



CENTRAL EUROPEAN UNIVERSITY
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Organizing Palliative Care in Slovene Health Care System

2004 / 2005

CPS INTERNATIONAL POLICY FELLOWSHIP PROGRAM ▲

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Abstract

This policy paper compares the current status of palliative care in the Slovene Health Care System with two EU countries, the United Kingdom and Spain. The paper offers a critical assessment of the requirements for such a system, the alternatives approaches to providing specific services, the relationship to general services and the types of education and training that are needed. A discussion of the development of quality standards, guidelines and clinical pathways follows and then some implications with regard to the financing of palliative care are considered. The paper argues that all these consideration are necessary in order to make sound policy recommendations for the Ministry of Health and to support the provision of a practical and well-organized system of palliative care.

This policy paper was produced under the 2004-05 International Policy Fellowship program. Urska Lunder was a member of the Public Health studies team, under the leadership of Dr. Kathleen M. Foley. More details about the work carried out for this project can be found at <http://www.policy.hu/lunder/>

The views contained inside remain solely those of the author, who may be contacted at lunder@policy.hu

July 2006

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Contents

Executive summary	4
1 Introduction	5
1.1 <i>Palliative Care Definitions</i>	6
1.2 <i>What is a 'good death'?</i>	8
2 A gap between evidence and reality at the patient's bedside	10
3 Why is palliative care a public health priority?	11
3.1 <i>The status of palliative care in Europe and other countries</i>	16
3.1.1 <i>Hospice and palliative care in the United Kingdom</i>	17
3.1.2 <i>Palliative Care in Catalonia, Spain</i>	19
4 The status of palliative care in Slovenia	22
4.1 <i>Reasons for the slow implementation of nationally-organized palliative care</i> ..	26
4.2 <i>Main issues and obstacles as regards strategies for the implementation of palliative care into the National Health System</i>	27
4.3 <i>An assessment of needs</i>	29
4.3.1 <i>Epidemiology</i>	29
4.3.2 <i>A comparison with services available</i>	30
5 Evidence of the effectiveness of palliative care	32
5.1 <i>Common protocol</i>	32
5.2 <i>A classifying of palliative care – some options</i>	33
5.3 <i>What are the specific challenges involved in implementing the clinical pathway?</i>	34
6 Discussion	35
7 Possible strategies for palliative care in Slovenia.....	36
7.1 <i>Option #1</i>	36
7.2 <i>Option #2</i>	37
7.3 <i>Option #3</i>	37
8 Recommendations.....	37
8.1 <i>Short-term strategies</i>	37
8.1.1 <i>Building services</i>	37
8.1.2 <i>Agreed definitions and standard sets</i>	38
8.2 <i>Long-term strategy</i>	38
References	39

Executive summary

Palliative care is an important public health issue. It concerns itself with suffering, dignity, care needs, and the quality of life for people at the end of their lives. It takes on board caring for and support given to involved people's families and friends. Palliative care has been a neglected topic in Slovenia: for indirect indicators of the status of palliative care, like opioid consumption, palliative care in education, epidemiological observations and lists of existing palliative care services indicate insufficient development of palliative care in Slovenia in comparison to the case of many other countries in Europe.

The most important principles are to see palliative care as a right for every person who needs it – and palliative care services as a generally available service that is integrated into the mainstream of the National Health system, with a focus on community- and home-care, underpinned with specialist care in health care institutions (i.e. 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 that will cover the entire population (both cancer and non-cancer patients) and also comprehensive geographic coverage; there should additionally be accessibility for all persons, equity, quality (effectiveness, efficiency), and systems for monitoring outcomes.

There are many forms of intervention that could be used to improve palliative care in the area of public health. There should be a specific strategy on a 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 a 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, so as to promote maximum integration. Social and political impetus is also required, which will entail changes in attitudes and widespread education of the public and of all professionals dealing with persons who have life-threatening illnesses.

This policy paper is a study of the current status of palliative care in the Slovene Health Care System and in two EU countries (United Kingdom and Catalonia,

Spain) – and it also makes an assessment of requirements, alternatives to the implementation of specific services, of measures resorted to within the context of general services; also, education and training. There is a discussion on the way of development of quality standards, guidelines and clinical pathways; and there are then some implications laid down with regard to financing. These are necessary elements if one wishes to make policy recommendations for the Ministry of Health – and provide a practical, organized palliative care model for use in all settings.

1 Introduction

Up until the last few decades, most people died quickly, owing to an infection or injury, or soon after initial symptoms had shown themselves as being advanced and untreatable (as with cancer, diabetes, or heart disease). Modern living conditions and advances in health care have ensured that most persons will now die more slowly, however – and mostly in old age (Lynn, 2000: 284). 75% of people will experience cancer, a stroke, heart disease, an obstructive lung disease, or dementia during their last year of life (Zdravstveni..., 1998–2002); and while medical advances have transformed many illnesses that once proved rapid and fatal into (merely) chronic conditions, it has been much more difficult to improve the quality of the resultant longer life (Meier, 2004: 296–7).

The modern hospice movement was established in response to the poor quality of care for dying patients within health systems (Clark, 2002: 905–7). The hospice model of care is now espoused as a model of excellence – and it has led to a worldwide movement aspiring to deliver high quality palliative care to dying persons in health systems. The aim of the introduction of palliative care services into a health care system is to improve the quality of care given to patients with advanced and non-curable diseases/illnesses. Palliative care services directly influence patient care and also play an advisory and educational role, which will be able to influence the quality of care in the community and in hospitals.

It is society's responsibility – via government, health care planners, professional organizations and the health professions – to provide resources ensuring a system of intensive care for dying patients and their families. This will necessitate the development of a field of palliative care making sure 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 their lives.

Public health aims and objectives would include coverage, equity, quality, comparability – and the introduction of changes into the organization of a country’s health care services.

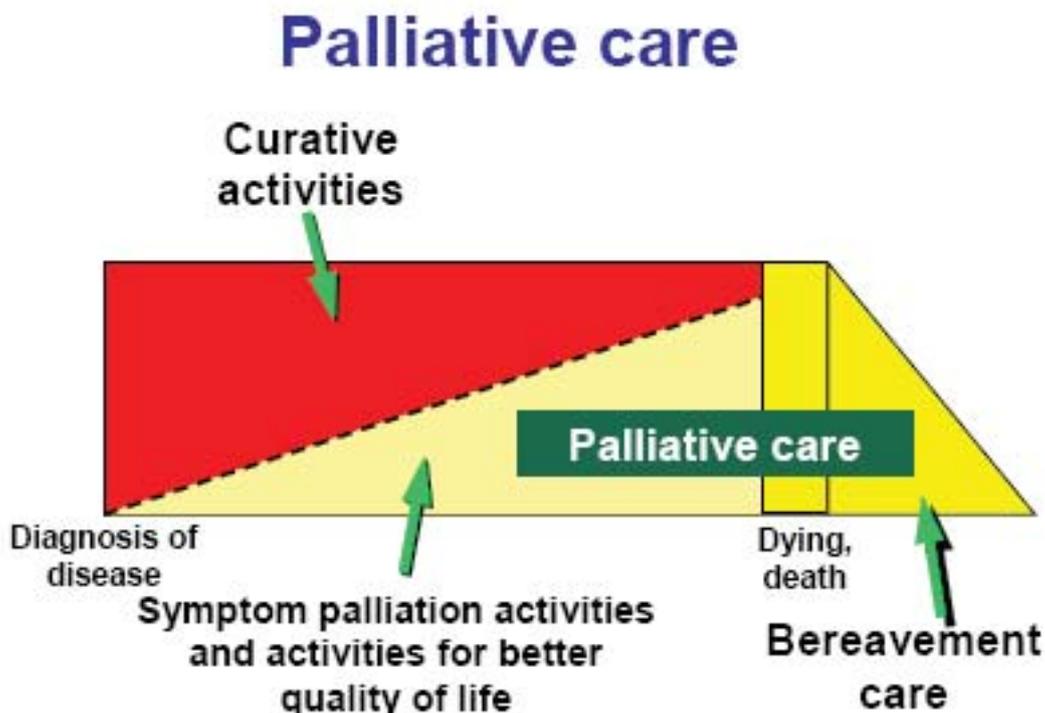
This paper suggests ways via which one might bring forward new opportunities to improve the delivery of palliative care; it additionally takes a look at such initiatives and accomplishments made so far; challenges as regards developing and implementing a national strategy dealing with palliative/end-of life care; and, finally, future directions for such collaborative initiatives.

