

The hospice movement: History and current worldwide situation

Nataša MILIĆEVIĆ

The suffering of terminally ill cancer patients underlines the need for good and well-organized palliative care. WHO defines the palliative care as the active total care of patients and their families when the patient's disease is no longer responsive to curative treatment. Such a care can be obtained in hospices providing good symptom relief of advanced cancer, and emotional support for both patient and his family. Modern hospice movement started in the United Kingdom in the late sixties of the past century, and spread out all over the world. This paper presents a short history of the hospice movement and current worldwide situation in this field.

KEY WORDS: Hospice Care; Neoplasms; Palliative Care; Life Support Care; World Health Organization

MEDICAL CENTER BEŽANIJSKA KOSA, BELGRADE, YUGOSLAVIA

Archive of Oncology 2002;10(1):29-32 ©2002, Institute of Oncology Sremska Kamenica, Yugoslavia

BACKGROUND

In spite of the development of new technologies and drugs for the therapy of malignant disease, one death to four still accounts to cancer. It is the main reason why the care of the terminal cancer patients became, together with the prevention, early detection and curative treatment, a high priority for the WHO. Although the patients may be in advanced stage of the disease, they may not necessarily die in a short time. Having advanced cancer means that one has a life-threatening illness and one's life may be described in terms of a few years or even a few weeks. There is a little chance of a cure but there is no more treatment that can be offered to prolong life. Care is now palliative, i.e. it is directed towards caring rather than curing. Palliative care is a human and rational approach to the care of the terminally ill patients.

WHO defines palliative care as "the active total care of patients and their families by a multiprofessional team when the patient's disease is no longer responsive to curative treatment" (1). The aim is to provide the highest possible quality of life for both the patient and his family. Generally, palliative care affirms life, but accepts death as inevitable. It neither hastens nor postpones

death, but provides relief for patients from pain and other distressing symptoms. At the same time it integrates the psychological, social and spiritual aspects of care, helping patients to come to terms with their own death as fully and constructively as possible. It provides a support system that enables patients to live as actively as possible until death and offers support for families both during the patient's illness and in bereavement (2). This positive aim helps patients to continue living with cancer until death, to see the remaining time as "last days but not lost days" (3).

Probably the best place for obtaining good palliative care is hospice. What does the word hospice mean?

Hospice is primarily a concept of care, not a specific place of care, i.e. a philosophy of care rather than a type of building or service. Hospice philosophy states that there is always something to be done to help patients. The hospice movement has had a major impact around the world promoting palliative care and improving care standards. This paper presents short history of the hospice movement and current worldwide situation in this field.

HISTORY

The roots of the words hospice and hospital are the same and ancient, dating as far back as the 4th century AD. The original Greek name has been *xenodochium* meaning hospitality. The original hospices go back to Fabiola, a Roman matron who opened her home for the poor, travelers, hungry, thirsty and sick. At that time, the word *hospis* meant both host and guest, and the *hospitium* the place where hospitality was given. Afterwards, many hospices were raised on the Crusaders' routes. They were

Address correspondence to:

Dr. Nataša Milićević, Đuke Dinić 5, 11000 Belgrade, Yugoslavia

The manuscript was received: 05. 11. 2001.

Provisionally accepted: 14. 11. 2001.

Accepted for publication: 23. 11. 2001.

also the places where the pilgrims on their journeys received food and medical care. None of these hospices cared specifically for the dying but they welcomed people to stay as long as they needed help (4). In the middle of 19th century, Jeanne Garnier established the first institution in Lyon, France, using the word "hospice" for care of the dying. In England, the first use of word "hospice" was by the Irish Sisters of Charity at St Joseph's in London in 1905. Their founder had already opened a hospice for the dying in Dublin in 1879 (5). Interestingly, there was only one hospice founded by a doctor. His name was Dr. Howard Barrett; of all the homes, his St Luke's Home for the Dying Poor, opened in 1893, was the most similar in principle to today's hospice (6).

