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*Palliative care – transiting old tradition and values
into the modern health care practice*

PALLIATIVE CARE VERSUS TERMINAL CARE

“The words ‘terminal’ care are the most insensitive ones in our medical jargon” says Ronald Fisher. “They obscure rather than clarify, they mislead, they are inadequate. So why add to the distress of patients and families by using such ill-chosen words? These two words: Terminal care are drab and discordant and diminish the care we are trying to give. The expression Palliative care, though not perfect, is far more acceptable and carries with it a hint of hope. So, we should not use those both terms as if they are synonymous (5)”. Palliative care (A) is a broad band of care of indeterminate length which should start the moment the cancer is diagnosed or even before, when there is a gleam of apprehension in the patient’s eye. It is at that point that District nurse should be introduced to the family concerned, even though the care required initially might only be intermittent. Terminal care (B) is only a part of the palliative care program and comes at the end of life, that is in the last hours or days (3, 5).

Palliative care (A)

Goal: to assure the environment where a human being is dying in peace and with respect to his/her dignity, free from disturbing symptoms and from not necessary medical and nursing interventions

Terminal care (B)

Goal: team approach toward assuring the best possible quality of life for the patient/ill person with regard to the non-curable disease (terminal)

The main difference is inside the goal formulation. Therefore, the modern oncology nursing is using the term “palliative care” as it is closest to the nature and essence of caring and nursing. In fact, terminal care concerns only the last phase of palliative care.

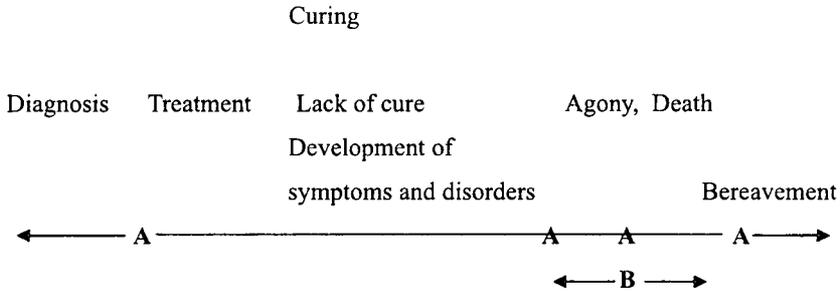


Fig. 1. The trajectory of human life

Palliative care is a patient centered approach. The rule of the caring team is to: provide constant and careful attention, interpret the patient’s needs, provide symptomatic relief, never to lose sight of patient’s family, provide the human presence, keep the patient in contact with reality.

This view of task creates a need for co-ordination and participation, and implies that each individual member of the team must accept his responsibilities, show courage, common sense and generosity in full measures, in a word, to be human (4).

MEMBERSHIP

The care of the dying has always to be undertaken by a caring team. The three most important members of this team are: the family, the doctor and the nurse. Very often the dying person has a much closer contact with others, e.g.: the psychologist, physiotherapist, spiritual representative (chaplain). These more social, than medical relations may be so important to the dying, that the person involved may even play a major role in the caring team. The primary role given to the parents of the dying child in the caring team should never be put into question (3).

“It is essential that each member be attuned to the «total» patient. Communication among team members is vital in order to ensure that all needs of the patient and family are addressed. The nurse’s role is a key part of the interdisciplinary palliative care team. Nurses are often the first to assess patients in the hospital, ambulatory, or home setting. They often have a prolonged, close contact with patients and family members, providing a unique opportunity to assess well-being, communicate adversities with the other palliative care team members, and strategize interventions that enhance quality of life (2)”.

COMMUNICATION

The good communication is essential to good care for a dying person. There should be good communication between members of the team so that each member of the staff is aware of what is being said to and by the patient and the family (10).

THE PLACE OF DEATH

There is much discussion about this question, since no solution is wholly satisfactory to the caring team, the family or the patient. Present trends waver between two possibilities: hospital or home care, although the hospice movement is a real opportunity in many countries (11).

Hospital routine however, as also in many respects the education of doctors, nurses and other personnel in medical care, has up to now been primarily directed towards topics such as exact diagnosis, saving and prolonging life or maintaining health. Whilst accepting this development, medical and hospital care must give more attention to the needs and the care for dying patients, to be looked upon as a very important part of the medical service (7, 8).

