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A model for classifying and paying for palliative care in Slovene health care system

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Research paper

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Content

Executive summary

will follow

I. Introduction

I.1. Palliative Care Definitions

European Association for Palliative Care for the educational purposes throughout the European Community recommends the following definition[1]:

"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 of definition of the patient's condition. Even thought the basic principles may be agreed, there are frequent differences of interpretation of 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[2] 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."

Palliative care[3] :

- 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
- Offer 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 indicated
- Will enhance quality of life, and may also positively influence the course of illness

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[1] 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.

[2] 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.

[3] World Health Organization. National cancer control programmes: policies and managerial guidelines, 2nd ed. Geneva: World Health Organization, 2002.

- 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 is a public health policy matter

The development of palliative care is a public health policy matter and the 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 [4].

There should be a specific strategy to develop and combine well-planned resources with an emphasis on training and teamwork. 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 should be adapted to 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.

I.2. Status of palliative care in Slovenia

Slovenia is a Central European country with approximately 2 million inhabitants. The life expectancy at birth is 71 years for men and 79 years for women[5]. The three main causes of death in Slovenia are diseases of circulatory system, neoplasms and diseases of respiratory system[6]. Slovenia is a country with a middle size morbidity and mortality rate caused by cancer. The leading cancer site for the male population is lung (19% out of all cancer sites) and for female population is breast (21%). Approximately 52 % of all deaths occur in hospitals and other institutions, and 48% occur at home. The financing of health care is based on a social security system, which covers practically the entire population.

The hospice movement, with home service and education programs, started in the middle of the 1990s in the capital city of Slovenia. This includes mostly nursing and volunteer activities. A physician is not yet involved in the care. New regional organizations in different parts of Slovenia are coming into action, particularly for education on psychosocial topics for volunteers and public.

A major institution for cancer patients in the country has established a consultant group for palliative care. Together with Palliative Care Development Institute, Ljubljana, in the last few years, regular education on different topics related to palliative care has been organized an become part of the curriculum for family medicine and oncology offered by the medical faculty.

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[4] Recommendation of the Committee of Ministers to member states on the organization of palliative care, Councle of Europe, article 15.b and article 11. Strasbourg 2002.

[5] Primic-Zakelj M, Ceh F, Pompe-Kirn V, Skrk J, Stabuc B. Vec znanja – manj bolezni: didakticni komplet za ucitelje (More knowledge – less illness: a didactic set for teachers). Ljubljana: zavod republike Slovenije za solstvo, 2001:7.

[6] Moravec-Burger D, Urdih-Lazar T. Zdravstveni sttistični letopis, Slovenija 2002 (Health statistics yearbook, Slovenia 2002). Zdravstveno varstvo 2003; letn42; suppl. 1.

Occasional seminars also are organized for health care professionals and others involved in the emergence of palliative care in Slovenia.

Pain is the major symptom for patients in palliative care and therefore also an indirect indicator of the development of palliative care. All the substantial drugs for pain relief are available in Slovenia, with a normal procedure for prescribing. Guidelines for pain management have been available for the last four years. Together with guidelines, there was a successful educational campaign organized to train doctors and nurses all over the region on the basics of pain management. Figure 1. Shows the rise of morphine consumption in Slovenia.