Modern hospice movement is connected with the name of Dame Cicely Saunders and started in the United Kingdom in 1967 with St. Christopher's Hospice. Cicely Saunders, born in 1918, was trained as a nurse and then as a social worker. During her work in a hospital she became aware of the psychological and spiritual needs of dying people, which often felt isolated and alone. As a social worker, Cicely Saunders met a patient, a Polish Jew called David Tasma. He asked her for "what is in your mind and in your heart". As he was dying with cancer and had pain, vomiting and other symptoms, she became interested in the medical treatment for cancer, especially the treatment for pain control. For that reason, she started medical training and qualified as a doctor in 1957. Listening carefully to her patients, their stories of illness and suffering she created the concept of "total pain". The other important fact was that she had an opportunity during her work as a volunteer in St. Joseph's Hospice to use strong opiodes and to see that "constant pain needs constant control". It means that analgesics should be given regularly to prevent pain, not on demand to alleviate it. Using her experiences as a nurse, social worker and a doctor as well, she integrated all the skills and opened the first modern hospice, St. Christopher's Hospice in London. This hospice, named after the travelers' protector Saint Christopher, combined the tradition of the middle age hospices with all the modern achievements of medicine, in order to relieve the suffering of terminally ill patients and their families (5,7).One of the pioneers from the United States in care of dying is Elisabeth Kubler-Ross. In the 1960's, she interviewed dying patients in general hospitals in Chicago and wrote a book "On death and dying" (8). This book had a lot of influence and caused much public reaction in the USA, throughout the century, thus bringing death to the public awareness. Both of these women accelerated the spread of hospices in the UK, USA and the whole world.

WORLDWIDE SITUATION

There are different models and systems of palliative care of cancer patients with advanced or terminal disease, which vary from

country to country. Keeping in mind that hospice is primarily a concept of care, and not a specific place of care, we can understand that various countries have chosen different types of hospices.

In United Kingdom (UK) they mostly have voluntary hospices.

An average voluntary hospice consists of:

- * Inpatient unit. The number of beds varies from 1 to 62 (the largest one used to be St. Christopher's Hospice with 62 beds, while the smallest one is in the far north in Sweden (with only 1 bed) (9).
- * Day care center. Patients are staying in these centers from Monday to Friday, for a few hours, for medical and nursing care, social reasons (e.g. loneliness) or to give the family a break.
- * Home care and outpatient clinic.
- * Bereavement support service (10).

These separate hospices have the clear advantage of being solely orientated towards the needs of dying patients and they usually offer to the patients a home-like atmosphere, unlike to rush hospital wards.

Some countries organize palliative care units (PCUs) within the general hospitals or cancer centers. These PCUs provide the patients with good symptom control and are usually dealing with the research as well. There are many practical advantages to this system. Sharing facilities with the hospital can reduce costs but the atmosphere is more like to the hospital one.

Besides this kind of inpatient units, there are many services based on palliative home care teams or hospital support teams. Usually, these teams consist of a doctor and a nurse, but many consultants are available as well.

Palliative home care teams are suitable for patients who are able to remain at home and who prefer to do so (7).

The types of hospices and their funding vary from country to country. Some hospices have 100% funding from the national health services, while most have to rely on voluntary donations for a considerable part of their income. There are some private hospices as well. Currently, according to the Hospice Information Service at St. Christopher's Hospice, there are more than 7,000 hospices or palliative care services in over 90 countries throughout the world adapted to suit local needs and culture. For example, in the UK there are 240 inpatient units with 3,397 beds dealing with palliative care and 147 of them are voluntary hospices with 2,192 beds and many different home-care and hospital based palliative care teams. It means that there are 54 beds per million population (11). In the USA there are about 3,000 hospices, mostly home care based, but some of them have inpatient units as well. About 650 hospices and other palliative care services exist in Canada, including hospital based and community programmes, and over 100 palliative care services in Latin America (12). Around 280 hospices and palliative care services

offer inpatient care, as well as home care and hospital based support in Australia, and about 40 in New Zealand (13). There are over 300 palliative care initiatives in Asia (A. Jackson, personal communication). Almost all countries in Africa have palliative care services or initiatives. Most of these services provide care for HIV/AIDS patients as well. Forty-five of them are in South Africa (14).