1.1 Palliative Care Definitions

The European Association for Palliative Care defines palliative care as (European Association for Palliative Care, 2003):

Palliative medicine is the appropriate medical care of patients with advanced and progressive diseases for whom the focus of care is the quality of life and in whom the prognosis is limited (though it may sometimes be several years). Palliative medicine also 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 clinical status. The core issue with palliative care is well understood – yet because of the complexities of palliative care there are various definitions that are used, around the world.

The World Health Organization's definition of palliative care (Sepulveda et al., 1992: 91–6) recommends:

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

Palliative care (World Health Organization, 2002):

- provides relief from pain and other distressing symptoms,
- affirms life, and regards dying as a normal process,
- intends neither to hasten nor postpone death,
- integrates both the psychological and spiritual aspects of patients' care,
- offers a support system to help patients live as actively as possible until the time of 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 counselling, if required,
- will enhance the quality of life, and may also positively influence the course of an illness,
- is applicable early in the course of an illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy; and includes investigations needed to better understand and manage distressing clinical complications that may arise.

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

- Care is holistic, multidisciplinary and client-centred;
- Care includes medical, nursing, and other connected 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 type of care and where such care should be delivered;
- Service delivery will be standardized between locations where care is to be delivered, whether that be in the community or in a health care institution.

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

In general, palliative care is best given if it is in close proximity to the person's home and community.

People involved in palliative care – coming together to become a sort of team – 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 in-patient palliative care settings, as well as independent nurse practitioners
- allied health professionals, including social workers, physiotherapists, occupational therapists, psychologists, pharmacists, dieticians and speech therapists
- volunteers
- support workers, including nurse assistants, personal care attendants
- bereavement counsellors
- spiritual carers with a range of pastoral, spiritual and cultural backgrounds.

Administrators and business managers will also be able to give essential support to such teams.

Furthermore, families will be able to get care from the palliative care team, and will also be crucial members of the team. In particular, when a person is being cared for at home, the family will usually be dealing with a bigger proportion of hands-on caring.

1.2 What is a 'good death'?

No one can answer this question with confidence. We have reliable and detailed statistics concerning life expectancy, age at death, and place and cause of death – yet we know little about the actual *experience* of death. We do not have data on how many died in pain, anxiety, were disturbed by other symptoms, 'hooked up' to a life support machine they didn't want, or who were alone. Although the oldest health statistics are based on death certificates, one of the weakest areas providing health information is that pertaining to how we die (Singer and Wolfson, 2003: 173–4). In the absence of systematic information and monitoring of end-of-life care and, also, comparisons that can be made across health regions (or health care organizations) there is no opportunity to

learn what may be possible (e.g. regions with the highest ratings) or to track whether improvements might be occurring. For the minority of persons who die under the care of a palliative care team, such an experience is probably beneficial and has its rewards, though there is a suspicion that, for the majority – those who die in an acute hospital or nursing home, or in their own home – the experience may be bad.

A 'good death' is clearly more than just being free of pain; and three issues emerged repeatedly – control, autonomy, and independence. The authors of the final report on The Future of the Health and Care of Older People have identified 12 core principles pertaining to a 'good death' (Age Health and Care Study Group, 1999):

Core Principles of a Good Death:

- to know when death is coming, and to understand what can be expected
- to be able to retain control of what happens
- to be given dignity and privacy
- to have control over pain relief and other symptom controls
- to have choice and control over where death occurs (at home or elsewhere)
- to have access to information and expertise of whatever kind is necessary
- to have access to any spiritual and/or emotional support required
- to have access to hospice care in any location, not only in hospital
- to have control over who is present and who will share one's demise
- to be able to issue advance directives which will ensure that wishes are respected
- to have time to say 'goodbye' to persons, and also control other aspects of timing
- to be able to 'leave' when it is time to go, and not to have life prolonged pointlessly.

Provision of good death is an important objective for health services and for us all (Smith, 2000: 129–30); and such core principles of the good death should be incorporated into the plans of individuals, professional codes, and should be among the aims of institutions and of the entire Health Service.

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

Advances made with regard to diagnoses and therapeutics have redefined the area of palliative care in the last few decades. But why is there a gap between evidence-based palliative care, or knowledge acquired during training – and the reality at a patient's bedside? And why are things so difficult and frustrating for those seeking to improve the quality of end-of-life care (Teno et al., 2001: 713–6)?

If we look at pain relief – i.e. where the majority of advances have been made in research – studies consistently demonstrate to us 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 (Lynn et al., 1997: 96–106; Addington-Hall and McCarthy, 1995: 295–305; Gagliese and Melzack, 1997: 3–14; Teno et al., 1997: 508–12; De Witt et al., 1999: 333–50).

There is much evidence, too, that people do not die in the place they wish, or with the peace they desire. In addition, too many die alone, in pain, afraid/terrified, mentally unaware of issues or what is going on, without dignity, and feeling alienated. Modern dying involves a struggle for control: some doctors have a sense of failure, seeing that they cannot keep somebody alive. Patients with life-threatening diseases, especially cancer, are often subjected to aggressive attempts to cure them – even when such efforts are likely to be futile (Seely and Mount, 1999: 1120–2). Singer et al recently showed that fear linked with the unwanted application of technology to prolong life was the most prevalent concern voiced by patients on dialysis, with AIDS, or when receiving long-term care (Singer et al., 1999: 163–8). All too frequently, patient care was portrayed as a war to be won or lost; and on such a battlefield, patients in the process of dying can only be seen as ultimate losers. The issue is therefore *not whether*, but *how*, to apply a palliative care that can include modern technology along with more 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 (McCue, 1995: 1039–43; SUPPORT Principal Investigators, 1995: 1591–8). Although the barriers to achieving a peaceful death are many, they can be grouped into three broad categories (Meier et al., 1997: 225–30):

- 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.

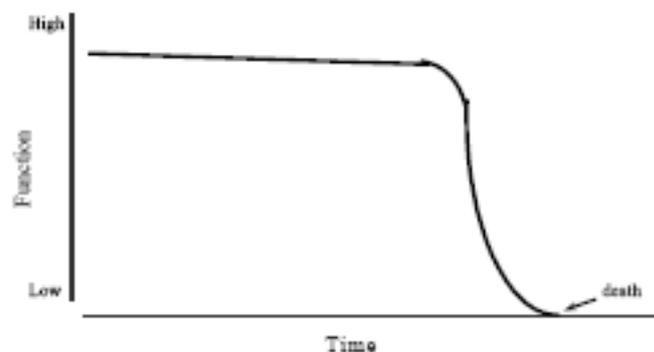
3 Why is palliative care a public health priority?

