MANAGEMENT IN HEALTH CARE PRACTICE
A Handbook for Teachers, Researchers and Health Professionals

Title	**PALLIATIVE CARE**
Module: 5.11	**ECTS (suggested): 0.2**
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Keywords	Palliative care, health care services
Learning objectives	After completing this module students and public health professionals should: • Recognise major palliative care development challenges and characteristics • increase knowledge of trajectories of advanced chronic diseases • understand the implications of future trends of demographics and diseases changes for health care organization • identifie most important decisions in the policy planning
Abstract	Population ageing and the implications these present for care towards the end of life are major public health issues for 21st century. In the line with aging of the population, the pattern of diseases that people suffer and die from is also changing. Palliative care should be an integral part of health care and take place in any setting. Palliative care services are structured in three levels of ascending specialization, referred to the expertise of the staff providing the service: palliative care approach, general palliative care and specialist palliative care. Priority care needs for the three illness trajectories, for short period of evident decline (mostly cancer), for chronic illnesses with intermittent exacerbations and sudden dying (organ system failure), and for slow dwindling (mostly frailty and dementia) are different and specific palliative care services are needed through different length of time.
Teaching methods	Short lectures give students theoretical knowledge and insight into a range of characteristics of palliative care and its services. With case study, small group discussions, illustrations from personal experiences, students determine existing palliative care services in their region and than they identify the main problems. Through study of recommended reading and internet search, they try to find or create their own solutions and models from range of views from all stakeholders.
Specific recommendations for teachers	• work under teacher supervision/individual students' work proportion: 30%/70%; • facilities: lecture room or a nursing home; • equipment: LCD projection equipment, internet connection, access to the bibliographic data-bases; • training materials: recommended readings or other related readings; • target audience: master degree students according to Bologna scheme.
Assessment of students	Multiple choice questionnaire (MCQ), seminar paper.

PALLIATIVE CARE
Urška Lunder

THEORETICAL BACKROUND

Introduction

Until the last few decades, most people died quickly, following an infection or injury, or soon after the initial symptoms of an advanced an untreatable condition like cancer, diabetes, or heart disease. Modern living conditions and advances in health care have ensured that most will die slowly, and mostly in old age (1).

In the line with aging of the population, the pattern of diseases that people suffer and die from is also changing. Increasingly, more people die as a result of serious chronic disease, and older people in particular are more likely to suffer from multi-organ failure towards the end of life (2). Diagnosing any one disease as the main cause of death can be difficult to do with certainty as many older people suffer from several conditions together that might all contribute to death. Dementia is an example of one condition that is regularly under-diagnosed.

The top five predicted causes of death for 2020 are (3):

1. heart disease,
2. cerebrovascular disease (including stroke),
3. chronic obstructive pulmonary disease,
4. lower respiratory infections (in situations with progressive dementia, or other frailty conditions), and
5. lung cancer.

Population ageing and its implications are major public health issues for 21st century, and palliative medicine and palliative care increasingly becoming more and more important.

Definition and description of palliative care

Definitions of palliative care and palliative medicine

The core of palliative care is well understood, but because of the complexity of palliative care there are various definitions used around the world. Palliative care is defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (4).

An important part of palliative care is palliative medicine. According to European Association for Palliative Care, palliative medicine is the appropriate medical care of patients with advanced and progressive disease for whom the focus of care is the quality of life and in whom the prognosis is limited (though sometimes may be several years). Palliative medicine includes consideration of the family's needs before and after the patient's death (5).

Palliative care characteristics

Palliative care provides relief from pain and other distressing symptoms, affirms life, regards dying as a normal process, and intends neither to hasten nor prolong death. Palliative care integrates the psychosocial and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until death. It also offers a support system to help family cope during the patient's illness and their own bereavement.

Using a team approach, palliative care addresses the needs of patients and their families, including bereavement counselling if necessary. It enhances quality of life, and may positively influence the course of the illness.

It is applicable early in the course of the clinical phase of the disease with other therapies, also such as chemotherapy and radiotherapy, and includes those investigations needed to understand distressing clinical complications (Figure 1).

