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List of Abbreviations

ACEIs: Angiotensin Converting Enzyme Inhibitors

ANH: Artificial Nutrition and Hydration

CAPC: Center to Advance Palliative Care

CBT: Cognitive Behavioral Therapy

CIE: Chemotherapy Induced Emesis

COPD: Chronic Obstructive Pulmonary Disease

CT: Computed Tomography

CXR: Chest X-Ray

ECOG: Eastern Co-operative Oncology Group

GI: Gastrointestinal

GERD: Gastro-Esophageal Reflux Disease

GP: General Practioner

HADS: Hospital Anxiety Depression Scale

ICU: Intensive Care Unit

KD: Ketogenic Diet

LCHF: Low Carbohydrates High Fat

MEDD: Morphine Equivalent Daily Dose

NSAIDs: Non-steroidal Anti-inflammatory Drugs

NHPCO: The National Hospice and Palliative Care Organization

NICE: The National Institute for Clinical Excellence

ORS: Oral Rehydration Solution

ONS : Oral Nutritional Supplementation

PCO2: Carbondioxide pressure

PEG: Percutaneous Endoscopic Gastrotomy

PG: Prostaglandins

PH Study: Blood Gases

PNDS: Post Nasal Drip Syndrome

PO: Per Oral

POLST: Physician Orders for Life Sustaining Treatment

TENS: Transcutaneous Electrical Nerve Stimulation

TPN: Total Parenteral Nutrition

WHO: The World Health Organization

5-FU: 5-Flurouracil

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Introduction

In most cancer patients, the disease is diagnosed in an advanced stage. As a result of public awareness and screening programs, cancer diagnosis can be made at an earlier and more treatable stage, but many oncologists are still faced with patients with advanced disease.

It is important to know that, even in advanced cancer anti-cancer treatment may improve survival and quality of life. Some tumors may be cured even in an advanced stage and also quality of life may be improved or maintained with anti-cancer therapy. Supportive and palliative care should always be integrated in anti-cancer therapy. Selection of patients for anti-cancer treatment is guided by general condition of the patient, tumor type and stage, and available treatment modalities**. (Ahmedazi et al.,2000)**

In spite of much hope and some illusions, the cancer problem is far from being solved. Global data show that the cancer mortality is increasing world-wide. In developing countries, cancer is one of the great challenges to health in this century**. (Tannerberg et al.,2004)**

There is much confusion about the definitions of palliative and supportive care, some of them have achieved wide acceptance. Oncologists have a unique perspective on the continuity of care and on the changing needs of cancer patients in different phases of the disease experience. The goals of care can be summarized as three care core elements: the prolongation of survival, the optimization of comfort and the optimization of function. **(Cherny et al.,2003)**

Pain is a complex physiological and emotional experience, and not a simple sensation. It always has social and spiritual components. The experience of chronic pain induces depression, exacerbates anxiety, causes sleep disturbance, contributes to fatigue and general deterioration and interferes with social activities. At the time of diagnosis, one-third of cancer patients may suffer from pain, However in advanced stages at least two-thirds of them may suffer. Cancer itself causes 80-90% of pain syndrome10-20% is therapy- induced. Only 2-4% of cancer patients suffer from chronic pain unrelated to cancer e.g.: migraine or low back pain**.(Daut and Cleeland,2002)**

Treatment of pain enforces an interdisciplinary and multiprofessional approach to equilibrate the individual risk-benefit ratio

of each therapeutic intervention. This includes disease-modifying therapies (chemotherapy, irradiation and surgery) as well as non medical options such as catheters ,stents, physical therapy and/or psychological support. It is greatly important to develop a therapeutic ladder with clearly defined aims, and to discuss this with the patient in the course of treatment and routine re-evaluation. **(Jadad,2005)**

Aim Of The Work

This essay aims to introduce the principles of palliative and end life care to health care professionals treating cancer patients and care-givers from family members. It aims to help them to initiate and recognize the different models for delivering this type of care, to improve the quality of life of cancer patients and enable them to manage pain and symptoms through evidence based techniques, since the current concept among oncologists is restricted to palliative chemotherapy, palliative radiation or hormonal therapy or even no treatment.

Chapter 1

DEFINITION AND CONCEPTS OF PALLIATIVE AND HOSPICE CARE

Denying the right of a cancer patient to have appropriate Palliative Care to deal with his physical, psycho-social and spiritual concerns during his stressful moments of life, is not only unacceptable, but also unhuman. The relief of suffering is an ethical imperative. Every patient with an active, progressive, far advanced cancer has the right to get palliative care. Every physician and nurse has a responsibility to employ the principles of Palliative Care in the care of these patients. (**Von Gunten, 2005)**

Palliative care: (is derived from the Latin word palliare and palliates which mean to "cloak or cover") is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms , delay, or reverse its progression. **(Abernathy, 2008)**

The World Health Organization (WHO) made an important advance in l986 by first defining palliative care and then updating this definition annually .

"Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering. By means of early identification and assessment and treatment of pain and othger problems: Physical , psychosocial and spiritual". **(Adams and Corrigan, 2002).**

The National Institute for Clinical Excellence (NICE) defines palliative care as : " The active holistic care of patients with advanced progressive illness to patients of all ages, who have a life limiting active, progressive illness, or far advanced disease, with little or no prospect of cure, and for whom the primary treatment goal is the relieve and prevention of suffering and improvement of their quality of life. Palliative care is a philosophy of care and an organized, highly structures system for delivering care. It is delivered concurrently with life-prolonging care or as the main focus of care." **(Kim et al., 2005)**

On the other hand, Billings defines palliative care as: "An Interdisciplinary Approach to the Comprehensive Management of Physical, Psychological, Social and Spiritual needs for patients who have progressive incurable illnesses in which prevention , and relief of pain and/or other physical and emotional distress are the cornerstone of treatment" **(Billings and Block ,2005)**

Palliative care is also referred to as : the comprehensive attention to pain symptoms, psychological suffering, social needs and existential distress of patients who face life threatening illnesss, with limited prognosis, in order to optimize their quality of life and that of their families or close friends. **(Ahmedzai et al., 2004)**

The concept of palliative care is to optimize quality of life by anticipatin, preventing and treating suffering of the patient, throughout the life-threatening illness. Palliative Care addresses physical, intellectual, emotional, social and spiritual needs and facilitates patient autonomy, access to information and choice. Palliative care is not dependent on prognosis and is offered early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy and all other forms of medical treatment. Palliative Care is operated through effective pain management and other distressing symptoms of a life-threatening illness, while incorporating psychosocial and spiritual care according to patient and family needs, values, beliefs and culture(s). **(Lorenz and Lynn, 2008)**

Ethics and Philosophy of Palliative and Hospice Care

Palliative Care is based on a number of ethical values, assumptions and beliefs in order to ensure high quality, patient-focused and evidence-based services that meet the patient and family needs.

- It provides relief from pain and other distressing symptoms;
- It affirms life and regards dying as a normal process;
- It neither hastens nor postpones death;
- It integrates psychological and spiritual aspects of patient care;
- It offers a support system to help patients live as actively as possible until death;
- It offers a support system to help the family cope during the patient's illness and in bereavement,
- It uses a team approach to address the needs of patients and their families, including bereavement counseling , when indicated ;
- It enhances quality of life, and positively influence the course of illness;
- It 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 the investigations needed to better understand and manage distressing clinical complications. (**Morrison et al., 2004)**

Many patients with advanced cancer do not receive palliative care : on the other hand some are referred too late in the course of their disease. The reasons for this may relate to the physician, the patient, or to social factors.

Barriers to Palliative Care

1.Physician factors :

- Lack of advance care planning and communication
- Late referral
- Lack of training and knowledge : Palliative Care is seen as a failure and not a priority as curative treatment.

2.Patient and family factors :

- Unrealistic expectations of treatment.
- Lack of guidance and information about comfort and end-of-life care
- Fear from opioids (opiophopia)
- Difficult access to drugs for pain and symptoms' relief.
- Difficult access to Palliative care for patients in remote areas.

3.Organizational and social factors :

- Inexistent and/or poor Palliative Care plan and services
- Lack of standards and infrastructures for Palliative Care.
- Inadequate and/or poor palliative care team leadership
- Lack of continuity of care plan for advanced cases
- Poor and /or inexistent coordination of services
- Strict regulations restricting the use of opioids.
- Inadequate funding for infrastructure, personnel and medications

- Lack of training for the health care professionals.
- Palliative care is not seen as a health priority. **(Miyashita et al., 2007)**

Hospice and Palliative Care

The term "hospice" (from the same linguistic root as " hospitality") can be traced back to medieval times when it referred to a place of shelter and rest for weary or ill travelers on a long journey. Now, this term is used interchangeably with hospice care and palliative care. Hospice means different things in different countries. It is variously used to describe : a philosophy and a program of care, to the site of care or buildings where it is practiced, to care offered by volunteers, or to care in the final days of life. Accordingly, it is better to adopt and use the term Palliative Care. **(Russel and susan, 2006)**

Hospice and palliative care programs share similar goals of providing symptom relief and pain management. In most countries, no differentiation is made between 'Hospice" and "Non-hospice palliative care . Hospice is seen as one part of the specialty of palliative care; hospices and non-hospice-based palliative care teams both provide care to those with life limiting illness at any stage of their disease. Hospice provides patients with: palliative care, terminal and emergency care, 24-hour telephone support, practical help, information , advice, and bereavement support for all family members. **(Nayak, 2006)**

The National Hospice and Palliative care organization (NHPCO) defines hospice care as a service delivery system and an organization that provides palliative care for patients with life-limiting disease or terminally ill dying patients. It aims to meet all the needs of patients, as they enter the terminal stage of an illness. **(Russel and susan ,2006)**

The goal of Hospice Care is not to cure, but to provide comfort, keep and maintain the highest possible quality of life for as long as life remains. Hospice stresses on peace, relief, comfort, and dignity, through symptom and pain management. The focus of hospice care is not on death, but on compassionate specialized whole care for the living and those who are sharing the patient's journey**. (Nayak, 2006)**