Some basic remarks are necessary concerning hospitals of all kinds where dying patients are admitted:

a) the setting should be adapted as far as possible to the needs and desires of the patients. For the dying, a separate room is often desirable, giving more opportunity for peace and silence and also better possibilities for the family and friends to visit without inconveniencing others. Sometimes, however, a community room may also be more suitable with respect to the possibility for stimulation and social contact with other patients,

b) attention should be given to the equipment of the room: for example, light which does not irritate or dazzle the eyes,

c) a comfortable chair for visitors should be made available in the patient's room,

d) there ought to be a special room connected to the ward or at any rate to the hospital for relatives and visitors looking after a dying patient, where they could rest. They should also be offered possibilities of having meals in the hospitals.

The hospital should offer similar conditions to those pertaining to home by improving reception arrangements such as: 1) permitting patients to keep^{1v} their personal belongings, 2) shielding them from psychological traumas, 3) equipping rooms with telephone and television, 4) introducing a valid choice of meals, 5) improving the sanitary facilities.

THE PATIENT'S HOME

This being so, the patient's home should, as many people agree, be the ideal place for him to die, attended if possible by his family, in his familiar surroundings, cushioned by his normal routine. Death would then mean "passing over", a natural process infinitely preferable to a medicalised, physical, social and temporal death in a specialized unit. The family should receive permanent medical, psychological and social aid, so that it could take total charge of the patient, on the understanding that he could be readmitted to hospital if his condition made this necessary or if the family were no longer capable of caring for him (13).

SPECIALIZED CARE UNITS (PALLIATIVE CARE WARDS AND HOSPICES)

In the last years special palliative care units have been established for special groups of patients with an advanced incurable disease (advanced malignant diseases). In these special units and hospices techniques of pain control and alleviation of the symptoms of suffering have been practiced to a very great extent as also a very extensive psychological and human art of caring (13, 14). The cancer care units are usually part of the national health service, and are built in the hospital grounds. The hospices and other homes are voluntary organizations relying on voluntary contributions for their survival.

There are five dimensions of Palliative care:

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|-------------------------------|---|-----------------------|
| 1. Care over physical needs | } | care are for patients |
| 2. Psychosocial care | | |
| 3. Spiritual care | | |
| 4. Care for the family | } | care for caregivers |
| 5. Care for the professionals | | |

CARE WITHIN THE PHYSICAL SPHERE

In the care for the dying, treatment of symptoms, alleviation of suffering, distress and anxiety should be the main priority. Basic care is important for the sick, including hygienic measures and the maintenance of somatic functions. Good bed care is essential, including the protection of the skin against chafing and bedsores. Catheterisation or other methods should be used to treat or prevent urine retention, but of course taking the patient's attitude into account.

Discomfort and symptoms of suffering such as pain, anxiety and depression should be treated as far as possible by suitable methods. If drugs are used, they should be administered in adequate doses to relieve symptoms. Problems of respiration should be constantly observed. Difficulties in breathing have to be relieved by various measures such as

suitable sleeping positions, administration of oxygen and relevant drugs, or, if available, services of physiotherapist. Artificial respiration and other respiratory techniques which extend life needlessly should be avoided. Fluids and nutriment may be administered through artificial means, only if this is in the interest of the patient and will alleviate his suffering. The aim is to alleviate suffering, not to prolong life. It is essential for the seriously sick and dying to receive psychological and emotional support, trusting the caring team and confiding in the health care personnel.

Pain: it is necessary to decide what objective is being pursued and make a selection from the range of drugs which act on the physical and psychological components of pain, while complying with a very strict code of use. If drugs are to be regularly used they should be administered in adequate doses and given enough to maintain a pain free-state.

Suffering is a highly complex phenomenon and cannot be reduced to its purely neuro-physiological component. Physical pain, mental suffering and anxiety are so interwoven that cannot be relieved separately, or even considered in isolation (3, 15).

PSYCHOSOCIAL CARE

“When patients are faced with death, life takes on a new meaning. Values may shift, and personal and family relationships become a high priority” (2).

Patients must experience physical comfort before they can move on to dealing with more pertinent psychosocial issues. There are basic human needs which are priority. Therefore, professional caregivers should be aware of: 1) The stages and phases of psychological reactions to dying; 2) Safety and security needs; 3) Love and belonging needs; 4) Self-esteem by others; 5) Self-actualization.

Psychological approaches may include the following: sensitive listening, relaxation therapy, hypnosis, distraction, imagery, massage, aromatherapy, visualization, meditation, praying.

SPIRITUAL CARE

“The person is an empty shell without the spirit. The human spirit is the energy within each person that search for a meaning and purpose to life. Spirituality is the need to feel connected to God or a higher power. Spirituality instills hope that extends beyond the grave and beyond life itself. It is an essential component of palliative care. It is also a coping mechanism, between religious belief and coping with illness” (2). Most of patients need spiritual care, even though they do not talk about that (1, 6). Chaplain presence and availability is important, and should be arranged according to patient’s need.