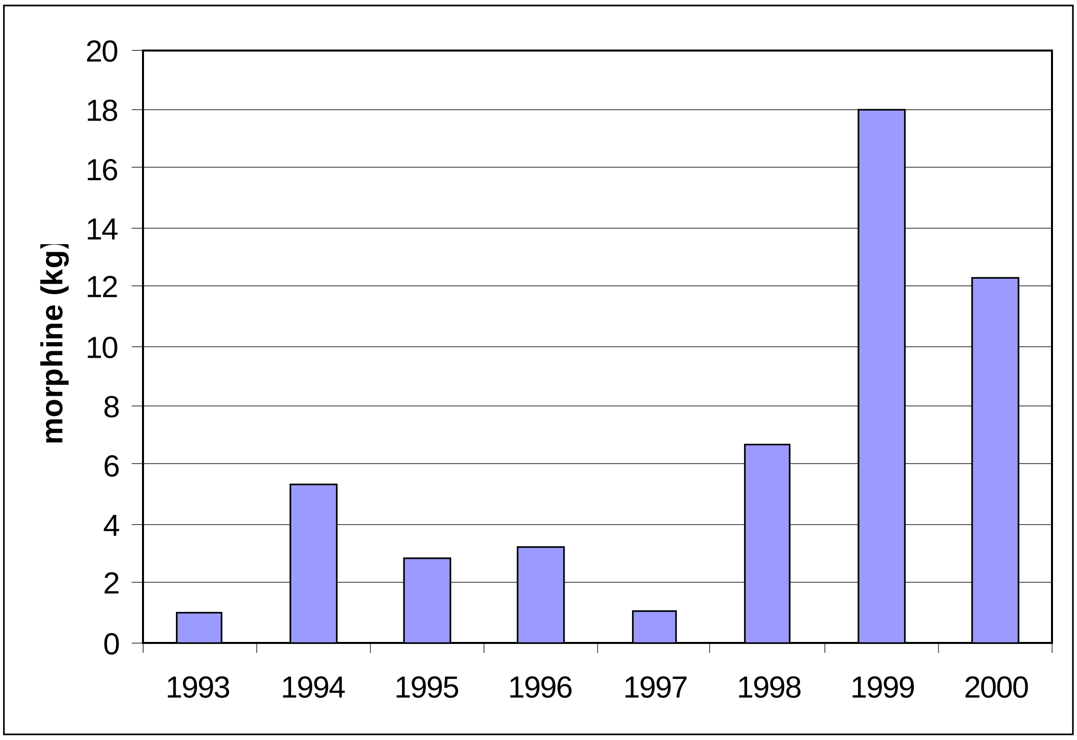

Fig. 1
Consumption of morphine in Slovenia.
Source: Ministry of Health of Slovenia

There was a sudden rise after 1998, most probably due to the activities listed above and new pain relief drugs available on the market. In 1999, when the highest consumption of opioids in Slovenia occurred, the comparison with the rest of Europe is encouraging (Figure 2).