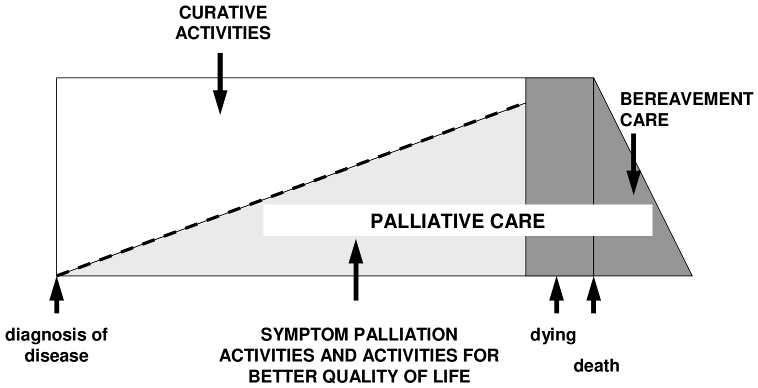

Figure 1. Schematic presentation of placement of palliative care into clinical phase of natural course of disease.

Palliative care should be offered as needs develop and before they become unmanageable.

Why palliative care is a public health problem?

Quality of care at the end of life is a global public health problem because of the large number people affected. Palliative care can with its patient centred care, and self-management orientation prevent needless suffering, Additionally, it could have a potential to prevent morbidity in the bereaved.

The range of problems for different diseases

People living with serious chronic diseases face a wide range of problems. Each disease brings specific symptoms (6), for example:

- ischemic heart disease may cause the chest pain of angina, breathlessness and fatigue,
- stroke may cause difficulty moving or talking, while
- chronic obstructive pulmonary disease may restrict activity because of breathlessness, fatigue and depression.

Chronic diseases often come together and so add up to cause many problems affecting the quality of people's lives. Prevalence of problems in the last year of life is presented in Figure 2.

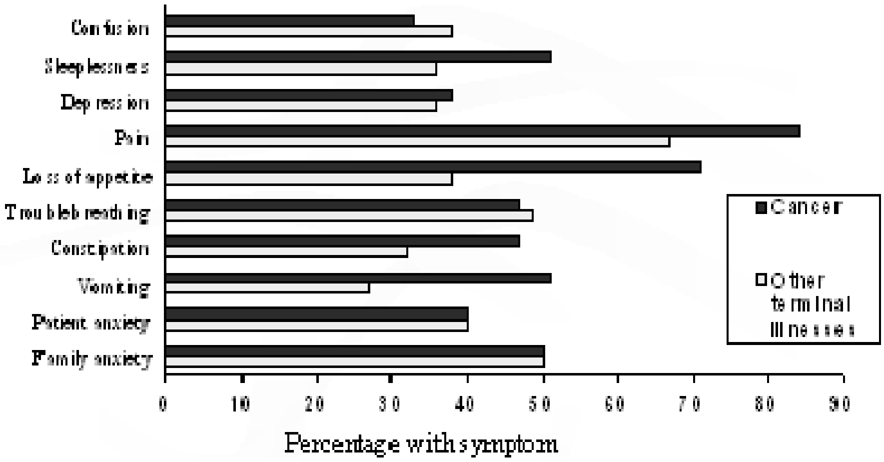

Figure 2. Prevalence of major problems in the last year of life (6).

Models of the typical disease trajectory for common serious chronic diseases

According to Lynn and Adamson (7), models of the typical disease trajectory for common serious chronic diseases are as follows**.**

1. Trajectory 1: short period of evident decline, typically cancer.
   This entails a reasonably predictable decline in physical health over a period of weeks, months, or, in some cases, years (Figure 3).

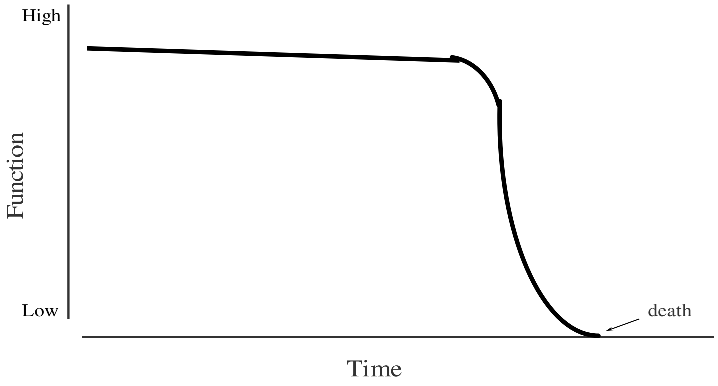

Figure 3. Model of typical trajectory of an illness due to cancer. Source: Lynn and Adamson 2003 (7).

This course may be punctuated by the positive or negative effects of palliative oncological treatment. Most weight loss, reduction in performance status, and impaired ability for self care occurs in patients' last few months. With the trend towards earlier diagnosis and greater openness about discussing prognosis, there is generally time to anticipate palliative needs and plan for end of life care. This trajectory enmeshes well with traditional specialist palliative care services, such as hospices and their associated community palliative care programmes, which concentrate on providing comprehensive services in the last weeks or months of life for people with cancer.