The impact of death on one's society is easily underestimated. Palliative care is delivered to patients with progressive illnesses, where the prognosis of dying is less than one year, and also to all chronically ill patients with proponent 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 (Davis and Higginson, 2004). Examples of the trajectory of cancer, heart failure and dementia illustrate this point (Lynn and Adamson, 2003).

Cancer

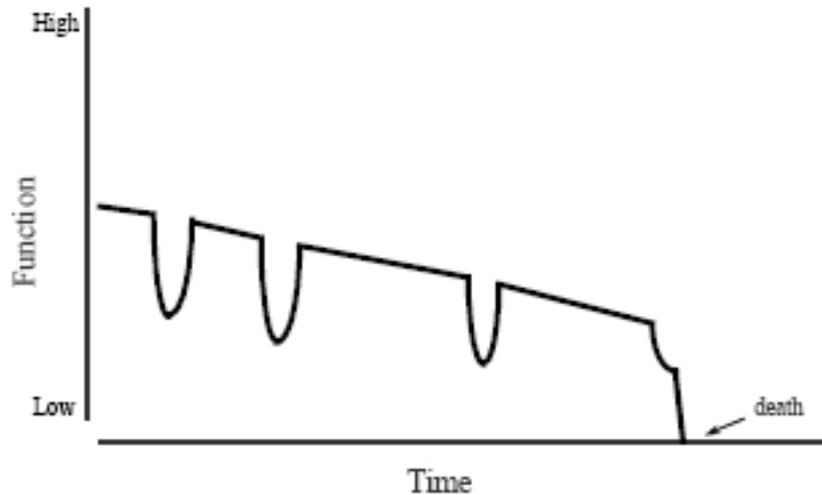
Depending on the site of the body affected there are many cancers, where the prognosis for any individual will depend on the extent of the growth at presentation and the response of the tumor to treatment, which may include surgery, radiotherapy and/or chemotherapy. Patients are not usually severely restricted in their activities until the final stages of the illness, that is, when there is no further response to treatment (Figure 1).

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



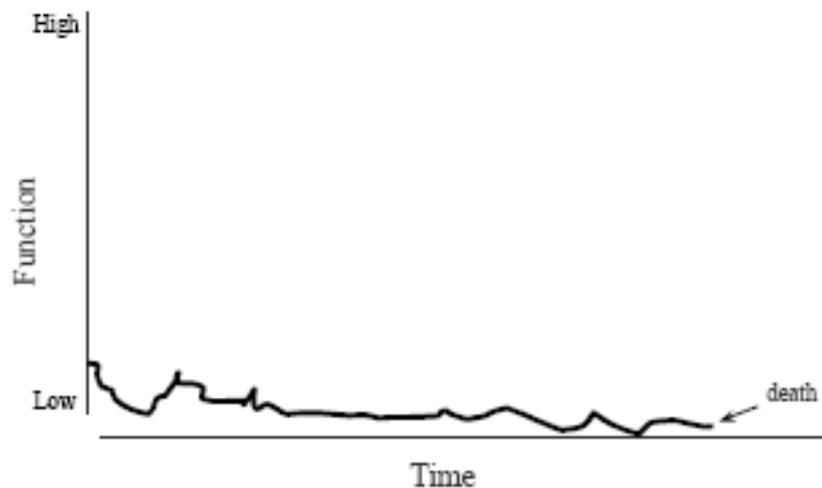
Heart failure

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



Dementia

Figure 3 Model of an illness trajectory for dementia or frailty



The quality of care at the end of someone’s 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 in this regard. And if each death affects five other people in terms of providing informal care along with grieving relatives and friends (Singer and Bowman, 2002: 1291–2), the number of people affected each year in Slovenia is about 100 000 people – or 5% of the population.

Palliative care can prevent needless suffering, and could have the potential to prevent morbidity for the bereaved. It provides patient-centred care, and it incorporates self-management programs. In the process of organized palliative care peer education and changes in clinical behaviour may be stimulated. In the majority of Western countries more than 50% of persons die in hospitals or other institution (Heyland et al., 2000: 10–6), and this is further proof that palliative care is a public health matter.

By recognizing that palliative care is a public health issue, rational planning, implementation and evaluation become priorities, and this requires 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 also so as to finance it as a part of the overall health care system (Council of Europe, 2002). 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:

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

- Key recommendation 1: Adopt policies, legislative and other, necessary for a coherent and comprehensive national policy framework dealing with palliative care.
- Key recommendation 2: Moving to this end, whenever feasible, measures given in the appendix to the recommendation, taking account of respective national circumstances.
- Key recommendation 3: Promoting international networking between organizations, research institutions and other agencies that are active in the field of palliative care.
- Key recommendation 4: Supporting an active, targeted dissemination of these recommendations, with an explanatory memorandum.
- In the appendices guiding principles, settings and services, policies with organization and quality improvement goals using research are to be 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.

The World Health Organization (WHO) Cancer Unit supports the development of palliative care services as basic elements of any national or regional comprehensive cancer program. In 2004, the World Health Organization 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 dealing with the concept of palliative care.

WHO policy implications¹

- 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 within end-of-life care are identified in relation to all common diseases, including cancer, ischaemic heart and cerebrovascular disease, chronic obstructive respiratory disease, end-stage liver and kidney diseases, 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 in helping to care for a patient and in coping with the loss such illness brings them
- Public health policy must acknowledge people’s rights to high quality care at the end of life, and help them make decisions about their form of 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 in all settings, especially in the areas of pain control and communication
- Palliative care services must be co-ordinated to work across different settings – of home, hospital, an in-patient hospice and other institution(s)
- 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 with regard to palliative care
- Health care organisations need to invest in locally-based systems to identify the most vulnerable groups and for monitoring and improving the quality of services they provide for people
- Policy makers need to promote the dissemination of good practices with regard to reaching vulnerable groups
- Policy makers and decision-makers should ‘reward’ health care organisations that engage in auditing and quality improvement schemes in the area of palliative care
- Policy makers should encourage the dissemination of examples of good practice – and constantly review the success of these methods in palliative care

¹ Publication requests on e-mail address: publicationrequests@euro.who.it

- Health care organisations need to develop and maintain cultures that enable health professionals to work well in teams so as to identify areas of end-of-life care that might be developed or improved upon
- Demonstrations of innovative approaches and evaluations of their merit in the area of 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 should include a public education component 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 to take in all illnesses/diseases
- Policy makers should invest in developing national datasets dealing with palliative care.

The European Federation of Older Persons (EURAG) published “Making Palliative Care a Priority Topic on the European Health Agenda”, a Promotion Campaign at an EU Level, in January 2004 (www.eurag-europe.org/EURAG_PalliativecareProject_2004.pdf).

- EURAG proposes to make palliative care a priority topic on the European Health Agenda, which would be best achieved by a decision made by 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 that adherence be made to other recent recommendations/summaries delivered by the Council of Europe’s Committee of ministers to member states on the organizing of palliative care.

National Hospice and Palliative Associations on the 2nd Global Summit, from March 2005, prepared the Korea Declaration on Hospice and Palliative Care, with clear agreement on the different activities within the realm of palliative care that national governments should be carrying out.

Effective measures in all relevant political fields in the national health care system will need to be supported to raise awareness about the needs of the terminally ill and persons’ knowledge with regard to solutions. The main factors involved in achieving such political commitment are as follows (Gomez-Batiste et al., 1999):

- Identification of the importance of clinical improvements related to widespread and common problems within the health care system; dealing with pain would be the most prominent example.
- Attaining high levels of satisfaction on the part of patients and families.
- This would have a major impact at a managerial level. In a situation 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 a moderate cost

along with great user satisfaction would give important recognition and acknowledgement to policymakers.

