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*Starting with the hospice/palliative care project – the philosophy  
and the practice*

The European Public Health Committee of the Council of Europe published a Final Report (1981) entitled: *Problems Related to Death: Care for the Dying*. In the introduction we may read:

[...] in our society a man dies badly if neither he nor his family accept the fact of dying; a man dies badly if the medical team is unaware of the problems, untrained to deal with them and not in control of the situation; a man dies badly if death is relegated to the realm of the irrational, the imaginary, the terrifying; a man dies badly if he dies alone in a society which no longer knows how to die.

Twenty years later, the problems related to death are still present. Hospice is a philosophy of care for people with prolonged, advanced disease and their families that focuses on palliation of symptoms and enhancing the quality of life during whatever time the patient has remaining. Hospice affirms life and neither hastens nor postpones death. The modern hospice movement began in London, England, in 1967 when Dame Cecily Saunders started St. Christopher's Hospice. Today, West Europe and North America adopted the hospice care model widely. There is a considerable growth of the hospice care organizations also in Central and Eastern Europe. What is the best in the hospice model and what can be adopted by the other countries or regions of the world? It is important to transfer the philosophy and the mission, however, it must be done in the cross-cultural manner and with sensitiveness to other non-Christian religions (13).

It is necessary to consider some basic issues, when planning to open a palliative care/hospice service: the needs of the dying within the biological, psycho-social and spiritual dimensions (family), the problem of telling patients the truth (cultural background, breaking bad news, communication knowledge – verbal and non-verbal), the treatment of pain (culture, myths and misinterpretations, use of opioids, morphine etc.), the affective reactions of families (culture, role within the family, support, engagement, grief and bereavement), the role and composition of caring teams (role, care, cooperation, interdisciplinary approach, continuity of care), assistance to patients in the terminal phase (cre-

ating the surroundings, accepting death and withdrawing from the unnecessary treatment, medical and nursing interventions), the choice of the optimum environment (patient's right to choose), the problems of training future health care staff, the integration of death within our mental universe (6, 7, 14, 15).

The needs of the family and the patient, symptoms control and treatment are related to: a) basic care (hygienic, bedside care, maintenance of the somatic functions), b) discomfort and symptoms of suffering (pain, anxiety, depression); drugs to be used, availability, proper dosage and administration, c) problems of respiration (observation and relief without the artificial respiration), d) fluids and nutrients (administration of artificial means only if they are given in the best interest of the patient, not solely to prolong life!), e) complications in the current disease should be treated accordingly, while keeping in mind the patient's integrity and own attitude to life, f) it is essential for the seriously sick and dying to receive psycho-social and emotional support so they can confide in and trust the medical staff and have confidence in their situation (1, 5).

The most prevalent physical problems of the dying patient are: nausea and vomiting, eating and feeding, anorexia, mouth care, ascites, constipation, intestinal obstruction, diarrhea, rectovaginal fistula, bladder pain, dyspnoea, itch, fungating lesions, weakness, hypercalcaemia, depression, fear and anxiety, insomnia, pain, confusion, incontinence, skin problems, lymphodema, cough (4).

The psycho-social needs of the patient are many and varied, reflecting the uniqueness of the individual. There are three areas of basic human needs: 1) the need to love and be loved, 2) the need to understand and be understood, 3) the need to choose and be chosen.

There is a model describing the self-esteem during the transition which could be related to the potentially life-threatening illness. Some people however, stick at one stage and do not progress through the whole process systematically: immobilization, minimization, depression, acceptance of reality, letting go, testing, search for meaning, internalization. It is important to remember about two other things: relationships and sexuality (10, 12).

The dying patient's needs are concerned with security and confidence in the ability of the nursing staff, the certainty that he will not be abandoned. He needs to be kept regularly informed in comprehensible and credible terms; to be given truth which opens up a dialogue of confidence, rather than lies which obstruct that dialogue; he needs the presence of another human being (8). The other needs are: belonging, consideration, availability (caring people/person should be available 24 hrs a day, 7 days a week), open and honest communication, respect, touch (as a basic human need, which increases when in extremal situations, in danger...), being in the control over his/her life or situation to the extent that is possible in his/her condition (2).

Family needs are very important. They need: to be with the dying person, to be assured of the comfort of the dying person, to be kept informed of the impending death, to ventilate emotions, to receive comfort and support from family members, to receive ac-

ceptance, support and comfort from health professionals. There is a need to continue sharing life with the patient and this may require permission to be included in the care-giving.

Different institutions may offer different facilities in regard to the death/dying care. The place of death can be in the hospitals (enhancing and improving quality of dying within the hospital, setting standards for the “terminal care”), the patient’s home and specialized care units (supervision and centers of excellence).

The palliative care/hospice should be a facility where: patients can be properly looked after in a home-like atmosphere without any of the pressures of a modern hospital ward (no high technology equipment); with max. 25 bed units – to be apart from the hospital; where every effort is made to ensure that the interior decoration is made as home-like as possible by the provision of comfortable furniture, decorative curtains, and carpeting throughout; where both bedrooms and dayrooms are laid out so as to give ample space to patients and their visitors; providing: television (radio, cassette player etc.) with individual earphones for room use, plants and flowers, garden (easy access from the patient’s room, from the day room etc.), telephones allowing private calls (in every patient’s room but also in separate places, where family can communicate with others); where personal belongings are arranged according to patients’ tastes and needs (need of using own clothes if possible), where patients’ pets can be brought (a cat, a dog).

