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**Organizing palliative care  
in Slovene health care system**

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**Policy Paper**

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Urska Lunder  
Ljubljana, Slovenia

International Policy Fellow 2004  
Center for Policy Studies  
Open Society Institute  
Budapest, Hungary

## Outline

<i>Executive summary</i>	3
<b>1. Introduction</b>	<b>4</b>
<b>1. 1. Palliative Care definitions</b>	<b>5</b>
<b>1. 2. What is good death?</b>	<b>7</b>
<b>2. A gap between evidence and the reality at the patient's bed</b>	<b>9</b>
<b>3. Why is palliative care public health priority?</b>	
<b>3. 1. Status of palliative care in Europe and some respective other countries</b>	<b>16</b>
<b>3. 1. 1. Hospice and palliative care in United Kingdom</b>	<b>16</b>
<b>3. 1. 2. Palliative care in Catalonia in Spain</b>	<b>19</b>
<b>4. Status of palliative care in Slovenia</b>	<b>22</b>
<b>4. 1. Reasons for slow implementation of nationally organized palliative care</b>	<b>28</b>
<b>4. 2. Main issues and obstacles for strategies for the implementation of palliative care into national health system</b>	<b>32</b>
<b>4. 3. Needs assessment</b>	<b>30</b>
<b>5. Evidence of effectiveness of palliative care</b>	<b>34</b>
<b>5. 1. Common protocol</b>	<b>35</b>
<b>5. 2. Classifying of palliative care – some options</b>	<b>36</b>
<b>5. 3. What are the specific challenges of implementing the clinical pathway?</b>	<b>37</b>
<b>6. Discussion</b>	<b>38</b>
<b>7. Possible strategies for palliative care in Slovenia</b>	<b>39</b>
<b>8. Recommendations</b>	<b>40</b>
<b>9. Appendix</b>	<b>42</b>

## *Executive summary*

Palliative care is an important public health issue. It is concerned with suffering, dignity, care needs, and quality of life for people at the end of their lives. It is also concerned with the care and the support of their families and friends. Palliative care was a neglected topic in Slovenia: indirect indicators of the status of palliative care, like opioid consumption, palliative care in education, epidemiological observations and lists of existing palliative care services can show insufficient development of palliative care in Slovenia in comparison to many other countries in Europe.

The most important principles are to consider palliative care as a right for every person who needs it, and palliative care services as a generally available service integrated into the mainstream of the national health care system, with focus on community and home care, underpinned with specialist care in health care institutions (acute and non-acute settings in hospitals and nursing homes).

The basic aims of the appropriate development of palliative care are to develop palliative care to gradually achieve populations (for cancer and non-cancer patients) and geographic coverage, accessibility, equity, quality (effectiveness, efficiency), and systems for monitoring outcomes.

There are many interventions that could be used to improve palliative care in the realm of public health. There should be a specific strategy on the national level to develop and combine well-planned resources with an emphasis on training and team work in order to integrate palliative care into the health system. The planning and implementation of palliative care must be comprehensive, with measures taken in all health care settings: in hospitals, nursing homes, hospices, or other health systems, and at the patient's home. This care should be adapted to the health and social system, and linked from the beginning, to relevant areas, particularly oncology, primary care, paediatrics, geriatrics, and neurology, in order to promote maximum integration. A social and political impetus is also required, entailing changes in attitudes and widespread education of the public and all professionals involved with patients who have life-threatening illness.

The elements of this policy paper are the study of the current status of palliative care and the assessment of needs in Slovene health care system and two EU countries (United Kingdom and

Catalonia, Spain); alternatives of possible implementation of specific services, measures in general services; education and training; a discussion on the development of quality standards, guidelines and clinical pathways, with some implications about financing. These are the necessary elements to propose policy recommendations to the Ministry of Health and provide a practical model of organized palliative care for all settings.

## ***1. Introduction***

Until the last few decades, most people died quickly, following an infection or injury, or soon after the initial symptoms of an advanced and 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<sup>1</sup>. Three quarters of us will experience cancer, stroke, heart disease, obstructive lung disease, or dementia during our last year of life<sup>2</sup>. While medical advances have transformed many illnesses that once proved rapidly fatal into chronic conditions, improving the quality of this resulting longer life has been much more difficult to achieve<sup>3</sup>.

The modern hospice movement was established in response to the poor quality of care of the dying patients in health systems<sup>4</sup>. The hospice model of care is now espoused as a model of excellence and has led to a worldwide movement aspiring to deliver high quality palliative care to dying patients in health systems. The aim of the introduction of palliative care services into the health care system is the improvement of the quality of care for patients with advanced non-curable disease. Palliative care services directly influence patient care and also have an advisory and educational role to influence the quality of care in the community and hospitals.

It is society's responsibility through government, health care planners, professional organizations, and health professions to provide the resources to ensure a system of intensive care for dying patients and their families. This necessitates the development of the field of palliative care to ensure that the appropriate expertise is widely and readily available as well as accessible to all. Health care systems will therefore be challenged to provide effective and compassionate care for larger numbers of people at the end of life.

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<sup>1</sup> Lynn J. Learning to care for people with chronic illness facing the end of life. JAMA 2000;284.

<sup>2</sup> Zdravstveni statistični letopis, Institute for Health Care Republic Slovenia, 1998 – 2002.

<sup>3</sup> Meier D, Variability in end of life care. BMJ 2004;4:296-7.

<sup>4</sup> Clark D. Between hope and acceptance. The medicalisation of dying. BMJ 2002;324:905-7.

Public health aims include coverage, equity, quality, comparability, and the introduction of changes into the organization of health care services.

This paper suggests to enhance new opportunities to improve the delivery of palliative care; an overview of these initiatives and accomplishments thus far; the challenges in developing and implementing a national strategy on palliative and end-of life care; and, future directions for this collaborative initiative.

## 1. 1. Palliative Care Definitions

The European Association for Palliative Care defines palliative care as<sup>5</sup>:

*“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.”*

There might be problems in defining the patient's condition. Even though the basic principles may be agreed upon, there are frequent differences of interpretation regarding the clinical status. The core of palliative care is well understood, but because of the complexity of palliative care there are various definitions used around the world.

World Health Organization's definition of palliative care<sup>6</sup> recommends:

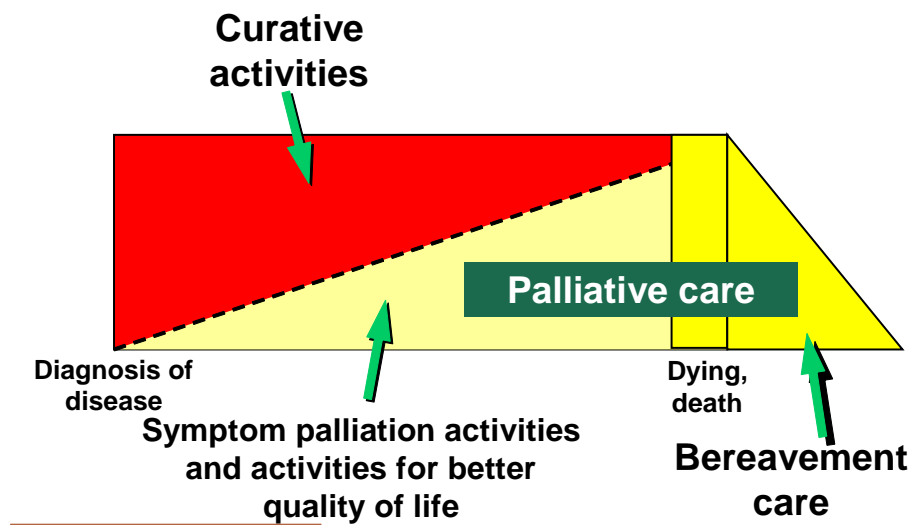
*“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.”*

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<sup>5</sup> European Association for Palliative Care: Report and recommendations of a workshop on palliative medicine. Education and training for doctors in Europe. Brussels, March 20-21, 1993.

<sup>6</sup> Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: The World Health Organization's Global Perspective. *J Pain Symptom Manage* 2002;24(2):91-6.