Resource constraints on hospices and their community teams, plus their association with dying, can limit their availability and acceptability.

2. Trajectory 2: long term limitations with intermittent serious episodes, typically organ failure (heart failure, respiratory failure, liver failure, renal failure).

   With conditions such as heart failure and chronic obstructive pulmonary disease, patients are usually ill for many months or years with occasional acute, often severe, exacerbations (Figure 4).

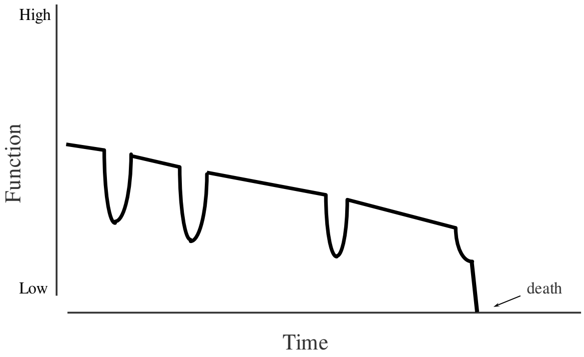

Figure 4. Model of a typical illness trajectory for organ failure such as heart failure. Source: Lynn and Adamson 2003 (7).

Deteriorations are generally associated with admission to hospital and intensive treatment. This clinically intuitive trajectory has sharper dips than are revealed by pooling quantitative data concerning activities of daily living. Each exacerbation may result in death, and although the patient usually survives many such episodes, a gradual deterioration in health and functional status is typical. The timing of death, however, remains uncertain. In one large study, most patients with advanced heart failure died when expected to live for at least a further six months. Many people with end stage heart failure and chronic obstructive pulmonary disease follow this trajectory, but this may not be the case for some other organ system failures.

3. Trajectory 3: prolonged dwindling, typically dementia.

   People who escape cancer and organ system failure are likely to die at an older age of either brain failure (such as Alzheimer's or other dementia) or generalised frailty of multiple body systems.

   This third trajectory is of progressive disability from an already low baseline of cognitive or physical functioning (Figure 5).

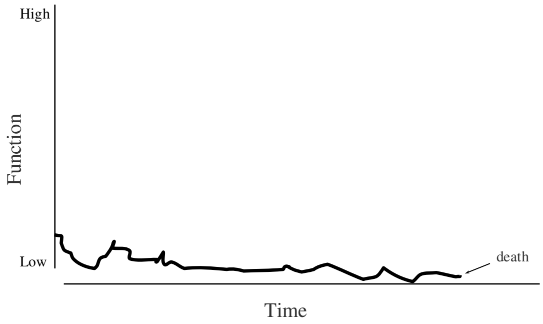

Figure 5.: Model of a typical illness trajectory for dementia or frailty. Source: Lynn and Adamson 2003 (7).

Such patients may lose weight and functional capacity and then succumb to minor physical events or daily social "hassles" that may in themselves seem trivial but, occurring in combination with declining reserves, can prove fatal. This trajectory may be cut short by death after an acute event such as a fractured neck of femur or pneumonia.

Clinical and organizational implications

Priority care needs for the three trajectories

Trajectories allow us to appreciate that "doing everything that can be done for a possible cure" may be misdirected. The priorities are needed, and priority care needs for the three illness trajectories are as follows (8):

1. Priority care needs for short period of evident decline (mostly cancer) are as follows:
    - adapting services to rapid changes in the patient,
    - controlling symptoms,
    - providing support for families: training, respite, and counselling through bereavement,
    - ensuring continuity of the clinical team,
    - life closure and completion.
2. Priority care needs for chronic illness with intermittent exacerbations and sudden dying (organ system failure) are as follows:
    - preventing exacerbations and providing early treatment,
    - planning for urgent situations,
    - making decisions about the benefits of low-yield treatments,
    - mobilizing services to the home,
    - preparing families for sudden death,
    - life closure and completion.
3. Priority care needs for slow dwindling (mostly frailty and dementia) are as follows:
    - fostering caregiver endurance, loyalty, and reliability,
    - providing long-term personal care services and supervision,
    - helping family caregivers to find meaning and avoid severe burdens,
    - avoiding undesired prolongation of life,
    - keeping skin intact,
    - finding pleasurable moments to enjoy,
    - life closure and completion.