- Highlighting the efficiency and cost-effectiveness of palliative care via a strategic approach. The Catalonian model shows a reduction in the use of emergency rooms, lengths of stay and an increased prevalence of home deaths, together with a reduction in in-patient care.
- New values would be added to the health care system, accompanied by wide recognition and improved work satisfaction on the part of professionals – for example, the effect of new professional roles associated with multidisciplinary teams, the perceived value of a comprehensive approach, or a burnout reduction.
- A high level of social and cultural regard. This is to be associated with a clear improvement in the quality of care, with broader discussions on ethical issues, and 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 an individual's fears of suffering, pain, isolation, and death within society).

As Gomez-Batiste et al. (1999) – who integrated palliative care into the Catalonian health system – has observed, to obtain a political commitment to palliative care there is often a lack of consensus between individual health care units, for example, oncology versus primary care versus a pain clinic. There has also been a lack of a public health approach and adequate training. The authors suggest that all such issues need to be addressed if coherent plans and broad agreement are to be gained.

3.1 The status of palliative care in Europe and 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 itself to facing different challenges. Cultures, economic, social and historical conditions vary across Europe, though 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 main disciplines involved in palliative care.

In the following sections one can read two brief presentations dealing with national palliative care in the United Kingdom and in Catalonia, Spain, which will illustrate palliative care developments in their diversity.

3.1.1 Hospice and palliative care in the United Kingdom

The modern hospice approach was developed in the United Kingdom in the late sixties – as a new type of service, being an in-patient unit initially based within an independent facility, and called a ‘hospice’; it also provided a home care service, and operated as a non-governmental, charitable organization. The early hospice movement was very strongly connected with the community it served. It brought with it a new philosophy, one with values that directly addressed patients and family needs when a person was in the last stages of a life-threatening disease.

In the United Kingdom, a place with a 52 million population, a total of 540,000 deaths occur every year. As in the majority of European countries, diseases of the circulatory system are the number one cause (42%) of death, and cancer is second (25%) (Office of National Statistics, 2002).

Since the mid-1960s the hospice movement in the United Kingdom has had a major effect on care given to dying people. A very strong and widespread hospice movement laid the foundation for the concept of hospice care, named “palliative care” – which was introduced in hospitals, too, and via home support teams in the health system, not only in the UK but also internationally (Mount, 1997). Palliative medicine was recognized as a special area by the Royal College of Physicians (London) in 1987 (Hockley, 1999).

From the National Survey 2003–2004 (National Council for Palliative Care, 2005) on hospice care (children hospices and palliative care services were not included in this report) 186 specialist units, with, all together, 2730 beds were identified; and someone’s length of stay was, at a mean average, 12.8 days. Each year, around 38,000 new patient admissions were recorded – and 27,000 deaths occurred in such units.

There were 417,064 home-care visits from 354 home care teams, mostly by community nurses (79%); and there were 427,766 phone calls (an average of 8 calls per patient). The average period of care at home lasted 111 days. Of patients cared for via a home-care service, only 28% went on to die in hospital. Altogether, 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.

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 most notable 'complaints' in over 50% of referrals – and 40% required psychological support. Social and financial problems were present in 7% of referrals. For 14% of referrals, carer support was one of the reasons for such referral.

Locations of death of patients cared for by palliative care services in the 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, taking on board a wide range of complex and often rare life-limiting illnesses, rather than for cancer. Many children's hospices are non-institutional, and they have no resident doctor. Care is family driven, with a great emphasis on "respite care". Some adult hospices admit children (with employed paediatric nurses to care for children).

From 1994-2004 a slight rise in the number of specialist units was recorded. In the United Kingdom one can probably say that a plateau has been reached for the number of specialist units operating within the existing financial model at the moment. It is estimated that coverage will be around 42% of patients who may need palliative care in any form. Palliative care services in the United Kingdom mostly cover 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; while 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, and with its enormous support from the public, decided to fund the work on a 50:50 basis. This meant that for every one 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 made

available to independent hospices. In the literature there is data available for 1993 in this regard, pointing to a figure of 43 million pounds.

Via the long tradition of hospice and palliative care service in the United Kingdom, important knowledge and research results were made available for global usage in newly evolving palliative care systems.

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

- the standard of care (in different parts of United Kingdom different standard documents have been developed)
- planning,
- equity – more than 94% of patients cared for in a palliative care service have cancer, and patients with another diagnosis do not have equal access to such palliative care,
- the majority of patients are Catholic, and there are not enough patients from other religions,
- accessibility,
- the financing regime.

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

3.1.2 Palliative Care in Catalonia, Spain

Catalonia has a total of 6,200,000 inhabitants, and has approximately 52,000 deaths per year; while there is cancer mortality rate making up 13,000 deaths per year (25%).

In 1989, the Catalonian Ministry of Health and the WHO Cancer Unit initiated formal co-operation to design and develop a WHO demonstration project on the implementation and development of palliative care in Catalonia (Gomez-Batiste et al., 1994: 45–9). 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
- a revision of processes of accreditation and standards
- a specific financial system
- legislative measures
- evaluations of results

After five years, there were 21 departments of palliative care services – with 350 palliative specialist beds and 18 palliative care teams – operating 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 of palliative

care. Geographical coverage was 80%. The use of opioids increased from 3.5 kg/million/year to 11.4 kg/mil/year (Gomez-Batiste et al., 1994: 98–101).

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

Figure 4

Year	1989	1995	2003
Palliative care units	2	21	50 (9.3 units/mil)
Palliative care beds	0	350	523 (87.2 beds/mil)
Home-care support teams	0	44	53 (8.8 teams/mil)
Opioid consumption (kg/mil)	3.5	11.4	17
% of deaths at home	31	60	61

The authors also reported a 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 see palliative care as a public health concern, with aims to cover both cancer and non-cancer patients. Combined measures included implementation of a wide range of specific services with a district-wide approach. All of these developments were possible because of extensive education and training at all levels of the health system, and strong leadership coming from experts; also, there was government support emanating from the public financing system. Via this project, community-based palliative care was emphasized; and the national health system promoted the development of non-acute hospital settings based in socio-health centres, places which have rehabilitation and long-term resources.

The results demonstrate both effectiveness in pain control and great efficiency in the provision of care, based on the dramatic change in the pattern of use of resources. Also there was:

- a reduction of the length of hospital stays,
- less frequent usage of hospital emergency facilities,

- an increase in home care,
- a high patient and family satisfaction level,
- a cost reduction;

Taking a look at the implementation process for the Catalonian project will be useful for anyone seeking newly-developed national policies.

Successful results had by Catalan-model policies are as follows:

- Achievement of very high patient coverage, 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 their life);
- With extensive training activities, good palliative care practices have been achieved – at any rate when being evaluated via indirect indicators and in evaluations of satisfaction coming from patients and their families;
- Development of non-acute settings in socio-health centres with geriatric and chronically ill patients;
- High geographical coverage;
- Morphine widely used in the late stages of life with patients receiving palliative care;
- A reduction in the length of stay in acute hospitals; and reduction in the use of emergency facilities;
- High involvement of home-care support teams;

Areas for improvement of the Catalonian model currently:

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

With these results Catalonia is presently one country in Europe with the most developed network of palliative care services, with accessibility having been achieved and coverage wide. The Catalonian model demonstrates the importance of government involvement in any strategically planned implementation of palliative care services at all levels of the health care system. Rational planning with a public health-based policy, and with the systematic implementation of specific resources and training will lead to good palliative care objectives being attained, and will improve geriatric care; also, there will be effectiveness, efficiency, and satisfaction for those involved.