# Palliative care



Palliative care<sup>7</sup> :

- provides relief from pain and other distressing symptoms,
- affirms life and regards dying as a normal process,
- intends neither to hasten or postpone death,
- integrates the psychological and spiritual aspects of patients care,
- offers a support system to help patients to live as actively as possible until death,
- offers a support system to help the family cope during the patient's illness and their own bereavement,
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated,
- will enhance quality of life, and may also positively influence the course of illness,
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative Care Program aims to achieve an integrated service across all aspects of care. This is supported by the underlying principles of Palliative Care Program, which are:

- Care is holistic, multidisciplinary and client-centered;

<sup>7</sup> World Health Organization. National cancer control programs: policies and managerial guidelines, 2<sup>nd</sup> ed. Geneva: World Health Organization, 2002.

- Care includes medical, nursing, allied health and volunteer services;
- Support is provided for families and friends, including grief and bereavement support;
- Patients can make informed choices about their care including the type of care and where the care is delivered;
- Service delivery is seamless between the locations where care is delivered, whether that be in the community or in a health care facility.

Palliative care services can be provided in the home, in community-based settings like nursing homes, palliative care units, and in hospitals. People who are dying need to be able to move freely between these places, in response to their medical care and support needs.

In general, palliative care is best provided within close proximity to the person's home and community.

People involved in palliative care may include:

- medical practitioners, including general practitioners, palliative care specialists, and other specialist physicians with a related interest
- nurses, including generalist and specialist nurses in the community, hospital and inpatient palliative care settings, and independent nurse practitioners
- allied health professionals, including social workers, physiotherapists, occupational therapists, psychologists, pharmacists, dietitians and speech pathologists
- volunteers
- support workers, including nurse assistants, personal care attendants
- bereavement counselors
- spiritual carers from a range of pastoral, spiritual and cultural backgrounds.

Administrators or business managers provide essential support to the team.

Families, also receive care from the palliative care team, and are critical members of the team. In particular, when a person is cared for at home, the family usually provides a large proportion of the hands-on care.

## **1. 2. What is a good death?**

No one can answer that question with confidence. We have reliable and detailed statistics on life expectancy, age at death, and place and cause of death, but we know little about the experience of death. We don't have data on how many died in pain, anxiety, disturbed by many other symptoms, "hooked up" to life support they didn't want, or alone. Although the oldest health statistics are based on death certificates, one of the weakest areas of health information is on how we die<sup>8</sup>. In the absence of systematic information and monitoring of end of life care and comparisons across health regions (or health care organizations) there is no opportunity to learn what is possible (those regions with the highest ratings), or tracking whether improvements are occurring. For the minority who die under the care of palliative care teams the experience is probably good, but there is a suspicion that for the majority, who die in acute hospitals or nursing homes or at their homes, the experience is bad.

A good death is clearly more than being free of pain and three issues emerged repeatedly; control, autonomy, and independence. The authors of the final report on *The Future of Health and Care of Older People* have identified 12 core principles of a good death<sup>9</sup>:

<b>Core Principles of Good Death</b>	
1	to know when death is coming, and to understand what can be expected
2	to be able to retain control of what happens
3	to be afforded dignity and privacy
4	to have control over pain relief and other symptom control
5	to have choice and control over where death occurs (at home or elsewhere)
6	to have access to information and expertise of whatever kind is necessary
7	to have access to any spiritual and emotional support required
8	to have access to hospice care in any location, not only in hospital
9	to have control over who is present and who shares the end
10	to be able to issue advance directives which ensure wishes are respected
11	to have time to say goodbye, and control over other aspects of timing
12	to be able to leave when it is time to go, and not to have life prolonged pointlessly



<sup>8</sup> Singer P, Wolfson M. "The best places to die". *BMJ* 2003;327:173-4.

<sup>9</sup> Debate of the Age Health and Care Study Group. *The future of health and care of older people: the best is yet to come*. London: Age Concern, 1999.



A good death is an important aim for health services and for us all<sup>10</sup>. These core principles of a good death should be incorporated into the plans of individuals, professional codes, and the aims of institutions and whole health services.

## 2. A gap between evidence and the reality at the patient's bedside

Advances in diagnosis and therapeutics have redefined the field of palliative care in the last decades. But why is there a gap between evidence based palliative care, or knowledge acquired during training and the reality at the patient's bedside? And why is it so difficult and frustrating, for those seeking to improve the quality of end-of-life care<sup>11</sup>?

If we look at pain relief, where the majority of advances have been made in research, but studies consistently demonstrate that pain relief in various patient populations is inadequate, despite the fact that we have known the principles of pain relief for over a generation.<sup>12, 13, 14, 15, 16</sup>

There is much evidence that people do not die in the place they wish, or with the peace they desire. Furthermore, too many die alone, in pain, terrified, mentally unaware, without dignity, and feeling alienated. Modern dying involves a struggle for control: some doctors fear failure they can not keep their patients alive. Patients with life threatening diseases, especially those with cancer, are often subjected to aggressive attempts to cure even when they are likely to be futile.<sup>17</sup> Singer and colleagues recently showed that fear about the unwanted application of technology to prolong life was the most prevalent concern voiced by patients on dialysis, with AIDS, or receiving long-term care.<sup>18</sup> All too frequently, patient care was portrayed as a war to be won or lost. On such a battlefield, patients in the process of dying could only be seen as the

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<sup>10</sup> Smith R. A good death. *BMJ* 2000;320:129-30.

<sup>11</sup> Teno M, Field M, Byock I. Preface: the road take and to be traveled in improving end-of-life care. *J Pain Symptom Manage* 2001;22:713-6.

<sup>12</sup> Lynn J et al. Perceptions by family members of the dying experience of older and seriously ill patients. *Ann Intern Med* 1997;126:96-106.

<sup>13</sup> Addington-Hall J, McCarthy M. Dying from Cancer: results of a national population-based investigation. *Palliat Med* 1995;9:295-305.

<sup>14</sup> Gagliese L, Melzack R. Chronic pain in elderly people. *Pain* 1997;70:3-14.

<sup>15</sup> Teno JM et al, for the SUPPORT (Study to Understand Prognoses and Preferences for outcomes and Risks of Treatment) investigators. Do advance directives provide instructions that direct care? *J Am Geriatr Soc* 1997;45:508-12.

<sup>16</sup> De Witt R, van Dam F, Vielvoye-Kerkmer A, Mattern C, Abu-Saad HH. The treatment of chronic cancer pain in a cancer hospital in teh netherlands. *J Pain Symptom Manage* 1999;17:333-50.

<sup>17</sup> Seely JF, Mount BM. Palliative medicine and modern technology. *JAMC* 1999;161(9):1120-2.

<sup>18</sup> Singer PA, Martin DK, Kelner M. Quality end-of-life Crae: patients' perspectives. *JAMA* 1999;281:163-8.

ultimate losers. The issue is not whether, but how, to apply palliative care which includes modern technology together with humanistic approaches to patient/family needs.

Data suggests that hospitals and health care professionals are not equipped or trained to handle the medical and psychosocial problems that face those who are chronically ill or dying<sup>19, 20</sup>. Although the barriers to achieving a peaceful death are many, they can be grouped into three broad categories<sup>21</sup>:

- professional knowledge of and skills in palliative care,
- professional and public attitudes about the goals of medicine,
- financial and structural aspects of the health care system;

### **3. Why is palliative care public health priority?**

The impact of death on our society is easily underestimated. Palliative care is delivered to patients with progressive illness where the prognosis of dying is less than one year and also to all chronically ill patients with prominent symptoms and a high burden of disease. This period can vary from a short time to many years. Because it is very difficult to predict the course of many chronic diseases, palliative care should be based on patient and family needs and not on prognosis<sup>22</sup>. The examples of the trajectory of cancer, heart failure and dementia illustrate this point<sup>23</sup>.

#### *Cancer*

Depending on the site of the body affected there are many cancers, where the prognosis for any individual depends on the extent of the growth at presentation and the response of the tumor to treatment, which may include surgery, radiotherapy and/or chemotherapy. Patients are not

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<sup>19</sup> McCue JD. The naturalness of dying. *JAMA* 1995;273:1039-43.

<sup>20</sup> A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks to treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA* 1995;274:1591-8.

<sup>21</sup> Meier D, Morrison S, Cassel C. Improving palliative care. *Ann Intern Med* 1997;127:225-30.

<sup>22</sup> Davis E, Higginson, editors. Better palliative care for older people. World Health Organization, 2004.