Palliative care services levels

Palliative care services are structured in three levels of ascending specialization. These levels refer to the expertise of the staff providing the service.

1. Level one - palliative care approach.
   Palliative care approach is that palliative care principles should be appropriately applied by all health care professionals.
2. Level two – general palliative care.
   At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care have had some additional training and experience in palliative care.
3. Level three – specialist palliative care.

Engaged in palliative care full time and palliative services are their core activities, provided by an inter-disciplinary team, under direction of a consultant physician in palliative medicine.

Palliative care services

Palliative care should be an integral part of health care and take place in any setting.

In each health area all three levels of services provision should be available in all care settings, including acute general hospitals and the community. Services should be sufficiently flexible to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences.

Palliative care in the community

The most palliative care is likely to be delivered in the primary care setting. Studies have indicated that people with terminal diseases spend most of their final year of life at home (9,10). One of the main principles in palliative care is to provide services to patients in a setting of their choice. Most people would prefer to die at their home (11,12). The development of community based palliative care services is vital in the future development of palliative care services in order to best meet the needs and personal preferences of patients with advanced cancer or progressive life-threatening disease of other aetiologies.

The majority of care in the community is provided by a family physician and a community nurse, and a specialized palliative care nurse can become involved in the care of patients with advanced incurable disease. Other disciplines are also involved in the care of patients in the community to varying degrees. These include the physiotherapist, the occupational therapist, and social worker.

There are many factors that prevent patients from receiving adequate care in the community and which result in the often unnecessary admission of patients to hospitals, nursing homes or specialist palliative care units. The main reason has been identified as a lack of support for carers in the community (9,10,13). Although most of the last year of life is spent at home, approximately 90% of patients dying from cancer are admitted to a hospital in their last year (9).

Specialist palliative care team

Hospital palliative care teams have evolved into specialist inter-disciplinary consulting teams, who offer advice and support to professional health care providers regarding the management of patients with progressive disease. Specialist palliative care team in the acute general hospital should consist of at least a consultant in palliative medicine, a specialist palliative care nurse, a social worker, and a secretary.

Specialist palliative units

A particular hospital, depending on the regional needs, may designate a ward or a unit to function as the specialist palliative care unit for patients requiring specialist palliative care. Specialist palliative care team in such a unit consists of full interdisciplinary teams (specialized physicians, nurses, social workers, psychologist, physiotherapist, occupational therapist, pharmacist, dietician, coordinator of spiritual care, volunteers).

Day care centres

Day care centres are usually attached to the specialist palliative care units. They offer access to specialist care, a change of environment for patients, and respite for their families and carers.

Above national palliative care programme, guidelines or standards for specialist palliative care settings should be established, which would ensure a national consistency of standards for all specialist palliative care centres.

Hospice

Hospice is usually nongovernmental organization, also with a holistic approach to the end of life care, dependant on attitude, expertise and understanding rather than a specific mechanism and setting. It most often includes a house and inpatient unit, but can be also organized as an institution with homecare teams and bereavement support only. It can increase the sensitivity for more holistic, proactive and anticipating approach towards the dying, through individual treatment, sincere communication, attention to detail, continuity of care, and team work. It is a concept of choice and empowerment at the end of life. It is a concept of dignity, autonomy and respect for the dying and the family. It is a potential denominator for public change in attitudes, behaviour, and life-decisions led by understanding and compassion. It can also be an important link to promote palliative care in the wider community.

Present status

Some countries are now developing national and regional palliative care strategies, and each country needs to decide which options of care are their priorities that can be offered or planned for. However, if people do not receive information on what care is available, it is difficult to argue that best care has been offered. Currently, most health care systems are not set up in a way that makes it easy for people to receive palliative care or to die where they would wish.

There is still too much unnecessary suffering at the end of life in contemporary society and inadequate services to relieve it through insufficient professional knowledge, organizational possibilities through inexistent services network and lack of interest in palliative care.

Another barrier to better development of palliative care is lack of policy-makers interest in organizational and strategic planning for people with palliative care needs already at the present and in the future.

At the same time, palliative care for non-malignant diseases has been voted in British Medical Journal in April 2008 as the area of health care in which doctors can make the greatest difference to patient care.

Palliative care and the future

The proportion of people in each trajectory will shift with medical advances and lifestyle changes:

- as people reduce smoking and otherwise prevent lethal cancer, more people will live long enough to develop vascular and heart disease,
- to the extent that prevention (through diet, medications, and exercise) is effective for heart disease, more people will live long enough to encounter dementia and frailty,
- dying from cancer tends to peak around seventy years of age, and heart and lung disease about a decade later,

- most people who survive past eighty-five eventually need daily care and accumulate evidence of multisystem lack of reserves.