4 The 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. Life expectancy at birth is 73.2 years for men and 80.7 years for women (Primic-Zakelj et al., 2001: 7). The three main causes of death in Slovenia are diseases of the circulatory system, neoplasm and diseases of the respiratory system (Moravec-Burger and Urdih-Lazar, 2003). Slovenia is a country with a medium rate of morbidity/mortality due to cancer. The leading type of cancer for the male population is lung cancer (19% of all cancer sites), and for females it is breast cancer (21%). Approximately 52% of all deaths occur in hospitals or other institution, while 48% occur at home (Figures 4 and 5). The financing of health care is based on a social security system, which practically covers the entire population.

Figure 5 Place of death in Slovenia, 2002

	Place of death	Number of deaths %
Health care institutions	10.993	52.2%
Home (or other places)	7.595	47.8%

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

Figure 6 Place of death in health care institutions, 2002

	Institution	Number of deaths %
Hospitals	7.781	41.3%
Nursing homes	3.212	17.2%

Source: Zdravstveni statistični letopis 2002, Institut za varovanje zdravja R Slovenije and Skupnost socialnih zavodov R Slovenije

The hospice movement, with a home service and education programs, began in the middle of the 1990's, in Ljubljana (the capital city of Slovenia). It is now present in seven cities in the country; in three of them – Ljubljana, Maribor and Celje – palliative care teams offer not just education to the public and volunteers (in the direction of home support for involved families) but a whole range of palliative home-care services. This includes palliative nursing care, along with social and psychological care for patients and their families, at their homes. Nurses in each hospice in Ljubljana, Maribor and Celje are paid for by National Health Insurance. A physician is not yet involved in the hospice care

on a professional basis. The hospices, together, provide home care for around 500 patients annually. They organize workshops, seminars and presentations. There are 104 volunteers working in such hospice organizations at present. New groups of volunteers are trained every year. Bereavement services are organized in all hospices, and there is also a traditional, bereaved children's group holiday every summer.

In Ljubljana there is already a house that might serve as an in-patient hospice, yet it needs to be renovated/rebuilt. When this has happened, it could start functioning in late 2006 or early in 2007. New regional, hospice organizations in different parts of Slovenia are being developed, particularly to deal with education in psycho-social topics for volunteers and the public. The hospice movement in Slovenia serves as an important model of hospice and palliative care that would need to be implemented into the National Health system.

Pain programs, as in other countries, started much earlier in most hospitals than did palliative care programs. There are out-patient pain clinics in nearly every hospital in Slovenia.

The University Clinic of Respiratory and Allergic Diseases, Golnik has established a palliative care unit within one of the hospital's long-term care departments. There is a palliative care team with a physician, four nurses, a social worker, psychologist and volunteers. There are three more acute-hospitals with established long-term care departments, and these are places where palliative care units with corresponding palliative care teams could be created.

The major institution for cancer patients, the Oncology Institute, Ljubljana, has established a consultative team to deal with palliative care.

General practitioners and community nurses are not involved in organized palliative care initiatives as yet. One 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 a primary care level needs to be closely examined.

In co-operation with a variety of health care institutions and the Palliative Care Development Institute, Ljubljana, in the last few years regular education on different topics related to palliative care has been organized and has become part of the curriculum handling family medicine, public health and oncology that the Medical Faculty of Ljubljana has on offer. 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

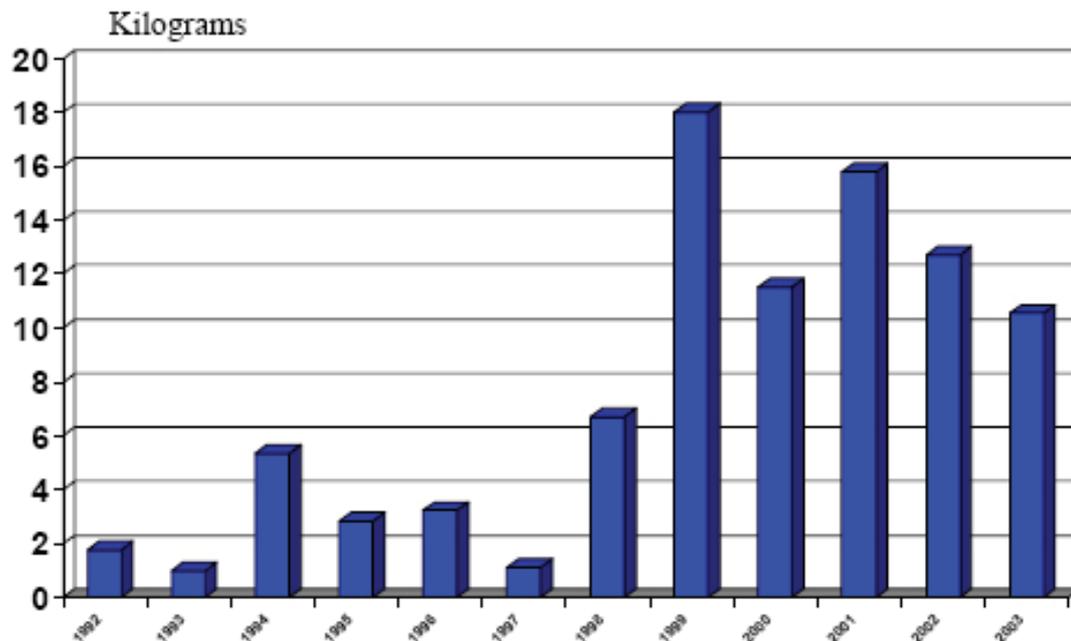
on palliative care communication have been specially developed, and health care professionals, especially physicians, are often sent to study abroad (to Salzburg, Stockholm, Manchester, Sheffield and Poznan).

The Palliative Care Development Institute was founded in 2000 as a training and resource centre, and as a place dealing with education, research and advocacy. The Institute plays a crucial role in strategic planning and policy development for palliative care on a national level. Through co-operation with the Ministry of Health, a National Strategic Plan for palliative care has been developed – and this has led to a process of wide discussion, confirmation and ratification. The National Committee for Palliative Care at the Ministry of Health is to oversee and co-ordinate 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 their life is under way, though it is still at an early stage in Slovenia.