<sup>23</sup> Lynn J, Adamson D. Living well at the end of life: adapting health care to serious chronic illness in old age. Arlington, VA, Rand Health, 2003.

usually severely restricted in their activity until the final stages of the illness when there is no further response to the treatment (Fig. 1).

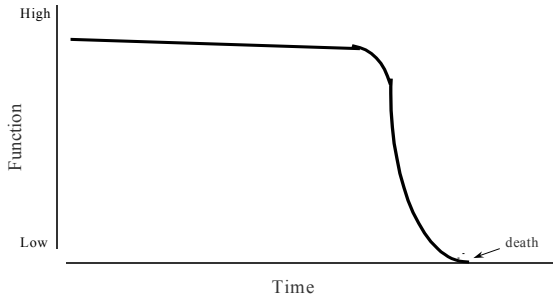


Fig. 1  
Model of a trajectory of an illness due to cancer.

*Heart failure*

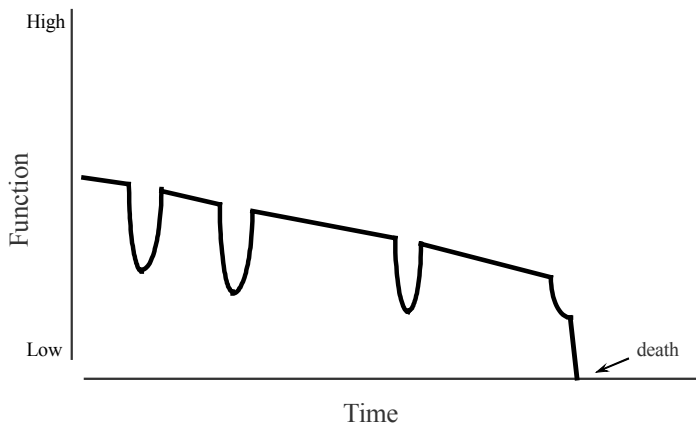
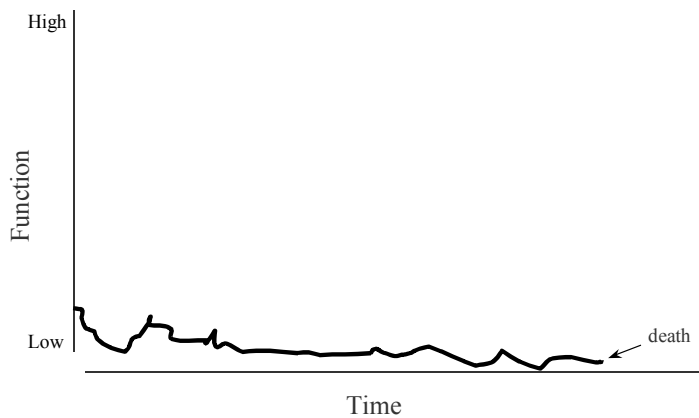


Fig. 2  
Model of an illness trajectory for organ failure such as heart failure.

*Dementia*

Fig. 3  
Model of an illness trajectory for dementia or frailty



Quality of care at the end of life is a global public health problem because of the large number of people affected. For example, in Slovenia 20,000 patients die each year. If each death affects five other people in terms of giving informal care and grieving relatives and friends<sup>24</sup>, the number of people affected each year in Slovenia is about 100 000 people or 5% of population.

Palliative care can prevent needless suffering, and could have a potential to prevent morbidity in the bereaved. It provides patient centered care, and it incorporates self-management programs. In the process of organized palliative care peer education and change in clinical behaviour can be stimulated. In the majority of Western countries more than half the people die in hospitals and other institutions<sup>25</sup>, and this is further proof that palliative care is a public health matter.

By recognizing that palliative care is a public health topic, rational planning, implementation and evaluation become priorities and require political commitment. Health administration has to be involved from the beginning in order to promote quality and equity in the provision of palliative care, and to finance it as a part of the overall health care system<sup>26</sup>. There are several international initiatives attempting to educate national policymakers towards a better understanding of the importance of palliative care in national health systems, for example,

- **Council of Europe, Report of the Committee of Experts on the Organisation of Palliative Care**, adopted by the Committee of Ministers, June 2003, with the key recommendations:

**Key recommendation 1:**

Adopt policies, legislative and other necessary for a coherent and comprehensive national policy framework for palliative care.

**Key recommendation 2:**

Take to this end, whenever feasible, the measures presented in the appendix to the recommendation, taking account of their respective national circumstances.

**Key recommendation 3:**

Promote international networking between organizations, research institutions and other agencies that are active in the palliative care field.

**Key recommendation 4:**

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<sup>24</sup> Singer P, Bowman K. Quality care at the end of life. *BMJ* 2002;324:1291-2.

<sup>25</sup> Heyland D, Lavery J, Tranmer J, Shortt S, Taylor S. Dying in Canada: is it an institutionalized, technologically supported experience? *J Palliat Care* 2000;16:10-6.

<sup>26</sup> Recommendation of the Committee of Ministers to member states on the organization of palliative care, Council of Europe, article 15.b and article 11. Strasbourg 2002.

Support an active, targeted dissemination of these recommendations and its explanatory memorandum.

In the appendices guiding principles, settings and services, policy with organization and quality improvement with research are recommended. This implies that **adequate resources and funds must be made available** to promote the development and integration of palliative medicine and care into healthcare services.

- **World Health Organization (WHO), Cancer Unit** supports the development of palliative care services as basic elements of any national or regional cancer comprehensive program. In 2004 the World Health Organization has published two booklets: “The solid facts – Palliative care” and “Better Palliative Care for Older People” to ensure the widest possible availability of authoritative information and guidance on palliative care. The purpose of both booklets is to provide a concise overview of the best available evidence on the concept of palliative care. See Figure 4.

Fig. 4

**WHO policy implications:**

- Policy makers must begin to plan now to meet the needs of ageing populations for care at the end of life
- Health care systems must change their focus from acute care to the care of people living with and dying from a range of serious chronic diseases
- Policy makers must invest in providing publicly funded palliative care services as a core part of health care and not as an “add on extra”
- Policy makers must take steps nationally to ensure that unmet needs for end of life care are identified for all common diseases, including cancer, ischaemic heart and cerebrovascular disease, chronic obstructive respiratory disease, end stage liver and kidney disease, infectious diseases and dementia
- Policies need to identify people living with serious chronic illnesses in widely different settings including the community, nursing homes and hospitals including intensive care
- Policies must also recognise the work of families and caregivers and support them to help care for the patient and to cope with the loss the illness brings for them
- Public health policy must acknowledge peoples’ right to high quality care at the end of life and to make decisions about their care whatever the nature of the disease they suffer from
- Policy makers should monitor where people who are seriously ill wish to be cared for and to die
- Policy makers need to promote the development of palliative care skills in staff working across all settings, especially in pain control and communication

- Palliative care services must be co-ordinated to work across different settings of home, hospital, in-patient hospice and other institutions
- Policy makers need to invest in the funding of the full range of effective palliative care services including specialist teams to ensure that patients and their families have access to the services they need
- Health policy makers need to ensure that national systems are in place to monitor access for all groups in society to palliative care
- Health care organisations need to invest in local systems for identifying vulnerable groups and for monitoring and improving the quality of services they provide for their populations
- Policy makers need to promote dissemination of good practice in reaching vulnerable groups
- Policy makers and decision-makers should reward health care organisations that engage in audit and quality improvement schemes in palliative care
- Policy makers should encourage the dissemination of examples of good practice and constantly review the success of these methods in palliative care
- Health care organisations need to develop and maintain cultures that support health professionals to work well in teams to identify areas of end of life care that might be developed or improved
- Demonstration of innovative approaches and evaluation of their merit in palliative care need to be widespread and encouraged
- Health care organisations need to develop cultures and working practices that allow the best use of the palliative care skills of health professionals
- Public health policies for palliative care must include a component of public education to increase awareness of end of life issues
- Policy makers need to develop national strategies for end of life research and expand investment in this area across all diseases
- Policy makers should invest in developing national datasets for palliative care.

(Publication requests on e-mail address: [publicationrequests@euro.who.it](mailto:publicationrequests@euro.who.it) )

- **European Federation of Older Persons (EURAG)** published “Making Palliative Care a Priority Topic on the European Health Agenda” – Promoting Campaign at EU Level, January 2004.