In general: as long as basic philosophy of being open to the individual’s needs is maintained, there will be no problem adopting them (3). The following guidelines are considered important in order for a specialized care unit to meet its objectives: love, compassion and individual concern characterize the basic attitude of the staff; individuals must choose the work in this area of care being aware of the spirit in which the work is carried out (this includes supportive staff such as domestic and secretarial). Volunteers also play a useful role; time for inter-staff communication and education should be allowed for in the work load; due to the role-model nature of this type of care, senior staff will have a very important public relations and educational role in and out of the unit. This should in the long run be taken into account in salary levels and in staff distribution; in order to meet patient needs the suggested nurse (nursing personnel) ratio should be at least 1:1; home care service based on such a unit should be available to all patients; a day center could also be a useful adjunct; home care service is available 24 hrs a day. Frequency and length of visits are adapted to the patient’s and family needs; necessary equipment should be available on a free loan basis for patients cared at home; regular life activities should be part of the unit. Flexibility is necessary in the care given to patients so that activities such as celebrations, work, play and involvement in the community can be possible; the in-patient facility should not exceed 20-25 beds in order to maintain a personal approach. Once a patient has been admitted he should be guaranteed in-patient or out-patient care any time he needs it. It is considered wiser to open a new independent unit than to enlarge an existing one above the 25 beds capacity; rooms of

various sizes (one to several beds) should be available so that needs for socializing and privacy can be met, thereby assuring flexibility of use.

In order to achieve less clinical atmosphere architecture and interior design should reflect individuality, personal tastes and comfort! These are some examples: wall-to-wall carpeting, different colour co-ordinating from room to room (could be wallpapers), paintings on the wall, coloured sheets, plants and flowers, different furniture. Hospice offers usually a choice of menus and a cocktail hour serving free alcohol is a great boost to the patient morale, free visiting should be available to all (family, friends, small children and pets), a quiet comfortable room should be available for distressed relatives, staff, patients, overnight accommodation should be provided, as well as a room with a double bed for couples should be available. The important part in improving the quality of care as well as the quality of life plays the complementary therapy: acupressure, herbs therapeutic touch, massage, aromatherapy, visualization, relaxation, meditation, music therapy, reflexology, prayer – it should be integrated into the daily nursing care.

In helping the dying, the caring team's task is: to provide constant and careful attention, to interpret the patient's needs, to provide symptomatic relief, never to lose sight of family, to provide human presence and to keep the patient in contact with reality. This view of the task creates a need for co-ordination and participation, and implies that each individual member of the team must accept his responsibilities, show up courage, common sense and generosity in full measures, in a word, to be human. The care of the dying has always to be undertaken by a caring team. The three most important members of the team are: the doctor, the nurse and the family. However, very often the dying have a much closer contact with others e.g.: the psychologist, physiotherapist, spiritual representative. 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 a dying child in the caring team should never be called in question (8).

It is important that those involved distinguish between curative treatment and relieving treatment. When curative treatment is no longer feasible then it should cease. Every doctor or nurse should ask himself the question "will this treatment or this procedure improve the quality of this patient's life?". If we are going to require the caring team to meet the dying patient's needs they must not only receive the know-how thorough education but also have an access to environments which allow professional care to be given to dying patients and where team members can support each other (9).

Educational needs of the caring team are the following: 1. Training (pre- and post diploma). 2. Basic education (programme & curricula); included as mandatory in the basic education for nurses, doctors and social workers. 3. Specialized education (1-6 months in the specialized centers). 4. Continuing education (keep up-to-date), on-the-job, in service. 5. Teaching (quality of teachers!)

The teacher of death and dying as it pertains to health professionals should be: a person who accepts his/her own mortality, a warm and caring human being, a non-moral-

ist, an effective problem-solver, knowledgeable of the subject matter, knowledgeable in the art of counselling, mature person, developed in the spiritual dimension. Course content facing one's own death (reading, discussion, role playing), understanding the dying person and his/her family (readings, live experience, films, theoretical content, etc.) and clinical experience with supervision. Way of teaching should focus on interdisciplinary groups, active methods of teaching (principles of teaching the adults), active learning and listening, working and socializing together, knowing, supporting each other and networking. Steps should be taken at national, regional and local level to stimulate public opinion and interest in the problem of the dying. Experienced specialized staff can give considerable help in this respect and their services should accordingly be used. In particular, families should be informed of all the possibilities available enabling their assistance and care for the dying at home and of the alternatives to home care (8, 11).

We should always remember: The care of the dying is the care of the living.

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### SUMMARY

The goals of the palliative care is the maximizing of the quality of life of people with the chronic progressive illness, their families and those who care about them.

The palliative care is characterized by the interdisciplinary and patient-centered approach which consists of five dimensions: the sphere of the biological, psycho-social and spiritual functioning centered on the patients life, and the others: the care for the family and care for ourselves concerned with the care for the caregivers.

The authors describe the development of the palliative care in the last twenty years and stress the importance of the difficult but necessary balance-keeping between the philosophy, mission and the practical needs.

#### Hospicjum – projekt opieki paliatywnej – pomiędzy filozofią a praktyką

Celem opieki paliatywnej jest maksymalizacja jakości życia chorych z przewlekłą, postępującą chorobą, a także ich rodzin oraz innych bliskich im osób. Opieka paliatywna posiada charakter interdyscyplinarny, a zarazem pacjentocentryczny. Posiada pięć wymiarów, z których pierwsze trzy: biologiczny, psychospołeczny i duchowy odnoszą się do sfery funkcjonowania osoby chorej, a dwa pozostałe: opieka nad rodziną i nad profesjonalnymi dawcami wsparcia – dotyczą opiekunów.

Analizując rozwój opieki paliatywnej na przestrzeni ostatnich dwudziestu lat, zgłoszono postulaty na rzecz utrzymania harmonii pomiędzy szczytną filozofią a wymaganiami ze strony praktyki.