Thus, to the extent that prevention and early treatment are successful, more people are likely to live their last years with frailty and dementia (8). In Figure 6, major medical conditions before death for Medicare beneficiaries are presented.

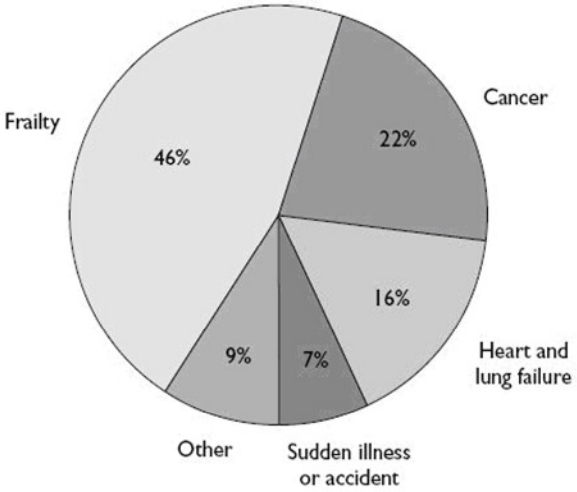

Figure 6. Major medical conditions before death, for Medicare beneficiaries. Source: Lunney, Lynn, and Hogan 2002 (14).

CASE STUDY: SOME PUBLIC HEALTH ASPECTS OF PALLIATIVE CARE IN SLOVENIA

This case study is basing on policy paper entitled "Organizing palliative care in Slovene health care system" which represents the last overview concerning the status of palliative care in Slovenia (15).

Epidemiological data

Some basic mortality and morbidity indicators

In Slovenia with approximately 2 million inhabitants there are around 19,000 deaths per year. The life expectancy at birth is 74.04 years for men, and 80.93 years for women (16).

The three main causes of death in Slovenia are cardiovascular diseases, neoplasm and diseases of respiratory system (17).

Regarding neoplasm, Slovenia is a country with a middle size morbidity and mortality rate caused by cancer. The leading cancer for the male population is lung cancer (16.8% out of all cancer sites in males) and for the female population is breast cancer (21.0% out of all cancer sites in females) (18).

Where majority of deaths occur?

According to data from 2002, approximately 59% of all deaths in Slovenia occur in hospitals and other institutions, and 41% occur at home (Table 1) (19). The situation is still approximately the same in present time.

Table 1. Place of death in Slovenia in 2002. Source: National Public Health Institute 2003 (19)

Place of death	Number of deaths	%
Health and social care institutions	10,993	59.14%
hospitals	7,781	41.86%
nursing homes	3,212	17.82%
Home (or other places)	7,595	40.86%
Total	18,588	

Table 2. Epidemiological estimation of symptoms in the last year of life in Slovenia (20)

Symptom	Patients with cancer	Patients with other terminal illnesses
Confusion	1,600	5,550
Sleeplessness	2,550	5,400
Depression	1,900	5,250
Pain	4,250	10,050
Loss of appetite	3,600	5,700
Trouble breathing	2,350	7,350
Constipation	2,350	4,950
Vomiting	2,550	3,900
Patient anxiety	2,000	,000
Family anxiety	2,500	7,500

Additionally, from the Table 2 data we can estimate the most frequent symptoms in the last year of life based on the work of Higginson (20). In this estimation we must be aware of the fact that patients often have many concurrent symptoms at the last days of life.

Epidemiology - numbers and causes of death can give indication of need for palliative care, especially when coupled with information on symptoms, emotional, social and spiritual problems. With this approach we have to be aware of data inconsistencies and gaps (e.g. recorded cause of death is subject of fashion, or can be inaccurate in older people where there are multiple causes) and different diseases have different patterns of progression. But this simple approach can provide us with useful insight for planning and implementation purposes

History and present state of palliative care in Slovenia

Short history

The hospice movement, with home service and education programs, started in the middle of the 1990's in Ljubljana, the capital city of Slovenia. Slowly, then in about a decade, palliative care started to penetrate the health care system.

Present situation

It is now present in seven cities in Slovenia, in three of them, Ljubljana, Maribor and Celje their palliative care teams offer not just education to the public and volunteers for home support for the families, but a whole range of palliative home care services. This includes palliative nursing care, social and psychological care for patients and their families at their homes.

Nurses in each hospice in Ljubljana, Maribor and Celje are paid by the National Health Insurance Company.

