieved, he was given the opportunity to talk about his fears and he was assured of the permanence of care with him and his family until the end, he wanted nothing more. He just stays in his house where he died two months later.

During that time, he made important decisions for those who remained and for his own peace of mind, in addition to taking advantage of that time with his loved ones and not in futile treatments.

…” I want to die in my house, and I want to be awake”.

Marta was 68 years old and had advanced breast cancer. She lived with her husband in her house and was cared for by her daughter-in-law and her son.

She expressed great anguish at the possibility of "being hospitalized again and dying while she slept." The Palliative Care team cared for her at her home until the end. Hours before her death he became excited. Considering her request instead of sedate her and maybe put her to sleep, she just reassured her. Now that she was dying, she announced to her son: "… at this moment I am dying."

Her family expressed great relief that they were able to respect her decision not to hospitalize her and not put her to sleep.

…” This is my place” … “I want to die here”.

Pedro was 62 years old and had advanced prostate cancer. He was very humble, he lived in a precarious little house with a lot of children, grandchildren and dogs. Since it was a very hot summer, they placed his bed under a tree from where he could see the everyday things that accompanied him throughout his life. The dogs surrounded him. His large family accompanied him and took care of him while he spent time off from “his place”.

These are some terminally ill patients who were assisted by a Palliative Care team in their own homes.

It is known that every year in the world there will be nine million new cases of cancer and that more than half will die from this cause.

Hospitals are prepared to diagnose and treat potentially curable diseases and to do so they use highly sophisticated human and technical resources, but they end up dehumanizing care for the sick person, who becomes a diseased organ or a bed number.

This reality becomes more cruel when the patient has no chance of healing, because he is out of place.

Nor is this highly trained human personnel for the use of this great technology prepared to attend to the current needs of this type of patient, where the healing objectives change for those of COMFORT.

They are COMFORT INTENSIVE CARE (Cecil Saunders)

So where can an incurable patient receive intensive comfort care better than at home?

For this to be the case, they must ensure a network of care where neither the patient nor the family is left to their own devices, because then any hospital or sanatorium will be better than nothing.

This care network must be made up of a minimum team (doctor, nurse, psychologist) to visit you at home, with permanent telephone availability, to control the physical symptoms and emotional support of both the patient and his environment.

The caregiver family is a fundamental link in the success of care, which is why they must be constantly stimulated and advised through family meetings.

Honesty is the foundation stone for reliability. That is why one of the premises of palliative care is NOT to lie, which is not the same as telling the whole truth.

The terminally ill patient has the right (but not the obligation) to know what is happening in her life, to decide what she wants and what she does not want. When we say the right to know, it means responding exclusively to the questions asked and in the most gentle, loving, and human way possible, which is often just an understanding look or a handshake or an active silence. And always based on hope based on current reality, that is; assure him that he will not have pain or other symptoms, that he will not be abandoned and that his family will also be taken care of.

Why Die at Home?

Home is the nest where we truly are who we are, where we authentically recognize ourselves. As humble as the place may be, familiar objects, familiar smells, customs, everyday noises, everyday faces give us security.

When the person is irremediably ill and has the possibility of being alleviated in their physical as well as emotional symptoms and has a half continent, that is: that they do not live alone, that they have the possibility of acquiring medicines, that they have a telephone to communicate permanently and that he is allowed to choose freely, the home becomes the preferred place mostly for patients because he is with his family, because he can receive friends or relatives and the schedules are set by him. He can make decisions that are sometimes crucial for the future of those who remain. The care provided by a committed spouse, or a child is always more pleasant than that provided by an employee of an institution. Food is generally tastier at home, and you can also choose what and at what time to eat it.

For the family, it is very important to be able to care for a patient at home whenever possible, because it helps prevent pathological grief. The poor elaboration of grief and the feelings of guilt caused by not "having done what was possible" are common queries from families who did not have the opportunity to participate more in the care of their loved one.

From public and private health, it is less onerous to care for a patient in their own home than the cost of a hospital bed in medical centers for acute or chronic patients.

The proximity of death can teach us how to live. Superfluous things are relativized and if we become more permeable, the amount of teaching that accompanying terminally ill patients can provide us with is enormous.

"IF THEY DON'T SUFFER, IF THEY ARE INSTALLED

COMFORTABLY, IF THEY ARE CARED FOR WITH LOVE AND

IF YOU HAVE THE COURAGE TO TAKE ALL OF THEM HOME AS MUCH AS POSSIBLE, THEN NOBODY WILL PROTEST AGAINST DEATH”

ELISABETH KUBLER-ROSS

Conclusion

The new care model of the third millennium, which is witnessing a greater population aging and an increase in chronic diseases (and therefore, in a substantial way, cancer) that entail long survival and high costs, must emphasize care and well-being over interventionism and the technological imperatives that only tend to increase the quantity and not the quality of life.

Palliative care teams (predominantly home) exemplify the paradigm shift, which places scientific emphasis on symptom control, with scientific aptitude, humanitarian attitude, and moral emphasis on a fairer allocation of resources.

In short, it is about a new social (and therefore medical) culture that does not see aging, disease, and death as implacable enemies, but as part of our human nature that medical science must help mitigate and accompany.

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