EURAG proposes to make palliative care a priority topic on the European Health Agenda, which would best be achieved by a decision of the European Union. The proposed draft of such a decision takes into account the role of the European Union in the field of health care and proposes the adherence to other recent summaries of recommendations delivered by the Council of Europe’s Committee of ministers to member states on the organization of palliative care.

( [www.eurag-europe.org/EURAG\\_PalliativecareProject\\_2004.pdf](http://www.eurag-europe.org/EURAG_PalliativecareProject_2004.pdf) )

- **National Hospice and Palliative Associations** on the 2<sup>nd</sup> Global Summit in March 2005 prepared Korea Declaration on Hospice and Palliative Care, with clear agreement on different activities in realm of palliative care national governments should perform.  
(Appendix 1)

Effective measures in all relevant political fields in the national health care system have to be supported to raise awareness about the needs of terminally ill and the knowledge of possible solutions. The main factors involved in achieving political commitment are as follows<sup>27</sup>:

- Identification of the importance of clinical improvement related to widespread and common problems within the health care system; Pain is the paramount example.
- High levels of satisfaction on the part of patients and families.  
This can have a major impact at the managerial level. In a context where health care managers are faced with problems of provider competition, low satisfaction with services and conflicts over resource allocation, the introduction of high quality services at moderate costs and high user satisfaction provides an important element of recognition for policymakers.
- Highlighting the efficiency and cost-effectiveness of palliative care within a strategic approach.  
The Catalonian model shows a reduction in the use of emergency rooms, length of stay and the increased prevalence of home deaths, together with a reduction in inpatient care.
- New values are added to the health care system, accompanied by wide recognition and improved work satisfaction on the part of the professionals; For example, the impact of new professional roles associated with multidisciplinary teams, the perceived value of a comprehensive approach, or the reduction of burnout.
- High level of social and cultural regard;

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<sup>27</sup> Gomez-Batiste X, Fontanals D, Roca J, Martinez F, Valles E, Roige-Canals P. Rational planning and policy implementation in palliative care. In: Clark D, Hockley J, Ahmedzai S., Editors: *New themes in palliative care*. Open University Press, Buckingham, Philadelphia, 1999.

This is associated with a clear improvement in the quality of care, with broader discussion on the ethical issues with better knowledge and insight, with the humanitarian values associated with palliative care as well as with deeper and more personal issues, for example, relating to individuals' fear of suffering, pain, isolation, and death in society.

As Gomez-Batiste et al who has integrated palliative care into Catalonian health system has observed to obtain political commitment to palliative care there has been often a lack of consensus between individual health care divisions, for example, oncology versus primary care versus a pain clinic. There has also been a lack of a public health approach and adequate training. He suggests that all of these issues must be addressed if coherent plans and broad agreement are to be achieved.

### **3. 1. Status of palliative care in Europe and some respective other countries**

The development of hospice and palliative care units in Europe has had an increasing impact on nearly every country although each has had to address different challenges. Cultures, economic, social and historical conditions vary across the Europe, but palliative care has been adapted to meet these different needs and circumstances.

The European Association of Palliative Care is a well established major leader in drawing together health care professionals of all the main disciplines involved in palliative care.

In the following paragraphs are two brief presentations described about national palliative care in the United Kingdom and in Catalonia, Spain to illustrate palliative care development in its diversity.

#### **3. 1. 1. Hospice and palliative care in United Kingdom**

The modern hospice approach was developed in the United Kingdom in the late sixties, as a new type of service: an inpatient unit initially based within an independent facility and called a hospice that also provided home care services, and was organized as non-governmental, charitable organization. The early hospice movement was very strongly connected with the



community it served. It brought a new philosophy with values that directly addressed patients and families needs in the last stages of life threatening diseases.

In the United Kingdom with a 52 million population, a total of 540,000 deaths occur every year. Like the majority of European countries, diseases of the circulatory system are the number one cause (42%) of deaths, and cancer is second (25%)<sup>28</sup>.

Since the mid-1960s the hospice movement in the United Kingdom has had a considerable impact on the care of dying people. A very strong and wide spread hospice movement laid the foundation for the concept of hospice care, named “palliative care”, which was introduced also in hospitals and home support teams in health systems not only in the UK but internationally<sup>29</sup>. Palliative medicine was recognized as a specialty by the Royal College of Physicians (London) in 1987.<sup>30</sup>

From the National Survey 2003 – 2004<sup>31</sup> on hospice care (children hospices and palliative care services are not included in this report) there are 186 specialist units, all together with 2730 beds and a mean length of stay of 12.8 days. Each year around 38,000 new patient admissions are recorded and 27,000 deaths in these units.

There were 417,064 home care visits from 354 home care teams, mostly by community nurses (79%) and 427,766 phone calls (average 8 calls per patient). Average care at a patient home was 111 days. Of patients cared by home care services, only 28% died in hospital. All together 1200 full time nurses are involved in home care services in the United Kingdom. The most prominent data for home care palliative care suggest that about 96,000 new patients are cared for each year, which is approximately 69% of the number of patients dying from cancer.

In 228 day care units 32,500 patients received services in 2004.

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<sup>28</sup> Office of National Statistics, United Kingdom, 2002. Population and mortality data.

<sup>29</sup> Mount B. The Royal Victoria Hospital Palliative Care Service: A Canadian experience. In: Saunders C, Kastenbaum R, eds. *Hospice care on the international scene*. New York: Springer, 1997.

<sup>30</sup> Hockley J. The evolution of hospice approach. In: Clark D, Hockley J, Ahmedzai S. eds. *New themes in palliative care*. Open University Press, Buckingham, Philadelphia, 1999.

<sup>31</sup> National Survey of Patient Activity Data for Specialist Palliative Care Services. Full Report for the year 2003-2004. The national council for palliative care, London, 2005.

There are 273 bereavement services in United Kingdom with approximately 27,000 clients yearly and an average of 3.2 contacts per client, most of the time with a social worker.

Pain and symptom control were the presenting complaints in over 50% of referrals and 40% required psychological support. Social and financial problems were present in 7% of referrals. For 14% of the referrals, carer support was one of the reasons for referral.

Places of death of patients cared for by palliative care services in United Kingdom:

Home	27%
Palliative care unit	32%
Hospital	36%
Other	5%

By 1996, there were eleven hospice units for children in the UK (St Christopher’s Information Service). Many of the admissions into children’s hospice units are for respite care with a wide range of complex and often rare life-limiting illnesses rather than for cancer. Many children’s hospices are non-institutional with no resident doctor. The care is family driven with a great emphasis on “respite care”. Some adult hospices admit children (with employed pediatric nurses to care for children).

From 1994-2004 a slight rise in the number of specialist units was recorded In the United Kingdom there is probably a plateau reached for the overall specialist units within the existing financial model at the moment. It is estimated that coverage is around 42% of patients who would need palliative care in any form. Palliative care services in United Kingdom cover mostly cancer patients (94% of all patients in palliative care have cancer).

Until recently funding for hospice units has been on an *ad-hoc* basis (19). A few units have been totally self-funded using fund-raising initiatives and charities to help support them, other units have been partially funded by the government, and still others are fully funded and run as NHS hospice units. In the mid-1980s the government, in acknowledgement of the success of the hospice movement with its enormous support from the public, decided to fund the work 50:50. This meant that for every Pound raised by hospice fund-raisers, the government would match it “pound for pound”. More recently a special allocation of Department of Health funds

has been available to independent hospices. In the literature there is data available for 1993 of a figure of 43 million pounds.

In a long tradition of hospice and palliative care service in the United Kingdom, an important knowledge and research resource evolved for global use in the new evolving palliative care systems worldwide.

Although there has been great success in the hospice and palliative care movement in the UK, there were some difficulties in the aspects of:

- standard of care (in different parts of United Kingdom there are different standard documents developed),
- planning,
- equity; more than 94% of patients cared for in palliative care services have cancer, patients with another diagnosis do not have equal access to palliative care,
- majority of patients are catholic, proportionally to the population not enough patients from other religions,
- accessibility,
- regimen of financing;

Only recently the development of public health palliative care services is supported by the UK government.

### **3. 1. 2. Palliative Care in Catalonia, Spain**

Catalonia has a total of 6,200,000 inhabitants, with approximately 52,000 deaths per year, with mortality rate for cancer 13,000 deaths per year (25 %).