Pain is the main symptom for patients in need of palliative care; thus, drug consumption for pain treatment is an indirect indicator of the level of development of palliative care. All essential drugs for pain relief are available in Slovenia, with a normal procedure for having them prescribed. National guidelines for pain management were published in 1999, and have now been updated. The WHO

Figure 7 Total consumption of morphine in Slovenia 1992-2003

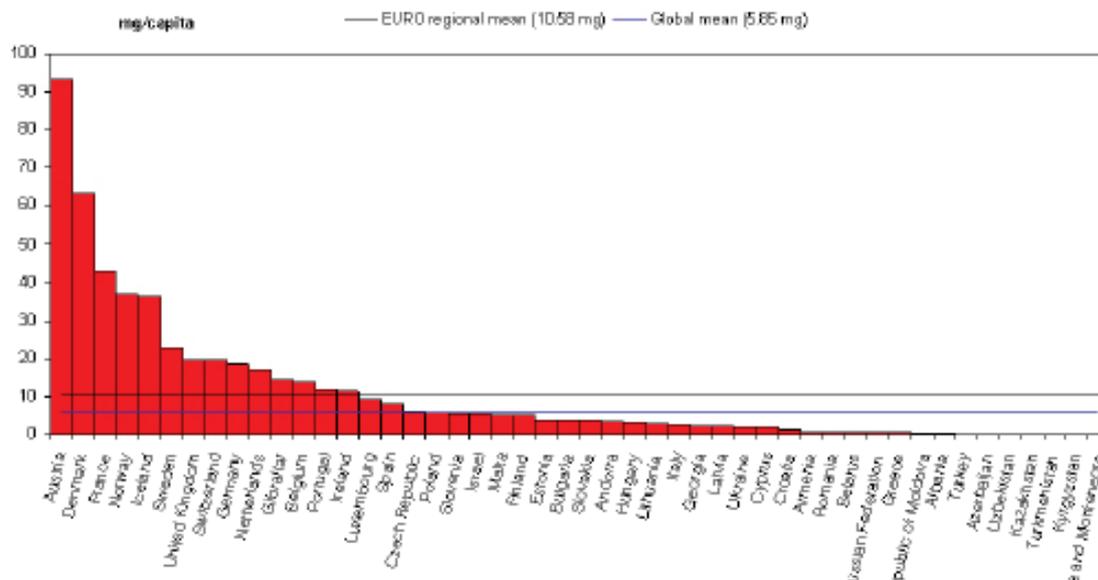


Source: International Narcotics Control Board; United Nations "Demographic Yearbook" by Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center, 2005

book on Pain and Symptom Management for Children with Cancer has been translated into Slovenian. In addition to these guidelines, there was a successful educational campaign organized to train doctors and nurses throughout the region on the basics of pain management. (Figure 7 shows total morphine consumption in Slovenia from 1992–2003.)

There was a sudden increase in opioid consumption after 1998, most probably being due to previously mentioned developments, and there are now new pain relief drugs available on the market. The decline in last three years demonstrates the need for regular and extensive postgraduate education so that relevant persons can handle pain management. As compared to the rest of Europe, morphine consumption in Slovenia is at the global mean level, though it was under the average European mean level in 2003 (Figure 8).

Figure 8 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 for Cancer, Ljubljana (Bernot, M et al., 2005) – made a retrospective analysis of the quality of care had by 145 patients in 2002 for the last 6 months of these persons’ lives. Results suggested that documentation among health care professionals is incomplete and co-ordination is often inappropriate. 75% of patients received opioids, with successful treatment aiming at a goal with mean VAS 3 in 47% of cases. The major weak points in patient care at the Oncology

Institute (as compared to what might be seen in the literature) were higher rates of prescriptions for antibiotics, transfusions, and parenteral hydration in people's last few days; there was also a lack of evaluation of commonplace complaints/symptoms arising within palliative care – except for evaluations of actual pain (e.g. breathlessness, nausea, vomiting, tiredness...). No patients received chemotherapy, albumin or vaso-active support in the last days of their life. In such documentation less data is available dealing with other symptoms – and there is, especially, little mention of psycho-social problems being experienced by patients or their families. No other symptoms, except for that of pain, were evaluated on a scale – so it was thereby impossible to evaluate the effects of treatment (as documented). From this study, it is therefore more than obvious how urgent it is to put palliative care standards in place. Extensive professional training, a better documentation system and co-ordination of/ among all professionals in the health system is urgently needed.

Slovenia is one of the few countries with a relatively low HIV infection rate. The total number of deaths from HIV/AIDS in the period from January 1, 1989 to June 30, 2005 was 75. In Slovenia there are 173 people who are listed as being infected with HIV, from among whom 43 have developed AIDS. The highest incidence of newly-recognized HIV infections was 12.5/mil persons, in 2004. The most affected group are homosexual men. Prevention measures for i.v. drug users have been quite successful, primarily owing to a variety of activities organized by different non-governmental organizations. A decrease can be seen for incidences of AIDS and AIDS-related deaths because of the better availability of very high quality anti-retroviral therapies.

4.1 Reasons for the slow implementation of nationally-organized palliative care

Possible reasons for the absence of a nationally-organized and effective palliative care program in Slovenia could be owing to the historical development of Slovene society. There has been long subjugation of the country to another's rule – so independence began only in 1991. This situation, lasting centuries, has contributed to the development of a closed national character. People are not used to discussing or solving their problems 'in public'; and 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 (Kersevan, 1981: 265–276). 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 most prominently involved in the care of a dying patient, still has little power because of its subordinated position within the health care system (Pahor, 2001).

Medical doctors, probably owing to a lack of palliative care program studies when they were studying, and also because of a lack of organizational solutions, do not feel comfortable in such an area – so would rather emphasize a curative approach.

Finally, there has been a complete absence of financial support from the government to deal with all non-acute diseases (and, thus, also for palliative care programs).

In conclusion:

- The incidence of chronic and progressive diseases in Slovenia is able to compare with that of central European countries, though it cannot be compared with their level of palliative care development – palliative care is neither well organized nor sufficiently developed in the Slovene health care system;
- In Slovenia, as in the majority of European countries, the older population is increasing in number, so needs for palliative care will become greater (Zdravstveni..., 1995–2002; Statisticni..., n.a.);
- Statistical data to make evaluations and look at the quality of services in palliative care are not available; so reliable qualitative information is not to be had, and only limited financial estimations of costs for existing initiatives in the area of palliative care exist.

Now is the appropriate moment for the introduction of a model of organized palliative care into the health system. Recently, health care reform has been taking place in Slovenia – and the health administration understands that there is a need in society for organized palliative care.

4.2 Main issues and obstacles as regards strategies for the implementation of palliative care into the National Health System

The main issues in the field of palliative care for Slovenia are:

- to develop a common vision of palliative care for the people who need it now – and also for the growing population of the more elderly, who will need it soon;
- to produce common standards as regards palliative care;
- to introduce regular undergraduate and postgraduate education programs and courses;

- to ensure better team-work and a continuity of care in/across all settings;
- to introduce efficient clinical and managerial solutions to ensure better health outcomes and patient satisfaction;
- to create a better understanding that every clinical decision is also a financial decision – so responsibility within clinical management should also be recognised and worked upon.

While the main obstacles to implementation of organized palliative care are:

- a lack of knowledge and/or an appropriate attitude among health care professionals;
- a lack of organizational motivation to attain better health ratings and better satisfaction outcomes;
- a lack of clearly defined common standards in palliative care;
- a lack of understanding with regard to team-work and the continuity of care;
- a lack of public understanding about what palliative care actually *is*;
- a lack of economic analyses made on end-of-life caring;
- a lack of governmental understanding of what palliative care is – and what its benefits can be;
- a lack of governmental recognition of the growing needs of patients with chronic and progressive diseases within the past, thus a lack of realistic financial rewards/incentives.

Common examples of attitudes serving to create firm and direct barriers in the way of palliative care development are:

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

Such remarks are often to be heard, and they illustrate a range of individual and institutional barriers – and a lack of understanding of the benefits which may be gained. To make a response to this situation, a combination of well-trained palliative care teams, with clear ideas and vision, are needed; and there should additionally be a generic form of education and a change of attitudes, creating an ability to build on earlier successes, so as to achieve worthwhile results here.

As Gomez-Batiste et al. (1994: 98–101) observed, individual and institutional resistance may be strong – and it is vital to get an understanding of the reasons that underpin this, and work towards achieving a consensus of views. This

would be able to help 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 would be particularly important where there is a form of political dependency, where one service depends on another (something rooted in local power positions). Once a number of good initiatives are underway, however – ones which can be consolidated – locally-gained experience will frequently be the most effective rejoinder to any criticism. It will then become possible to focus more on issues of extension and coverage.

