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HOSPICE

INTRODUCTION

Hospice is an alternative to the medical center with its cold architecture and emphasis put on procedures. It indicates a place centered or focused on the patient. It is a place that exists for the patient, not for procedures. Hospice is an alternative way to plan a place for terminal-ill patients reconsidering the needs of the dying person and then fashioning a setting and required support areas around the patient and these defined needs.

The challenge is to create an environment that allows and assists the search for meaning in life for each individual. Home-like settings have become a topical subject in health care design.

THE TOPIC OF THE WORK

- . The humanization of the hospital environment with the emphasis on the missing items in the health service system – hospice.
- . Hospice is comprehensive care in the last months of life. It is a special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments.
- . The goal of hospice care is to improve the quality of a patient's last days by offering comfort and dignity.
- . Hospice care is provided by a team-oriented group of specially trained professionals, volunteers and family members.
- . Hospice addresses all symptoms of a disease, with a special emphasis on controlling a patient's pain and discomfort.
- . Hospice deals with the emotional, social and spiritual impact of the disease on the patient and the patient's family and friends.

THE MAIN THEMES OF THE WORK

- . To design logical units and disposition relations of the new typological classes – the hospices for adults, for children, pure and combined hospices, universal or specific hospices.
- . To define new possibilities for development of hospices in Slovakia.

THE ACTUAL SITUATION OF THE PROBLEM

Hospice - the situation in health service in Slovakia

According to the health service statistics from the year 1995 more than 500.000 inhabitants in Slovakia suffer from chronic

diseases. There are 6 hospitals for long-term ill patients in Slovakia with 600 beds and the possibility of the acceptance of 3534 patients within a year. The hospitals for long-term ill patients do not satisfy the standards in compliance with definition of The World Health Organization (WHO) and with the basic principles of palliative care. One of the standards is also an aspect of architecture.

The basic cells of the hospice care in Slovakia are parish and see charities. They propagate the hospice care and they try to change an attitude of public towards dying people. The hospice movement starts to work in terrain – directly in families, because a family is the most natural, social and emotional background for everyone. That is a place where “ADS” – The Agencies of Home Care start to work. They offer the service of professional charity nurses and social workers. In the case when health care service is necessary (reduction of pain) patients can use the service of “ADOS” – The Agencies of Home Nursing Care. The founding of ADOS is a competence of the town / village according to the law 416/2001.

In the public notice 770/2004 Ministry of Health Care established a mobile hospice as an health service institution of the ambulant health care and a hospice as an health service institution of the institutional health care. The law 578/2004 says that hospice provides palliative health care.

There should be built a network of „pure“ hospices in Slovakia in the future. But the present-day situation is not encouraging. There is only one pure hospice in Slovakia now and there are several buildings reconstructed in order to found there a hospice (for example: Bardejovská Nová Ves, Bratislava, Trstice).

Hospice – is a missing item in the system of health care in Slovakia.

The cultural heritage and traditions

Formal religion and view of spirituality, focused on existential issues have had a strong influence on the ethical and moral basis of European palliative care. Some palliative care founders have been opposed to euthanasia, whereas others look for a degree of accommodation between two radically different approaches to end-of-life issues. Across Europe, what counts as the 'good death' also varies, from the slow slipping away of the senses which the Spanish call “agonia”, to the conscious awareness of Northern Europe. Likewise, there are different cultural assumptions about so-called 'truth telling' and about the nature of 'autonomy'.

Traditions – that is a very strong aspect for establishing of hospice in Slovakia. People are used to take care of their old and ill



parents and grand-parents. Naturally, a desire of every person is to die among his close, loved and loving members of family, not in cool impersonal hospital room. Taking care of old parents is also a duty or responsibility of children, but sometimes it may become very difficult. Especially when children have their own families and work and they are not able to provide proper care to their dying member of family. Slovak people have to learn to recognize the best solution in specific situations and to decide what is really good for patient and for his family.

Hospice – it is not a depository of ill and old people, it is an opportunity for dignified and valuable life till the end.

FORMS AND METHODS OF THE RESEARCH

- . Study of the actual situation of the problem
- . Analysing the problem
- . Definition of the problem
- . Solving the problem
- . Discovery of the solution
- . Verification of the solution.

HISTORY AND PHILOSOPHY OF HOSPICE

THE EVOLUTION OF INSTITUTIONS FOR PATIENTS IN TERMINAL STAGE OF ILLNESS – HISTORY OF HOSPICE

The roots of the hospice reach deep in to the history. It was the Christian charity that has been involved mostly.

The core of the word “hospice” is in the Latin word “hospes” what means – a guest but also a refuge or asylum. It was originally used to describe a place of shelter for weary and sick travelers on difficult journeys.