In 1989, the Catalonian Ministry of Health and the WHO Cancer Unit initiated a formal co-operation to design and develop a WHO demonstration project on the implementation and development of palliative care in Catalonia<sup>32</sup>. At the beginning there were only two palliative care services present in Catalonia. The project included several measures:

- an improvement in professional and structural resources
- training
- policies to make opioids more easily available

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<sup>32</sup> Gomez-Batiste X et al. Catalonia's five-year plan: basic principles. *Eur J Palliat Care* 1994;1:45-9.

- a revision of accreditation and standards
- a specific financial system
- legislative measures
- evaluation of results

After five years there were 21 departments of palliative care services with 350 palliative specialist beds and 18 palliative care teams in hospitals. There were an additional 44 home care support teams. This network of palliative care services covered 38.5 % of cancer patients in need for palliative care. Geographical coverage was 80%. The use of opioids increased from 3.5 kg/million/year to 11.4 kg/mil/year<sup>33</sup>.

As it is showed in Figure 5, by 2003<sup>34</sup> there were 50 departments of palliative care services, with 523 beds in Catalonia. There were 52 palliative home care teams achieving “coverage” for 67.1 % of cancer patients, and geographical coverage of 95 %. Opioid consumption rose to 17 kg/mil/year. Death at a patient’s home occurred in 2003 in 61 % of all deaths (home deaths in 1989: 31 %).

Fig. 5

	Year	1989	1995	2003
Palliative care units		2	21	50 (8,3 units/mil)
Palliative care beds		0	350	523 (87,2 beds/mil)
Home care support teams		0	44	53 (8,8 teams/mil)
Opioid consump. (kg/mil)		3, 5	11, 4	17
% of deaths at home		31	60	61

<sup>33</sup> Gomez-Batiste X et al. Catalonia’s five-year plan: preliminary results. Eur J Palliat Care 1994;1:98-101.

Authors also report the dramatic fall in the use of hospital and emergency resources in the last 5 weeks of life, and the increasing use of home care and community resources.

The principles of this program were to consider palliative care as a public health concern, with the aims of coverage for both cancer and non-cancer patients. The combined measures included the implementation of a wide range of specific services with a district wide approach. All these developments were possible because of the extensive education and training of all levels of the health system and strong leadership of experts with government support from the public financing system. With this project community based palliative care was emphasized and also the national health system promoted the development of non-acute hospital settings based in socio-health centres, which have rehabilitation and long-term resources.

The results demonstrate both, **effectiveness** in pain control, and strong **efficiency** in the provision of care, based on the dramatic change in the pattern of use of resources:

- reduction of the length of hospital stay,
- less frequent use of hospital emergency facilities,
- increase in home care,
- high patient and family satisfaction level,
- cost reduction;

Observing the implementation process of the Catalonian project is useful for all suggesting newly developed national policies:

Successful results of policies of the Catalan model:

- Achievement of very high coverage of patients, especially of cancer patients (more than two thirds of cancer patients are cared for by specialist palliative care teams, mostly in the last weeks of life);
- With extensive training activities good palliative care practice has been achieved at least when evaluated by indirect indicators and evaluation of satisfaction of patients and their families;
- Development of non-acute settings in socio-health centres with geriatric and chronically ill patients;
- The high geographical coverage;

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<sup>34</sup> Gomez-Batiste X. The Catalan experience. International Conference: Palliative care policy development, Budapest, October 16-18, 2003. Book of abstracts.

- Morphine widely used in the late stages of life in patients receiving palliative care;
- Reduction in the length of stay in acute hospitals, reduction in the use of emergency facilities;
- High involvement of home care support teams;

Areas for improvements of the Catalanian model at the present time:

- The implementation of resources at hospital settings has been slow, and there is still a need for more palliative care departments in hospitals to care for complex patients not only with cancer, but also with other chronic diseases;
- Support to prevent professional burnout;
- More social workers and psychologists are needed;
- Promotion of education and training in medical schools, recognition of palliative care as a specialization;
- Promotion of research, with more emphasize on the nursing, social, emotional, spiritual and ethical aspects in palliative care;
- Systematic evaluation of the effectiveness, cost/effectiveness, efficiency, and satisfaction;

With these results Catalonia is presently one country in Europe with the most developed network of palliative care services with accessibility and coverage achieved. The Catalanian model shows the importance of government involvement in a strategically planned implementation of palliative care services on all levels of the health care system. Rational planning with public health based policy, with a systematic implementation of specific resources and training achieves good palliative care goals, improves geriatric care, with effectiveness, efficiency, and satisfaction.

#### **4. Status of palliative care in Slovenia**

Slovenia is a Central European country with approximately 2 million inhabitants. There are around 19,000 deaths a year. The life expectancy at birth is 73.2 years for men and 80.7 years for women<sup>35</sup>. The three main causes of death in Slovenia are diseases of circulatory system,

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<sup>35</sup> Primic-Zakelj M, Ceh F, Pompe-Kirn V, Skrk J, Stabuc B. Vec znanja – manj bolezn: didakticni komplet za ucitelje (More knowledge – less illness: a didactic set for teachers). Ljubljana: Zavod republike Slovenije za solstvo, 2001:7.

neoplasm and diseases of respiratory system<sup>36</sup>. Slovenia is a country with a middle size morbidity and mortality rate caused by cancer. The leading cancer for the male population is lung (19% out of all cancer sites) and for the female population is breast (21%). Approximately 52 % of all deaths occur in hospitals and other institutions, and 48% occur at home (Figures 4 and 5). The financing of health care is based on a social security system, which covers practically the entire population.

Fig. 4

Place of death in Slovenia in 2002

Source: Zdravstveni statistični letopis 2002, Institut za varovanje zdravja R Slovenije.

Place of death	Number of deaths	%
Health care institutions	10,993	<b>52.2 %</b>
Home (or other places)	7,595	<b>47.8%</b>

Fig. 5

Place of death in health care institutions in 2002

Source: \* Zdravstveni statistični letopis 2002, Institut za varovanje zdravja R Slovenije.

\*\*Skupnost socialnih zavodov R Slovenije

Institution	Number of deaths	%
Hospitals*	7,781	<b>41.3%</b>
Nursing homes**	3,212	<b>17.2%</b>

The hospice movement, with home service and education programs, started in the middle of the 1990's in Ljubljana, the capital city of Slovenia. 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

<sup>36</sup> Moravec-Burger D, Urdih-Lazar T. Zdravstveni statistični letopis, Slovenija 2002 (Health statistics yearbook, Slovenia 2002). Zdravstveno varstvo 2003; letn 42; suppl. 1.

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. A physician is not yet involved in the hospice care professionally. Both hospices together, provide home care for around 500 patients annually. They organize of workshops, seminars and presentations. There are 104 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.

In Ljubljana there is already a house available for inpatient hospice, but it needs to be renovated or rebuilt. It is planned to start functioning in late 2006 or early in 2007. 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.

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. There are three more acute-hospitals with established long-term care departments where palliative care units with corresponding palliative care teams are planned.

The major institution for cancer patients, Oncology Institute Ljubljana, has established a consult team for palliative care.

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.