General practitioners and community nurses are not involved in organized palliative care initiatives yet. A particular concern is that Slovenia lacks around 200 primary care physicians and even more nurses at the present time. The problem of palliative care implementation on the primary care level needs to be closely examined, and solutions wisely proposed together with a sensitive evaluation of the possible reality.

All hospices together, provide home care for around 500 patients annually. They organize of workshops, seminars and presentations.

There are around 110 volunteers working in the hospice organizations at the moment. New groups of volunteers are trained every year.

Bereavement services are organized in all hospices, and there is also a traditional bereavement children's group holiday every summer.

New regional organizations of hospice in different parts of Slovenia are developing, particularly for education on psychosocial topics for volunteers and the public. Hospice movement in Slovenia serves as an important model of hospice and palliative care to be implemented into national health system.

Pain programs, like in other countries, started much earlier in most hospitals than the palliative care programs. There are outpatient pain clinics in nearly every hospital in Slovenia.

Main palliative care services in Slovenia

Main palliative care services in Slovenia are:

1. The University Clinic of Respiratory and Allergic Diseases Golnik has established a palliative care unit within a long-term care department of the hospital. There is a palliative care team with a physician four nurses, social worker, psychologist and volunteers.
2. The major institution for cancer patients, Institute of Oncology Ljubljana, has recently established a Department for palliative care.
3. At General hospital Jesenice few hospital beds are available for palliative care as well.
4. The Palliative Care Development Institute was founded in 2000 as a training and resource centre, education, research and advocacy. The Institute plays a crucial role in the strategic planning and policy development of palliative care on the national level.

Palliative care policy

The Palliative Care Development Institute in co-operation with the Ministry of Health prepared a National strategic plan for palliative, but it is still in the process of wide discussion, confirmation and ratification.

The National Committee for Palliative Care at the Ministry of Health is overseeing and co-ordinating a pilot study on palliative care implementation in the health care system.

The process of developing standards of care for patients at the end of life is under way, but still at an early stage in Slovenia.

Pain as the main palliative care problem

Pain is the major symptom for patients in need of palliative care and therefore drug consumption for pain treatment is an indirect indicator of the development of palliative care. All the essential drugs for pain relief are available in Slovenia, with a normal procedure for prescribing.

Figure 7 shows total morphine consumption in Slovenia from 1992-2003 (21).

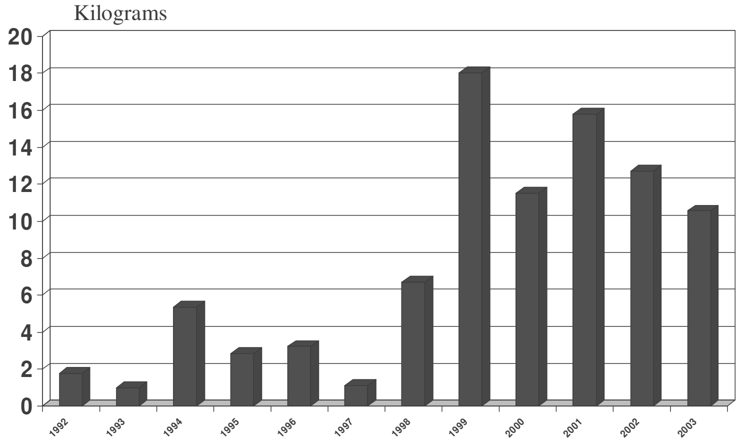

Figure 7. Total consumption of morphine in Slovenia in 1992–2003. Source: International Narcotics Control Board 2005 (21).

There was a sudden increase in opioid consumption after 1998, most probably due to the activities listed previously and new pain relief drugs available on the market. The decline in last three years demonstrates the need for regular extensive postgraduate education on pain management. As compared to the rest of Europe, consumption of morphine in Slovenia is at the global mean level, but under the average European mean level in 2003 (Figure 8).