During the 1960's, Dr. Cicely Saunders, a British physician began the modern hospice movement by establishing St. Christopher's Hospice near London. St. Christopher's Hospice organized a team approach to professional caregiving, and was the first programme to use modern pain management techniques to compassionately care for the dying. St. Christopher's Hospice in London has served as a model for the whole modern hospice movement. But Cicely Saunders also saw herself as standing on the shoulders of other giants. She felt inspired by the 19th century achievements of Mary Aikenhead and the Irish Sisters of Charity as well as Jeanne Garnier and Les Dames du Calvaire in France. She was influenced by the moral philosophy of Frankl, by the theology of Buber and she built on the pain research of Leriche.

Across the countries of Europe, founding initiative began in many different settings: in hospitals, in home care, in nursing homes, and only infrequently in hospices. Medical leadership came from various sources: from anaesthesiology, from geriatrics, from

oncology, from public health. Different priorities were given to areas such as the role of nurses and other health professionals, the involvement of volunteers, and the importance of research. The first hospice in the United States was established in New Haven, Connecticut in 1974.

NEEDS OF SERIOUSLY ILL AND DYING PATIENTS:

The biological needs

Every patient needs to receive food, to get rid of some products of metabolism, to breathe easily and also to keep up the body in activity so that its functions would not stop working. Very important biological need is a placid sleep and soothing a pain.

Hospice care neither prolongs life nor hastens death. Hospice staff and volunteers offer a specialized knowledge of medical care, including pain management.

Hospice addresses all symptoms of a disease, with a special emphasis on controlling a patient's pain and discomfort.

The psychological needs

The main psychological need and at the same time the main goal of hospice care is to improve the quality of a patient's last days by offering dignity and comfort.

Hospice professionals help patients and their families to understand and to accept the course of illness, they believe in the individuality of each person served. While those affected by terminal illness struggle to come to terms, hospice gently helps them find their way at their own speed.

The social needs

Because of human beings are social creatures, usually nobody wants to live and die alone. That is why patients are interested in visitors and they need them.

The spiritual needs

The fear of death is often due to the fear of pain and abandonment. Hospice staff include bereavement and spiritual counselors who help patients and families come to terms with dying. They assist patients in finishing important tasks, saying their final goodbyes, healing broken family relationships, distributing precious objects, and completing a spiritual journey.

Unfinished business can make dying harder and grieving more difficult for those left behind. Hospice staff recognizes that a person who comes to terms with dying has a less stressful death, and that the family benefits from a less complicated grieving process. A source of relief and comfort for many hospice



patients is the knowledge that the family will receive ongoing bereavement support.

HOSPIC IN SLOVAKIA

The existing health care institutions for the long-term patients in Slovakia are located in the following cities: Banská Bystrica, Bardejovská Nová Ves, Bratislava, Košice, Martin, Nitra, Trenčín.



There have been prepared a lot of projects of hospice in Slovakia, but till the present day only one hospice and one mobile hospice work in Bratislava, one hospice was opened in Bardejovská Nová Ves and one hospice works in St. Elizabeth Health-social Centre in Trstice. Departments of palliative care (as parts of existing health-care institutions) started to work in Bratislava, Trstená, Humenné and Trnava.

The legislative background of the design of health care institutions for long-term and terminal ill patients in Slovakia and the system of the hospice financing:

- The changes of the legislation in Slovakia and the present situation in legislation:

The application of palliative care into practice was enabled by the acceptance of the Palliative care concept (made public in an official publication of The Ministry of Health Care, part 25-26 from 19.8.2002). The Ministry of Health Care took the initiative in changing the Price order of Finance Department where the price for providing the palliative care in hospice is listed. It is 300 till 900 Slovak Crowns per bed and day. In the public notice 770/2004, The Ministry of Health Care established a mobile hospice as an health service institution of the ambulant health care and a hospice as an health service institution of the institutional health care. The law 578/2004 says that hospice provides palliative



health care.



- The institutions, organizations and supporting programmes concerned with hospice care:

In the year 2002 and 2003 The Ministry of Health Care provided financial support from lotteries for reconstruction of about 30 objects where hospices and departments for palliative care would be established.

The Association of Hospice Care in Banská Bystrica works in the whole Slovak Republic.

Very important institutions for the expansion of a hospice movement are:

- See charity in Banská Bystrica, Košice
- Slovak Catholic Charity
- The National Oncology Institute – Department of Palliative care in Bratislava
- the association -The League Against Cancer
- The Foundation Hospice Martin in Martin and many others.