In co-operation with a variety health care institutions and Palliative Care Development Institute, Ljubljana, in the last few years, regular education on different topics related to



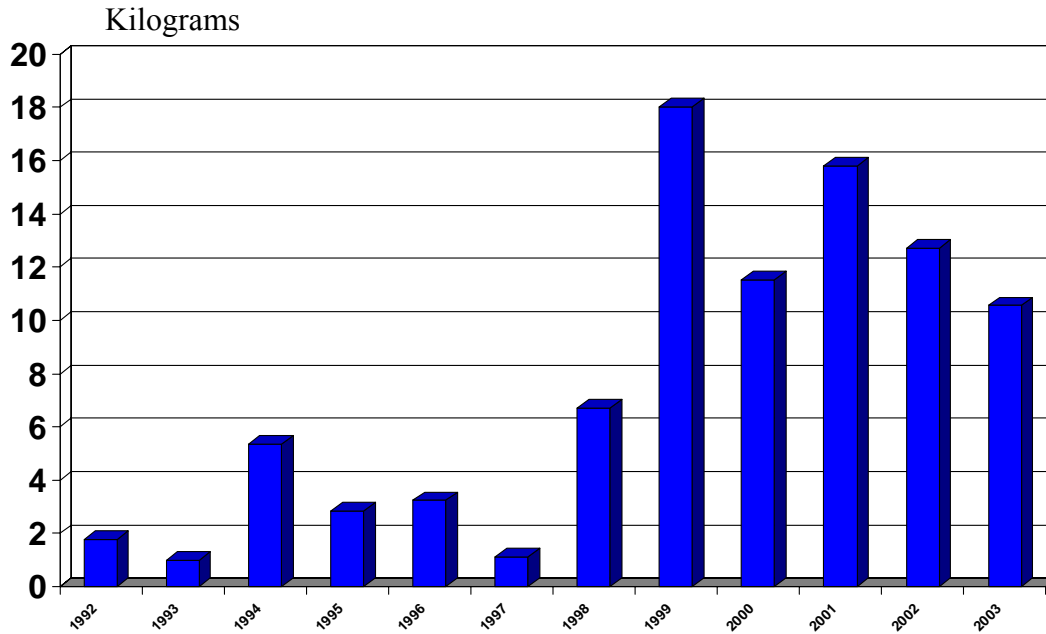
palliative care has been organized and become part of the curriculum for family medicine, public health and oncology offered by the Medical Faculty Ljubljana. Traditional courses and seminars are also organized for health care professionals of all disciplines involved in the emergence of palliative care in Slovenia. Two-weekend experiential workshops on palliative care communication have been specially developed and health care professionals, especially physicians, are often sent to study abroad (Salzburg, Stockholm, Manchester, Sheffield and Poznan).

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. Through co-operation with the Ministry of Health, a National strategic plan for palliative care has been prepared and is 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 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. 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. Fig. 6 shows total morphine consumption in Slovenia from 1992 - 2003.

Fig.6  
Total Consumption of Morphine in Slovenia in 1992 - 2003



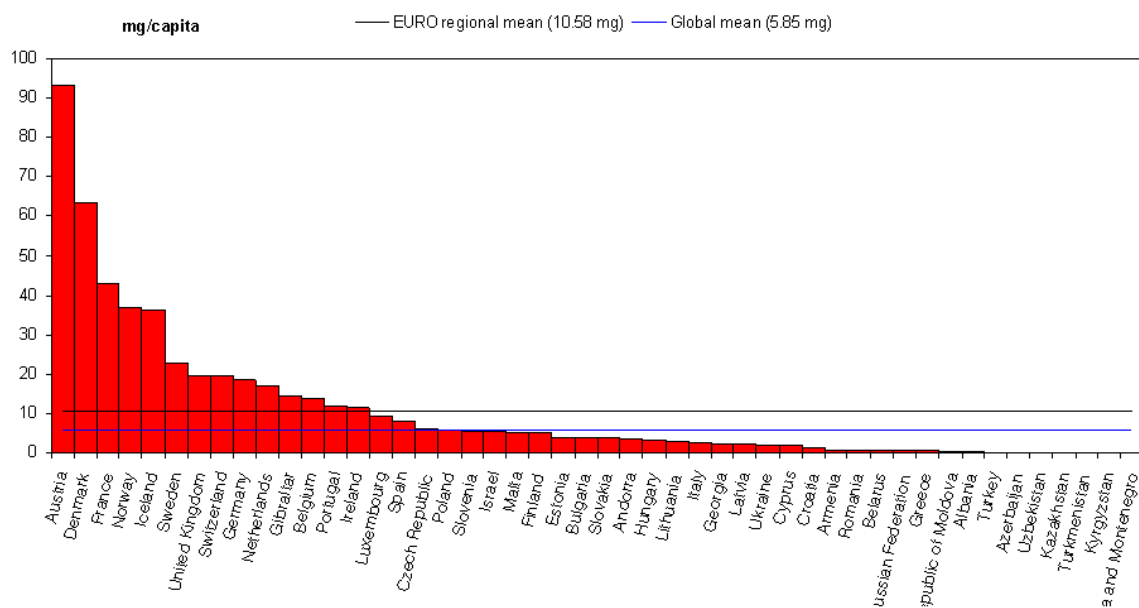
Source: International Narcotics Control Board; United Nations "Demographic Yearbook  
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2005

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 (Fig. 7).

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Fig. 7

## Consumption of Morphine, Europe mg/capita, 2003



Source: International Narcotics Control Board; United Nations Demographic Yearbook  
By: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2005

A recent 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 <sup>37</sup>, showed a retrospective record analyses of quality of care for 145 patients in 2002 for the last 6 months of life. The results suggest, that the documentation among health care professionals is 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,...). No patients received chemotherapy, albumin or vaso-active support in the last days of life. In the documentation less data is 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 is more than obvious how urgent it is to put palliative care standards in place.

<sup>37</sup> Bernot M et al. Obravnava bolnikov z rakom v zadnjih sestih mesecih življenja. 18. Onkološki vikend: Palliative care in cancer. Ljubljana, June 2005.

Extensive professional training, a better documentation system and co-ordination among all professionals in the health system is urgently needed.

Slovenia is one of the few countries with a relatively low infection rate of HIV. Total number of deaths from HIV/AIDS in period from January 1, 1989 to June 30, 2005 is 75. In Slovenia there is at list 173 people infected with HIV, from those 43 developed AIDS. The highest incidence of newly recognized infections with HIV was 12.5/mil inhabitants in 2004. The most affected group are homosexual men. Prevention measures in the group of i.v. drug users are quite successful mainly due to a variety of activities organized by different non-governmental organizations. A decrease is reported in the incidence of AIDS and deaths from AIDS due to better availability of very high quality anti retroviral therapies.

#### **4. 1. Reasons for slow implementation of nationally organized palliative care**

The possible reasons for the absence of nationally organized effective palliative care program 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<sup>38</sup>. 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<sup>39</sup>.

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<sup>38</sup> Kersevan M. Odnosi do mrtvih v socialisticnih druzbah (Attitudes toward the dead in Socialist societies). *Anthropos* 1981;4-6:265-276.

<sup>39</sup> Pahor M. Nurses in Slovenia and professionalisation: one step forward, two backward. Paper presented at the 5<sup>th</sup> conference of the European Sociological Association "Visions and Divisions: Challenges to European Sociology" at Helsinki, August 28 – September 1, 2001.

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).

In conclusion:

- 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 older population is increasing, needs for palliative care will become larger<sup>40, 41</sup>;
- 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;

Now is the appropriate moment for the introduction of a model of organized palliative care into the health system. Recently, health care reform is taking place in Slovenia and an understanding in the health administration about the needs of society for organized palliative care is present.

#### **4. 2. 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;

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<sup>40</sup> Zdravstveni statistični letopis 1995-2002, Inštitut za varovanje zdravja R Slovenije.

<sup>41</sup> Statistični urad Republike Slovenije. <http://www.sigov.si/zrs/slo>

5. to introduce efficient clinical and managerial solutions to ensure better health outcomes and patient satisfaction;
6. to bring better understanding that every clinical decision is also a financial decision and therefore responsibility in the clinical management should be introduced;

**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;
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<sup>42</sup> 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.

### **4. 3. 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 ([www.kcl.ac.uk/palliative](http://www.kcl.ac.uk/palliative)). It has three components:

- epidemiology
- comparison with services available
- effectiveness and cost-effectiveness / national and local