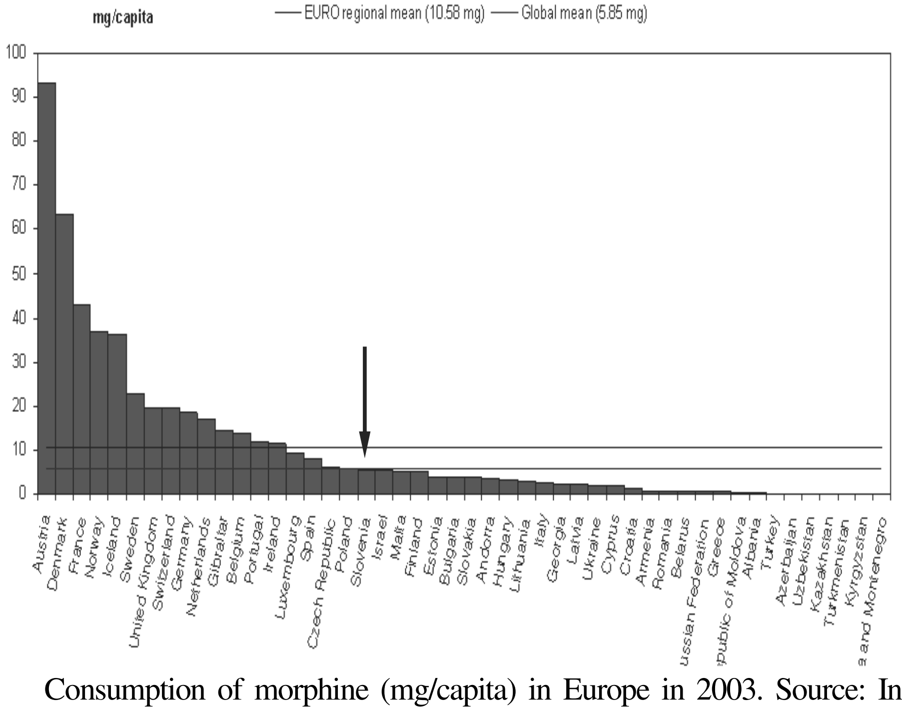

Figure 8. Consumption of morphine (mg/capita) in Europe in 2003. Source: International Narcotics Control Board 2005 (21).

A study of quality of care at the end of life at the Oncology Institute, Ljubljana, presented at the International Conference on Palliative Care in Cancer, Ljubljana (22), showed a retrospective record analysis of quality of care for 145 patients in 2002 for the last 6 months of life. The results suggested, that the documentation among health care professionals was incomplete and co-ordination often inappropriate. 75% of patients received opioids, with successful treatment to the goal of mean VAS 3 in 47% of patients. The major weak points in the care of patients at the Oncology Institute as compared to the literature were higher rates of prescriptions for antibiotics, transfusions, and parenteral hydration in the last days, and lack of evaluation of the common symptoms in palliative care except pain (e.g. breathlessness, nausea, vomiting, tiredness, etc.). No patient received chemotherapy, albumin or vasoactive support in the last days of life. In the documentation less data was available on other symptoms and especially about psychosocial problems of patients and their families. No other symptoms except pain were evaluated by a scale, so it was impossible to evaluate the effects of treatment, as documented. From the study, it was more than obvious how urgent it is to put palliative care standards in place. The study indicated urgent need for extensive professional training, a better documentation system and co-ordination among all professionals in the health system.

National guidelines for pain management have been published in 1999, and have already been updated. The WHO-book on Pain and Symptom Management for Children with Cancer has been translated into Slovenian. In addition to the guidelines, there was a successful educational campaign organized to train doctors and nurses all over the region on the basics of pain management.

The future of implementation of organized palliative care in Slovenia

Reasons for slow implementation of nationally organized palliative care in Slovenia

The possible reasons for the absence of nationally organized effective palliative care programme in Slovenia could be the historical development of the Slovene society. There has been long subjugation of the country to another's rule; our independence began only in 1991. This situation through the centuries contributed to the development of a closed national character. People are not used to discussing and solving their problems publicly. The suicide rate in Slovenia is one of the highest in Europe.

In the period of socialism, death was pushed into the sphere of the private, and the Church, which was competing for the public's attention, would not enter the private sphere (23). There was no interest in the development of public institutions, like palliative care units in hospitals or hospices. There was a strict hierarchical organization of the health care system, and the concept of team work was not developed. Nursing, which is the most involved in the care of the dying patient, still has little power because of its subordinate position within the health care system (24).

Medical doctors, probably because of the lack of palliative care program during their study and lack of organizational solutions, do not feel comfortable in the area of palliation and rather emphasize the curative approach.

Finally, there was a complete absence of financial support from the government for all non-acute diseases (therefore also for the palliative care programs).We could conclude that:

- the incidence of chronic and progressive diseases in Slovenia compares to central European countries, but not to their level of palliative care development: palliative care is not organized nor sufficiently developed in the Slovene health care system;
- in Slovenia, like in the majority of European countries, the proportion of older population is increasing, needs for palliative care will become larger (25);
- statistical data about evaluation measures and quality of services in palliative care are not available, and therefore not very reliable qualitative and financial estimations of costs for existing initiatives of palliative care are possible.