HOSPICE AS A TYPOLOGICAL CLASS

The basic characterization of the hospice:

The status of hospice in the system of health care:

Hospice is for patients whose illness no longer responds to aggressive, cure-oriented treatments. Hospice provides pain and symptom relief, as well as emotional and spiritual support for patients and their families.

Hospice is serious medicine. Most hospices are certified, that means that they employ experienced medical and nursing personnel with skills in symptom control. Hospices offer state-of-the-art palliative care, using advanced technologies to prevent or alleviate distressing symptoms.

The basic functions of the hospice:

- Physician services
- Nursing services
- Home health care
- Spiritual, dietary, and other counseling
- Continuous care during crisis periods
- Bereavement services.

The categories of hospices:

according to the function:

pure – only for terminal-ill patients:

Hospice provides pain and symptom relief, emotional and spiritual support for patients and their families.

- combined – with extended activities – for example: ADOS, stationary for daily-coming patients with various services (physiotherapeutics, psychotherapeutics, rehabilitation), educational centre and shops. As a family-centered concept of care, hospice focuses as much on the grieving family as on the dying patient. Most hospices make their grief services available to the community at large, serving schools, churches and the workplace.

according to the sort of patients:

- hospice for adults
Hospice patients typically are in their last six months of life. Approximately 2/3 of hospice patients are over the age of 65.
- hospice for children

Although the majority of hospice patients are older, hospices serve patients of all ages. Many hospices offer clinical staff with expertise in pediatric hospice care.

The first hospice for children – Helen House in Oxford was founded in 1982. The main aim of the hospice for children is to upkeep the quality of life of a child and to provide the support to all family members. Hospice for children offers several types of care: resting (reposing) care - for several hours, days or for one





week; hospice care – full hospice care for a child and support for his family; home care – for the case, when family decides to take care of the patient at home.

• **according to the disease**

-- universal – for all types of diseases in terminal phase
While many hospice patients are diagnosed with cancer, hospice services are also available to patients with pulmonary disease, heart disease, neurological disorders, Alzheimer's Disease. Increasingly, hospices are also serving families coping with the end-stages of chronic diseases, like emphysema, cardiovascular and neuromuscular diseases.

-- specific, e.g. AIDS patients.

Especially in urban areas, hospices serve a large number of HIV/AIDS patients.

THE PLANNING OF THE INSTITUTIONS FOR TERMINAL ILL PATIENTS

Urban (macroenvironmental) aspects of hospice planning:

The complex analysis of the environment (physical, social and cultural environment):

In the past a quantitative classification according to tributary area was very popular. It is not possible to design hospice following these directives at the present time. Now the sensitive social-demographic research of every locality is needed. The important entries for design of hospice are: character of the locality, founders of the hospice, area that the hospice should serve for (an amount of inhabitants, commuting distances, ...), organizations working in the area (charity, NGO,...).

Architectural (microenvironmental) aspects of hospice planning:

Function and operation relations and basic functional units of the hospice:

For designing of hospice, the knowledge of requirements of all functional units is very important. There are specific demands for their measurements, mutual links and dispositions. The aim of the PhD thesis will be to design a new locality model programme for hospice. It will follow the knowledge of typology of existing health-care institutions.

The main function units of hospice:

- entrance area : entry, entrance hall – lounge , porter's room, room for meeting the visitors,...
- social part : dayroom, dining-room, chapel, priest'room, winter garden,...
- service and management: offices (for director, economist, nurses and volunteers),
- dining (refectory) part : a kitchen, a dining-room, stocks, dressing room for staff, ...
- laundry part: a washery, a drier, an iron-room, stocks,...
- garages and workrooms,

- bereavement room – a place for last taking leave of deceased: a room for preparing the dead body, a room for family members,...
- accomodation part: 90% of single rooms, 10% - double or four bed rooms with bathroom, a kitchen for family members, a room for nurses, a lift for connection with exterior space, ...

Standards; requirements for space:

- minimal width of a room (for accomodation of hospice patient) is 3400 mm
- minimal width of a corridor – 2400 mm
- minimal width of a door – 900 mm
- at least one lift should have the minimal measures 2400 x 1400 mm with the width of door - 1300 mm
- a dimension of the module – optimum: 7200 m.

THE EXAMPLES OF THE HOSPICES REALIZED IN ACCORDANCE WITH THE PRINCIPLES OF HOSPITAL-ENVIRONMENT DESIGN:

The presentation of the foreign examples :

Very successful project was realized in Czech Republic in Červený Kostelec – Hospice Anežky České. It was built in 1996. The capacity of the hospice is 30 beds for patients mostly in single rooms.

Hospice Anežky České in Červený Kostelec is the example of a "pure hospice". Every single room has a possibility of accomodation also for a family member. All rooms of patients have large glass-covered walls and terraces for better connection of interior space with exterior.

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