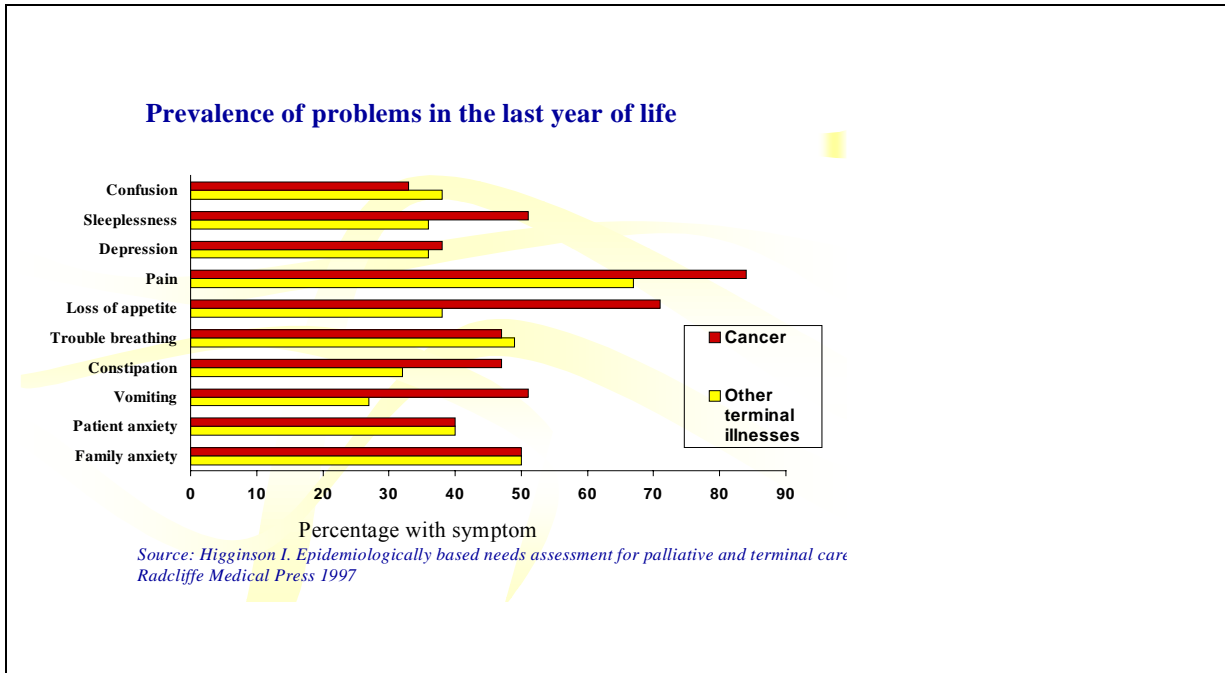
#### *Epidemiology*

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 (Fig. 8). 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.

Fig. 8

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<sup>42</sup> Gomez-Batiste X et al. Catalonia's five-year plan: preliminary results. Eur J Palliat Care 1994;1:98-101.



There are roughly 20,000 deaths a year in Slovenia and 25% are caused by cancer. From the Fig. 8 data we can estimate the most frequent symptoms in the last year of life based on the work of Higginson<sup>43</sup> (Fig. 9):

Fig. 9: Epidemiological estimation of symptoms in the last year of life in Slovenia

<u>Symptom</u>	<u>Pts. with cancer</u>	<u>Pts. with other terminal illnesses</u>
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	6 000
Family anxiety	2 500	7 500

In this estimation we must be aware of the fact that patients often have many concurrent symptoms at the last days of life.

#### *Comparison with services available*

##### Primary health care

Based on epidemiologic estimates, an “average” general practitioner practice of 2 500 patients will have 24 deaths per year or 2 per month of whom 20 would have a period of progressive illness.

All patients in Slovenia have to have a general practitioner. When a person has a life-threatening disease and wants to be at home during the end of life, that person will have access to some home care nursing. There are limitations, because the health care system cannot provide round-the-clock care at home. Patients who are severely ill have to rely on family members for care in order to stay at home. Family members can be paid their part time salary for two weeks in order to take care of a dying father, mother, husband or wife.

Even if we know, that more than half of deaths occur in hospitals, the mean stay in hospital is short. General practitioners care for even more terminally ill patients on their way through progressive illness who are frequently hospitalized only for short periods of time, and spend most of the time at home.

##### Hospitals

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<sup>43</sup> Higginson I. *Epidemiologically based need assessment for palliative care and terminal care*. Radcliffe Medical Press, 1997.

A hospital serving an area of 25 000 would have 560 deaths each year, 1230 from circulatory diseases, 300 from respiratory diseases, 60 from other diseases, where patients and carers would benefit from palliative care.

Hospitals in Slovenia have 47% of all deaths.

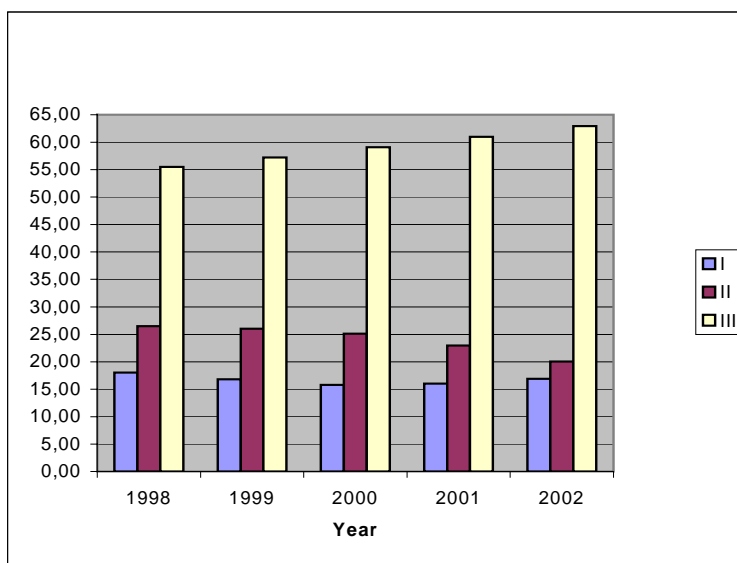
### Nursing homes

In Slovenia nursing homes are governed by Ministry of Social Affairs. Only small proportion of nursing services in each nursing home is governed by the Ministry of Health. Medical care is most often provided by the regular visits of family physicians from the regional primary health setting. It seems that the highest category of nursing includes palliative care services, but no direct measures of quality of care are available (Fig. 10).

Fig. 11

Nursing home residents' categories of nursing (from I to III)

Source: Skupnost socialnih zavodov R Slovenije



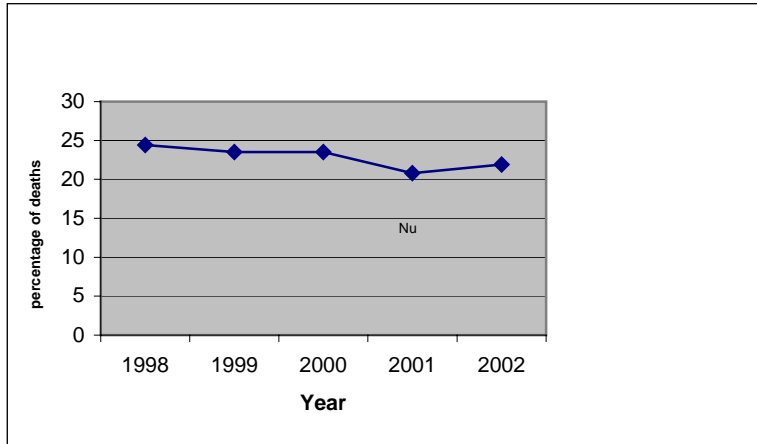
In the global view, nursing homes have a long history of attracting vigorous criticism of the quality of care they provide<sup>44</sup>. There are no direct data available in Slovene nursing homes about quality of palliative care. Report on staff shortages, coupled with widely reported nursing home incident in October 2003 in a resident home Crni les (inappropriate measures of nursing for several residents), provide some strong evidence that organizational and educational development in nursing homes for palliative care would be needed.

<sup>44</sup> Wayne R. Improving quality of long-term care. Medical care 2000;38:1151-3.

Fig. 11

Percentage of deaths in nursing homes from all residents

Source: Skupnost socialnih zavodov R Slovenije



In planning it is therefore important to emphasize the importance of connecting or linking palliative care in primary care with specialist palliative care in hospitals.

## 5. Evidence of effectiveness of palliative care

### 5. 1. Common protocol

The importance of the quality of clinical care is emphasized lately in new plans of health systems. The objective of clinical governance is to ensure that the patient receives the best quality of care throughout their journey and to learn from patient experiences in order to provide services that better meet patient need. Clinical pathways (CP) are a tool that can help to meet the requirements of the clinical governance agenda, providing demonstrable standards and outcomes of care for patients. CP is defined as “systematically developed statements to assist both practitioner and patient decisions about appropriate care for specific clinical circumstances<sup>45</sup> .

The development of clinical guidelines has been driven by concerns over the rapid escalation of care costs and quality of care. Many attempts and a lot of energy have been put into all

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<sup>45</sup> Field M, Lohr K. *Clinical practice guidelines*. Washington, DC, Institute of Medicine, 1990.

kinds of different guidelines for better quality of clinical practice but have been only moderately successful or not at all.