Patients may look for answer to specific questions: sense of life, system of values, sense of suffering and pain, filing guilty, questions regarding God, life after death.

CARE FOR THE FAMILY

We, as the professional caregivers, should have a clear picture of who is the family, and who is who for the patient. We should recognize who is the closest person to the dying patient. The family also suffer and undergo through different and confusing emotions. They could unpredictably help in the situation of prolonged and overwhelming stress.

Nurses, doctors and other professional caregivers offer comfort through: 1) clear and open communicating, 2) showing empathy, 3) answering questions and referring to other professionals, 4) providing education and ongoing support, 5) acting as a liaison between the patient, doctor and family members, 6) creating the private, intimate and sensitive atmosphere during the whole, 7) process of caring, 8) being a solicitous human being.

CARE FOR PROFESSIONALS

Caring is fascinating and gives a lot of satisfaction, but is also demanding and exhausting. Therefore, since there is a need for understanding our own emotions and our own needs, we should:

a) provide and offer support for each other (what was good in care, if there were some problems ask why, how we should modify care to avoid it, what we have learned from that; discussion and sharing the problems and feelings),

b) create the forum for the discussion between the different members of the caring team, so that everybody could speak and listen to the concerns of others. The open communication within the team is therefore a necessity,

c) remember that every team member is aware of emotions and reactions toward the death and dying (9).

In order to avoid a burn-out syndrome we need to remember those three simple messages:

1. Knowledge + Skills = Good care. 2. Thinking about our own values and feelings, emotions in regard to the serious illness, suffering and death is helpful. We should remember, even deeply involved in care, that this is not our suffering, not our death. 3. We should care for our own personal life, specially outside the hospital or hospice. It is necessary to build up a strong social network in order to protect our well-being (9).

“We have accomplished so much, yet we have so much work to do. The threat of legalized assisted suicide threatens the naturalness of dying and the «final stage of growth». We need to continue to educate nurses and in the art of palliative care, emphasizing holistic care that encompasses the mind, body, and spirit. Total suffering involves all three of these components, and end-of-life care must include the same. We can master the art by learning from our mentors and by listening to the experts on suffering – the

patients themselves. We can promote a dignified death by managing deleterious symptoms. We can instill hope that goes beyond the grave. We can make the difference in the lives of people dying of cancer. Furthermore, we can be the leaders in palliative care for those suffering and dying from other diseases. We, as oncology nurses, have a unique opportunity to chart the course of palliative care in the 21st century by refocusing attention on the naturalness of dying and challenging clinical research in the area of palliative care" (2).

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SUMMARY

Care of the dying patient is care for the patient who is still living, it is helping that patient to live his or her life to the fullest whether at home or hospice, or in hospital. It is care that is not just centered on the individual but includes members of the family. It is focused on improving the quality of patients' life, by incorporating into the professional care most of unique human values, such as respect, empathy, compassion and tender loving care. Palliative care is a broad band of care of indeterminate length, and does not necessarily end with the death of the patient. Until life begins to glow again, some surviving relatives may need support during the bereavement period. Thanks to Dr Elisabeth Kübler-Ross and Dame Cicely Saunders, two great women visionaries and leaders of the emergence of Palliative Care, one of the best things that has happened to medicine in the 20th century, the development of care for dying patients and their families was possible.

Opieka paliatywna. Przeniesienie tradycji i starych wartości do nowoczesnej opieki

Opieka paliatywna jest opieką holistyczną, zogniskowaną na pacjencie z daleko zaawansowaną, postępującą chorobą oraz na najbliższych mu osobach – świadczoną w warunkach domowych lub w hospicjach przez zespół interdyscyplinarny. Opieka paliatywna ma za zadanie maksymalizację jakości życia osoby chorej, a śmierć traktuje jako naturalny koniec każdego życia ludzkiego. Zintegrowana opieka świadczona jest we wszystkich wymiarach egzystencjalnych ciężko chorego-umierającego człowieka oraz jego rodziny. Filozofia opieki paliatywnej odwołuje się do ogólnoludzkich humanistycznych wartości, a w sposób szczególny czerpie z chrześcijańskiego miłosierdzia i tradycji opieki. Prekursorami współczesnej opieki paliatywnej są dwie charyzmatyczne kobiety: dr Elisabeth Kübler-Ross i Cicely Saunders.