4.3 An assessment of needs

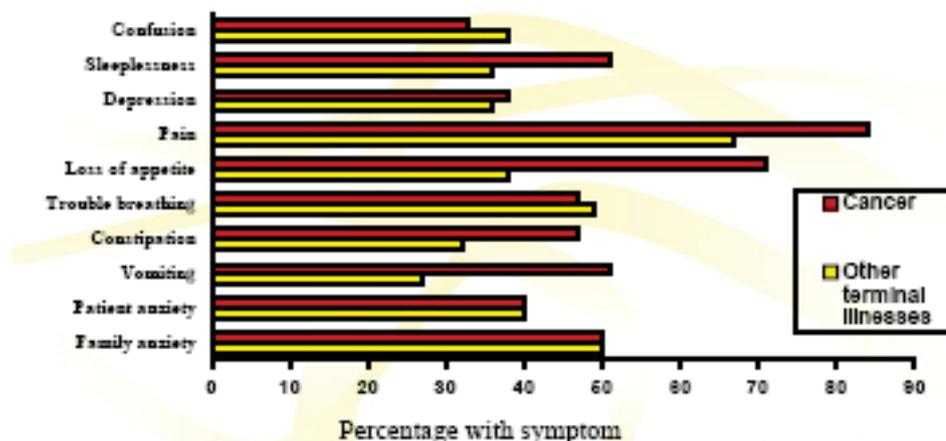
Baseline studies to assess needs provide vital information regarding the kinds of services that should be developed. Objective assessments of needs and an analysis of baseline context are also crucial for any effective monitoring of the results of new initiatives. We can use a simple and pragmatic approach so as to estimate the needs of palliative care in Higginson (www.kcl.ac.uk/palliative), one that has three components:

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

4.3.1 Epidemiology

Epidemiology – numbers and causes of death can give an indication of needs as regards palliative care, especially when coupled with information on symptoms, and emotional, social and spiritual problems (Fig. 9). With this

Figure 9 Prevalence of problems in the last year of life



Source: Higginson, I, (1997), *Epidemiologically based needs assessment for palliative and terminal care*, Radcliffe Medical Press

approach we have to be aware, though, of data inconsistencies and gaps (e.g. the recorded cause of death is a subject of changing fashions; or it may be inaccurate in the case of older people, where there could be multiple causes); also, different diseases have different progression patterns. Nevertheless, this simple approach may provide us with useful insights when it comes to planning and needs for implementation.

There are roughly 20,000 deaths a year in Slovenia, and 25% are due to cancer. From Figure 9 data we can estimate the most frequently-occurring symptoms in the last year of life, as based on the work of Higginson (1997) (Figure 10):

Figure 10 An epidemiological estimation of symptoms in the last year of life in Slovenia

Symptom	Pts. with cancer	Pts. with other terminal illnesses
Confusion	1600	5550
Sleeplessness	2550	5400
Depression	1900	5250
Pain	4250	10050
Loss of appetite	3600	5700
Trouble breathing	2350	7350
Constipation	2350	4950
Vomiting	2550	3900
Patient anxiety	2000	6000
Family anxiety	2500	7500

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

4.3.2 A comparison with services available

Primary health care

Based on epidemiologic estimates, an “average” general practitioner practice having 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/illness and wants to be at home for the end of their life, that person will have access to some home care nursing. There are

limitations, though, because the health care system cannot provide round-the-clock care at home. Patients who are severely ill will have to rely on family members for their care, i.e. in order to be able to remain at home. Family members can be paid a part-time salary for two weeks in order to be able to look after a dying father, mother, husband or wife.

Even if we know that more than 50% of deaths occur in hospitals, the mean-average stay in a hospital is short. General practitioners do care for more terminally ill patients going through a progressive illness, and who are frequently hospitalized only for short periods of time, so spend most of their time at home.

Hospitals

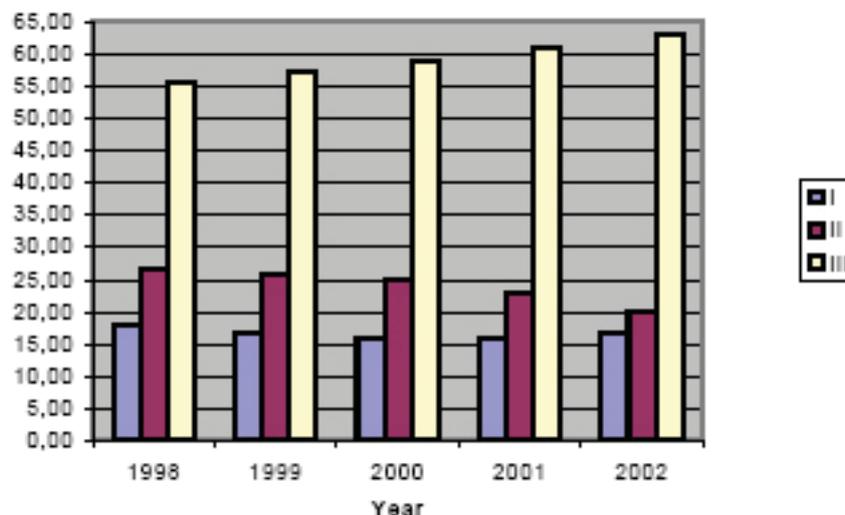
A hospital serving an area of 25 000 would have 560 deaths each year, 1230 from circulatory disease, 300 from respiratory diseases, 60 from other diseases – and where patients and carers would benefit from palliative care.

Hospitals in Slovenia are the witnesses to 47% of all deaths.

Nursing homes

In Slovenia, nursing homes are governed by the Ministry of Social Affairs. Only a small proportion of nursing services in each nursing home are overseen by the Ministry of Health. Medical care is most often provided via regular visits from family physicians from the region's primary health site. It seems that the highest category of nursing will include that of palliative care services, though no direct measurements of the quality of care are available (Figure 11).

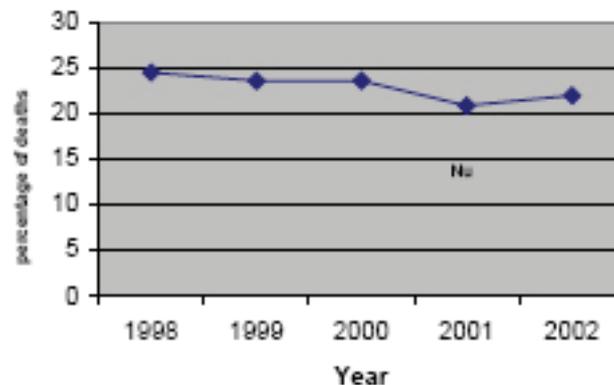
Figure 11 Nursing home residents' categories of nursing (from I to III)



Source: Skupnost socialnih zavodov R Slovenije

In a global perspective, nursing homes have a long history of attracting vigorous criticism of the quality of care they provide (Wayne, 2000: 1151–3). There is no direct data available for Slovene nursing homes about quality of their palliative care. Reports of staff shortages, coupled with a widely-reported nursing home ‘incident’ in October 2003 in a resident home Crni Les (i.e. inappropriate measures of nursing for several residents) give us strong evidence that organizational and educational developments for nursing homes in the area of palliative care are needed.