The Liverpool Clinical Pathway (LCP) is currently incorporated in the Cancer Collaborative project in the Merseyside and North Cheshire Cancer Network. Outside England it is being implemented in different hospitals and home care system in Netherlands, New Zealand and recently also in Sweden.

LCP -

- offers clear criteria when palliative care for the patient can start and end (identification of patients for palliative care)
- brings better outcomes and satisfaction for the patients,
- improves teamwork,
- improves communication between clinicians and patients/their relatives,
- educates clinicians and prevent omissions or duplication of services
- implements evidence based knowledge (or standards) into practice
- keeps patients and their families informed
- offers the same level of standard for the same type of services in all settings
- offers better education opportunity
- improves communication among different professions and among different settings
- offers easily comparable outcomes and quality measures
- supports effective planning

## **5. 2. Classifying of palliative care – some options**

Some consideration should be given in determining the potential basis for the classification of palliative care in the immediate future in Slovenia<sup>46</sup>:

- The diagnosis related groups (DRG) classification is now being used in Slovenia for acute inpatient care. It defines about 665 types of complete inpatient episodes – that is, it classifies on a per case basis. Its main weakness is that it was not designed to categorize palliative care:

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<sup>46</sup>Hindle D. A background paper: Classifying and paying for palliative care. An occasional paper, Ministry of Health of Slovenia, 2003.

it relies heavily on diagnosis and surgical procedures, and neither of these variables is a good discriminator of palliative care needs or care processes.

- Resource Utilization Groups (RUG) were designed mainly to categorize inpatient days in specialized nursing and intermediate care facilities in the United States. The main variables are level of dependence for activities of daily living, broad categories of medical and nursing care, and the level of provision of general kinds of therapy. Several versions have evolved: RUG-3, and splits on activity of daily living (ADL) from 4-18, and RUG-3 ADL index. In summary RUG -3 is more relevant to palliative care than the DRG classification, but it is unable to effectively describe or capture the specific care needs of palliative care patients, except in terms of activities of daily living.
- The most widely used classification in Australia is called Sub-acute and non-acute inpatient (SNAP) classification, which is designed to categorize days of inpatient care rather than complete inpatient episodes. It took account of work in developing the DRG and RUG-3 classifications, and then extended the basic ideas specifically to palliative care.
- In Catalonia a new classification system is being developed in connection with national standards of practice and the specific organization of non-acute inpatient and mobile outpatient services in palliative care<sup>47</sup>.

It is probably that the potential for a solid basis for further developments in Slovenia with SNAP classification from Australia and the experiences from Catalonia will occur.

The collection of data for classifying purposes can also be an efficient information for clinical management and planning and for measuring health outcomes.

### **5. 3. What are the specific challenges of implementing the clinical pathway?**

There are many challenges in the process of implementing the clinical pathway. The most difficult dilemma for clinicians and nurses is to diagnose dying or when to start using the CP. This is particularly difficult when a patient is acutely ill, or when the disease trajectory may be

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<sup>47</sup> Gomez-Batiste X, Porta J. Tuca A, et al. Spain: The WHO demonstration project of palliative care implementation in Catalonia: Results at 10 Years (1991-2001). *J Pain Symptom Manage* 2002;24(2):239-244.

unpredictable, or in a post-operative state. It is also a very unrealistic to expect to achieve a fixed number of patients in the CP in a short period of time. We have learned that there can be valid reasons why CP was not used in many patients: in the case of sudden death, a cardiac arrest, or in case where it was hard to diagnose dying. Sometimes it was simply that a member of the staff in charge, or on duty over the weekend was not familiar with the CP tool.

Diagnosing dying (the last hours or days of life) is often a very complex process. In cancer patients, the following signs<sup>48</sup> are often associated with the dying phase:

- The patient becomes bed bound
- The patient is semicomatose
- The patient is able to take only sips of fluid
- The patient is no longer able to take oral drugs

This predictability of the dying phase is not always as clear in other chronic incurable diseases.

We did not realize how costly and time consuming this project would be. A careful, sensitive evaluation of every new patient was needed as well as personal training and involvement with the coaching staff on how to use the tool. Most of the time staff found it very difficult to accept the idea that the CP could replace all other forms of documentation, so they decided to complete both. This meant a lot of additional work for staff and negative attitudes were encountered occasionally.

## **6. Discussion**

Palliative care is an important public health issue. The goal of palliative care is the improvement of the quality of care for patients with advanced non-curable disease and support of their families. Public health aims include coverage, equity, quality, comparability, and the introduction of changes into the organization of health care services. Translating scientific evidence into policy and action is a complex process.

Standards in palliative care are the priority in palliative care development and a precondition for identifying best practice. With the quality indicators from the standards two main purposes will be met: quality improvement (internal use for monitoring or continuous quality improvement)

and accountability (external use by regulators, health care purchasers, or consumers). For example for quality indicators of pain, there is a standard that requires all national health institutions to demonstrate that they adequately monitor and manage the pain of patients. Similar indicators should be developed for other common physical, emotional, psychological and spiritual problems. An important aspect of demonstration and validation is monitoring for potential unintended consequences (e.g. patients are sedated contrary to their preferences) to improve accountability statistics.

To apply standards into practice the clinical pathway is the best tool to change practice for better meeting the needs of the dying and their families. The process of implementing, the CP requires education, team work and awareness or even change of attitude toward dying.

Palliative care reform expert Joanne Lynn<sup>49</sup> suggests that the reform in palliative care require changes in regulation, payment, education, and standards of care at all levels of the health care system. Especially in the early days of palliative care development within a country, clear professional leadership is crucial. In most cases the synergistic combination of well-trained, strongly committed and respected professional is a key factor and determinant of success. The involvement of individuals with clinical, educational, planning and managerial abilities is vital. Political will and leadership is critically important.

## **7. Possible strategies for palliative care in Slovenia**

### **Option # 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.

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<sup>48</sup> Ellershaw J, Wilkinson S. *Care of the dying. A pathway to excellence*. Oxford University Press, 2003.

<sup>49</sup> Lynn J. Learning to care for people with chronic illness facing the end of life. *JAMA* 2000;284:14.

It would also be possible to expect similar events of misuse and exploitation of the circumstances like the events in Hotel Crni 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.

### **Option # 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.

### **Option # 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.

## **8. Recommendations**

Government agencies urgently need to encourage the implementation of palliative care with funding, and evidence-based regulation incentives. We propose a step-by-step approach for the future policy strategy for palliative care across all settings:

Short term strategies:

### **Building services**



- Create network of palliative care teams in hospitals, rather than individual services isolated from the beginning in special units. For units from the beginning on it is more difficult to integrate palliative care into overall care of the patients
- Create primary care palliative care consult teams for every corresponding hospital and for several nursing homes in the smaller region.
- Create in patient palliative care units of palliative care in large hospitals with palliative care specialist teams who also serve a consulting role for the whole hospital and for primary care in the smaller region.

### **Agreed definitions and standard sets**

- The most important task is to clarify what constitutes good clinical practice Definitions and standard sets together with clinical protocols (clinical pathway) should be developed with palliative care providers, insurers and representatives from the public. Standard sets include standards on care services and a decision about standard costs for a few most typical clinical protocols. This procedure also includes extensive training of health care professionals in the process of implementation of clinical protocols. But whatever happens it will not be successful unless the appropriate infrastructure is established.
- Agreement on data collection for palliative care. Only monitoring of processes can offer qualitative and financial evaluation and further development. The most needed data upon admission among demographic variables and main diagnosis at admission severity score (there are several instruments in the use), major symptoms requiring attention, source for referral to palliative care team (acute care hospital, nursing hospital unit, home, nursing home), phase of care. At discharge needed data include cause of death or, if not death, destination after discharge, major symptoms requiring attention and phase of care. Possible lower priority data elements would be cohabitants at admission, cohabitants at discharge, carers at admission, and predictors of bereavement difficulties.

#### Long term strategy

- Elementary changes according to evaluation results

- Designing of an appropriate payment model, which reflects and encourages good clinical practice at the same time.

For the systematic changes, systematic procedures and projects are proposed. Influential leadership of committed experts on the national level in the process of organized implementation and co-ordination together with evaluation seems to be of paramount importance.

## ***9. Appendix***

### ***Appendix 1: Korea declaration***