In Europe, both distribution and kinds of palliative care services vary a lot. Besides UK, the largest number of palliative care services is situated in Poland, France, Germany and Sweden. In Poland, there are currently 246 hospices and palliative care services including inpatient services and home care teams. Many of them were founded by individual health care professionals or priests and funded by the National Health Service or from voluntary source (15). In Germany, the first palliative care unit was opened in 1983, but now there are 121 hospices or palliative care inpatients units, providing more than 1,200 beds and more than 500 palliative home care services dealing with cancer patients or other incurable diseases. Current available capacities in France are between 160 -200 services including inpatient units and hospital-based teams; Sweden has 60 palliative care services, 26 of which being palliative care inpatient units (16). The situation in neighboring countries is not satisfactory at all, but there are some initiatives and even some inpatient units. In Hungary, they have the organized palliative care services for longer than 10 years and few inpatient hospices. Romania opened their first inpatient hospice, supported by Ellenor Foundation from the UK, in Brasov last December. Croatia, Bosnia and Herzegovina, Bulgaria and Albania have organized palliative home care services (15). The WHO encourages the organization of appropriate services in developing countries.

In our country, there is neither government policy nor organized palliative care for these patients. Patients are usually looked after by the home care centers, but the staff in these centers is not well educated to meet the needs of dying patients and their families. Patients usually die at home or in general hospitals where the staff is not able to offer them the proper care (17). We are probably the unique country in Europe without any PCU or hospice.

CHALLENGES FOR THE FUTURE

The main challenge for developing countries is to find out the best way for proper care for seriously ill patients. It is of utter importance to obtain good education for the health care professionals together with the good national policy in the field of palliative care. The type of palliative care services is less important. Some countries would chose home care teams, while others might prefer hospices or PCUs. Many health professionals think that the principles and organization of palliative cancer care should be applied to the other chronic and terminally illness such as HIV/AIDS,

motor neuron disease, terminal renal or cardiac failure etc. Many European Union countries involved in the hospice movement need to recognize the potential challenges, since the European euthanasia debate may result in its legal acceptance throughout the EU, irrespective of the wishes of individual member states (18). As we are at the beginning of the 21st century, the evidence of research should prove the philosophy and practice of palliative care.

Hospice movement has bridged the gap between the regular hospitals and home cancer care. It remains to be seen whether or not the hospice idea could survive the future challenges and remain as the model for good and human advanced cancer care.

REFERENCES

1. World Health Organization. Cancer Pain Relief and Palliative care. Technical Report Series No. 804. Geneva: World Health Organization, 1990.
2. Twycross R. Introducing Palliative Care. 3rd ed. Abingdon: Radcliffe Medical Press Ltd; 1999.
3. Twycross R. Palliative care helping patients and families. OIP 1994;1:2-3.
4. Waller A, Bercovitch M, Adunsky A. Palliative care: Past, Present, Future. Support 1999;12:2-4.
5. Clark D. Palliative care history: a ritual process? Eur J Palliative Care 2000;7(2):50-5.
6. Saunders C. The evolution of the hospices. In: Mann RD, editor. The history of the management of pain; from early principles to present practice. Parthenon Publishing; 1988. p. 167-78.
7. Shirley du Boulay. Cicely Saunders. 2nd ed. London: Hodder and Stoughton; 1994.
8. Kubler-Ross E. On Death and Dying. New York: Macmillan Publishing Co; 1969.
9. Furst CJ. Perspectives on palliative care: Sweden. Support Care Cancer 2000;8:441-3.
10. Brady D. Hospice and palliative care. St. Christopher's Hospice. London, 1996.
11. The Hospice Information Service. Hospice and Palliative Care Facts and Figures 2001, St. Christopher's Hospice, London, 2001.
12. The Hospice Information Service. Hospice Worldwide: North and Latin America, St. Christopher's Hospice, London, 2001.
13. The Hospice Information Service. Hospice Worldwide: Australia and New Zealand, St. Christopher's Hospice, London, 2001.
14. The Hospice Information Service. Hospice Worldwide: Africa, St. Christopher's Hospice, London, 2001.
15. The Hospice Information Service. Hospice Worldwide: Eastern and central Europe, St Christopher's Hospice, London, 2001.
16. The Hospice Information Service. Hospice worldwide: Europe (excluding Eastern and Central and UK), St Christopher's Hospice, London, 2001.
17. Milićević N, Kovčin V, Babić M. Palliative cancer care (in Serbian). Srp Arh Celok Lek 2001;129:22-8.
18. Walsh H. Euthanasia: a European debate. Eur J Palliative Care 2000;7:130-3.