Main issues and obstacles for strategies for the implementation of palliative care into national health system

The main issues in palliative care for Slovenia are:

1. to develop common vision for palliative care for the people who need it now and for the growing population of elderly, who will need it very soon;
2. to produce common standards in palliative care;
3. to introduce regular undergraduate and postgraduate education;
4. to ensure better teamwork and continuity of care across all settings;
5. to introduce efficient clinical and managerial solutions to ensure better health outcomes and patient satisfaction; and
6. to bring better understanding that every clinical decision is also a financial decision and therefore responsibility in the clinical management should be introduced.

On the other side, the main obstacles for the implementation of organized palliative care are:

1. lack of knowledge and appropriate attitude among health care professionals;
2. lack of organizational motivation to reach better health and satisfaction outcomes;
3. lack of clearly defined common standards in palliative care;
4. lack of understanding of team work and continuity of care;
5. lack of the public understanding what palliative care is;
6. lack of economic analyses on end-of-life care:;
7. lack of governmental understanding of palliative care and its benefits; and
8. lack of governmental recognition of the growing needs of patients with chronic and progressive diseases in the past, and therefore lack of financial incentives.

Common examples of attitudes presenting direct barriers to palliative care development are:

- “We are already providing this form of care.”
- “We do not have enough money for this development.”
- “We only need to train general practitioners.”
- “We already are starting non-acute departments where nurses are offering care to patients.”
- “In tertiary hospitals we should not have this type of patients.”
- “Nursing homes should provide such services.”

Such remarks are often heard and illustrate a range of individual and institutional barriers and lack of understanding of benefits which can be achieved. To respond to this situation a combination of well trained palliative care teams with clear ideas and vision on the one hand are needed, along with generic education and a change of attitudes with the ability to build on earlier successes in order to achieve worthwhile results.

As Gomez-Batiste et al (26) observed, individual and institutional resistance might be very strong and it is vital to understand the reasons that underpin it and work towards achieving a consensus of views. This can help to distinguish between palliative care services and for example, pain clinic or oncology services, in a context where palliative care standards have been clearly defined. This is particularly important where there is a political dependency of one service on another, rooted in local power positions. Once a number of good initiatives are underway, however, and this has been consolidated, local experience is frequently the most effective rejoinder to criticism. It then becomes possible to focus more on issues of extension and coverage.

Assessment of needs

Baseline studies to assess needs provide vital information on kinds of services that should be developed. Objective assessment of needs and analysis of baseline context is also crucial for effective monitoring of the results of a new initiative. We can use a simple and pragmatic approach to estimate need in palliative care by Higginson that has three components (20):

- epidemiology;
- comparison with services available; and
- effectiveness and cost-effectiveness analysis - national and local.

Possible strategies for palliative care in Slovenia

There are three main options of possible strategies for palliative care in Slovenia:

1. No change in the current government policy or strategy.
   This would most probably lead to a variety of very slowly evolving and differently formulated palliative care services on different levels of the health care system, not being integrated into a useful network of the path of every patient, without proper quality standards, coverage, equity, possibilities for quality measures and planning towards meeting needs. It would definitely be a very unsatisfactory experience for patients and their families, and health care professionals as well.

   It would also be possible to expect similar events of misuse and exploitation of the circumstances like the events in Hotel Črni les, in the 2001- 2003, as reported in the media. Inappropriate care and financial exploitation was discovered in the situation of absence of organized palliative care on the national level.
2. Incremental or modest policy change; the development of palliative care units within nursing departments in every large hospital.
   If new governmental policy helps alleviate some of the aspects of the current problem, like supporting the development of long-term nursing departments in hospitals only and not acting strategically on all levels of health care where patients die, very similar results to the first option can be expected. Public health goals (coverage, equity, quality standard care, efficiency and efficacy) could not be reached in this way.
3. Radical policy alternatives.
   By applying bold changes, most if not all of the policy goals could be achieved. To guide reforms, many participants in health care should embark on an era of innovation, evaluation, and learning. Among those are clinicians, educators, insurance house, provider organizations and government agencies together with the development of palliative care teams and patient advocacy organizations.

EXERCISES

Task 1

Carefully read the part on theoretical background of this module. Critically discuss the characteristics of palliative care services and their supportive role in different trajectories of disease in a small group of students (fishbowl method could be used).

Task 2

From domestic and international bibliographic data-bases find out how different successful models of palliative care services can meet people's needs at the end of life.

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RECOMMENDED READINGS

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