Figure 12 Percentage of deaths in nursing homes, among all residents



Source: Skupnost socialnih zavodov R Slovenije

In any 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 the effectiveness of palliative care

5.1 Common protocol

The importance of the quality of clinical care has been emphasized lately in new plans that have been laid down for health systems. The objective of clinical governance is to ensure that a patient receives the best quality of care throughout their time/‘journey’; and patient experiences should be looked at and assessed so as to learn from, and then be able to provide the services that better meet patient needs. Clinical pathways (CP) are a tool that can help to meet the requirements of the clinical governance agenda, providing

demonstrable standards and care outcomes for patients. CP can be defined as “systematically-developed statements to assist both the practitioner and patient decision-making about appropriate care for when in specific clinical circumstances (Field and Lohr, 1990).

The development of clinical guidelines has been driven by concerns over the rapid escalation of care costs and the quality of care. Many attempts and a lot of energy have been put into all kinds of different guidelines for better quality of clinical practice – yet they have been only moderately successful, or not at all.

The Liverpool Clinical Pathway (LCP) is currently incorporated within 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 the Netherlands, New Zealand and (recently) also in Sweden.

The Liverpool Clinical Pathway

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

5.2 A classifying of palliative care – some options

Some consideration should be given to determine the potential basis for a classification of palliative care in the immediate future in Slovenia (Hindle, 2003):

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

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

- Resource Utilization Groups (RUG) were designed principally to categorize in-patient days in specialized nursing and intermediate care facilities in the United States. The main variables are level of dependency in relation to daily living activities, 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 daily living activity (ADL) from 4-18, and the RUG-3 ADL index. In summary, RUG -3 is more relevant to palliative care than the DRG classification, yet it is unable to effectively outline or capture the specific care needs of palliative care patients, except in terms of activities related to one's daily living.
- The most widely-used classification in Australia is the sub-acute and non-acute in-patient (SNAP) classification, which is designed to categorize days of in-patient care rather than complete in-patient episodes. It has taken account of work done to develop the DRG and RUG-3 classifications, and then extended the basic ideas specifically into the area of 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, in-patient and mobile out-patient services in palliative care (Gomez-Batiste et al., 2002: 239–244).

It is most likely that the potential for a solid base for further developments in Slovenia using the SNAP classification from Australia and experiences gained from Catalonia will formulate itself.

Data collection of for classification purposes may also be efficient as information needed for clinical management and planning, and also for measuring health outcomes.

5.3 What are the specific challenges involved in implementing the clinical pathway?

There are many challenges when it comes to trying to implement the clinical pathway. The most difficult dilemma for clinicians and nurses is to diagnose somebody's dying, or when to actually start using the CP. This is particularly difficult when a patient is acutely ill, or when the disease trajectory may be unpredictable, or s/he is in a post-operative state. It is also 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 with many patients: in a case of sudden death, cardiac arrest, or where it was hard to diagnose the fact of someone's dying. At times it was simply that the member

of staff in charge, or who was on duty over the weekend, was not familiar with the CP tool.

Diagnosing dying (the last hours or days of somebody's life) is often a very complex process. In cancer patients, the following signs (Ellershaw and Wilkinson, 2003) are often associated with the dying phase:

- The patient becomes bed-ridden
- The patient is semi-comatose
- The patient is able to take only sips of fluid
- The patient is no longer able to take drugs orally

This predictability of the dying phase is not always as clear with other chronic and 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 an 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 maintain both sorts. This meant a lot of additional work for staff – so 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 diseases/illnesses and to give support to 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, however.

Standards related to palliative care are to be prioritized with regard to palliative care development – and are a precondition for identifying best practices. With quality indicators from these standards, two main objectives will be met: quality improvement (for internal use, for monitoring or continual quality improvements) and accountability (for external usage, by regulators, health care purchasers and/or consumers). For example, regarding quality indicators of pain, there is a standard that requires all national health institutions to demonstrate that they adequately monitor and deal with the pain of patients. Similar indicators should be developed to handle other common physical, emotional, psychological

and spiritual problems. An important aspect of demonstration and validation is monitoring for potential and unintended consequences (e.g. patients are sedated, going against their preferences), to thereby improve accountability statistics.

To put standards into practice the clinical pathway is the best tool, via which practice can be changed for the better, thereby meeting the needs of the dying and their families. And the process of implementing the CP will require education, team-work and awareness and change of attitude towards the phenomenon and actuality of dying.

Palliative care reform expert Joanne Lynn (2000: 14) suggests that reforms in palliative care require changes in regulation, payments, 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 professionals is the key factor and the determinant of success. The involvement of individuals with clinical, educational, planning and managerial abilities is vital, too. While political will and leadership is also critically important.

7 Possible strategies for palliative care in Slovenia

7.1 *Option #1*

No change in current government policy or strategy...

This would most probably lead to a variety of very slowly evolving and differently formulated palliative care services at different levels of the health care system; these would not be integrated into a useful network that would manage the path of every patient; and there would be no appropriate quality standards, comprehensive coverage, equity, possibilities for quality assessments or adequate planning towards meeting persons' needs. It would be a very unsatisfactory experience for patients and their families, and for health care professionals, too.

It would also be possible to expect similar events pointing to misuse and exploitation of 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 a situation arising because there was an absence of organized palliative care at a national level.

7.2 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, though not acting strategically at all levels of health care where patients are dying – very similar results to the first option can be expected. Public health goals (coverage, equity, quality and standardized care, efficiency and efficacy) could not be attained in this way.

7.3 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 such persons will be clinicians, educators, insurance provision, and other organizations and government agencies. One would also see the development of palliative care teams and patient advocacy organizations.

8 Recommendations

Government agencies urgently need to step up the implementation of palliative care with funding, and evidence-based regulation incentives. So a step-by-step approach for a future policy strategy dealing with palliative care, for all settings is proposed:

8.1 Short-term strategies

8.1.1 Building services

- Creating 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 the *overall* care of patients

- Creating primary care palliative care consulting teams for every related hospital and for nursing homes in lesser regions.
- Creating in-patient palliative care units in large hospitals, with specialist palliative care teams; these will have a consulting role throughout the hospital and handle primary care in smaller regions, too.

8.1.2 Agreed definitions and standard sets

- The most important task is to have clarified what constitutes good clinical practice. Definitions and standardized ways of operating along with clinical protocols (the clinical pathway) should be developed with palliative care providers, insurers and representatives from the public. Standards would include standards regarding care services and decisions about standardized costs for some of the most typical clinical protocols. This procedure will also include the extensive training of health care professionals during the process of implementation of such clinical protocols. Nonetheless, whatever happens, this will not be successful unless the appropriate infrastructure has been established.
- Agreement on data collection for palliative care. Only a monitoring of processes can offer qualitative and financial evaluations and point towards ways of further development. The most needed data upon admission – with demographic variables and the main diagnosis upon admission – will be an assessment of severity (there are several instruments for use here), the main symptoms requiring attention, source of referral to a palliative care team (acute care hospital, nursing hospital unit, home, nursing home), and the time phase of care. Upon discharge, required data will have within it cause of death – or, if not death, destination after discharge, major symptoms requiring attention and time phase for care. Possible and lower-priority data elements would be cohabitants at admission, cohabitants at discharge, carers upon admission, and predicting bereavement-related difficulties.

8.2 Long-term strategy

- Elementary changes according to evaluation results
- Designing an appropriate payment model, which will reflect and encourage good clinical practice (at the same time).

For systematic changes, systematic procedures and projects are being proposed here; and influential leadership coming from committed experts on a national level within the process of organized implementation and co-ordination, together with evaluation, will additionally be of major importance.

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