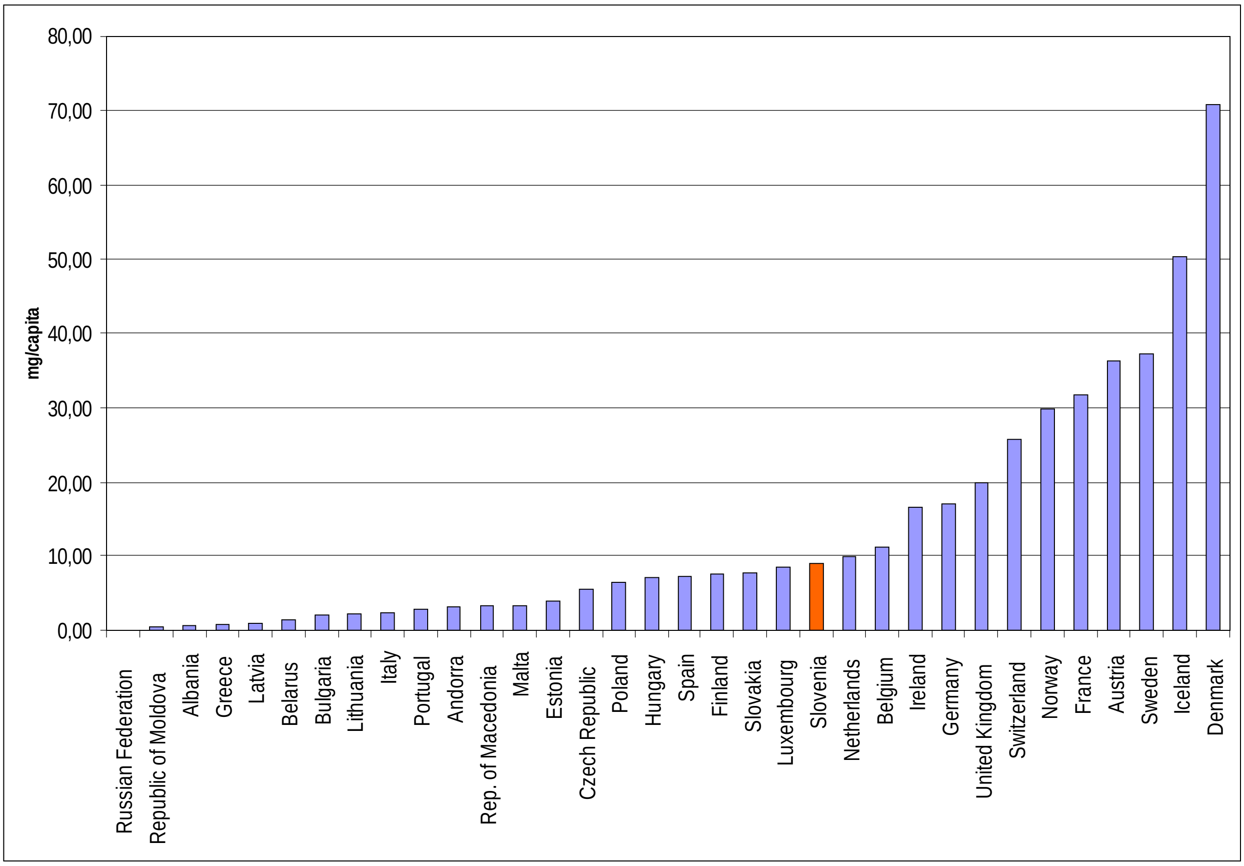

Fig. 2
Opioid consumption in 1999. Comparison of European countries.
Source: Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Centre.

Possible reasons for absence of nationally organized effective palliative care in Slovenia could be the historical development of 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. Suicide rate in Slovenia is one of the highest in Europe.

In the period of socialism, death was pushed into the sphere of private, and the Church, which was competing for the public attention, would not enter the public sphere[7]. There was no interest in the development of public institutions, like palliative care wards in hospitals or hospices. There was a strict hierarchical organization of the health care system, and teamwork approach 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[8].

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[7] Kersevan M. Odnosi do mrtvih v socialisticnih druzbah (Attitudes toward the dead in Socialist societies). Anthropos 1981;4-6:265-276.

[8] Pahor M. Nurses in Slovenia and professionalisation: one step forward, two backward. Paper presented at the 5th 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 for all non-acute diseases and also for the palliative care programs on the part of the young state in the past.

In the conclusion:

- Incidence of chronic and progressive diseases in Slovenia can compare to central European countries, but not to the level of development of palliative care: palliative care is not organized and developed in Slovene health care system;
- In Slovenia, like in the majority of European countries, older population is growing, needs for palliative care will be even larger [9], [10].
- Statistical data about services in palliative care are not available, and therefore no financial estimation of existing initiatives of palliative care is possible;
- Classification system DRG, which is most widely used in Slovene health care system is not appropriate for palliative care, other system of classification needs to be established for palliative care.

It is now a very suitable moment for the introduction of a model of organized palliative care into health care system. Since recently, the health care reform is taking place in Slovenia and understanding in the health administration about the needs of society for organized palliative care is present.

I.3. 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 bring common vision for palliative care for the growing population who need it now and will need it even more in the growing population of the elderly in the future.
2. to produce common standards in palliative care
3. to introduce regular undergraduate and postgraduate education
4. to ensure better teamwork and continuity of care across all settings
5. to introduce efficient clinical and managerial solutions to ensure better health outcomes and satisfaction of patients
6. to bring better understanding that every clinical decision is also 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 in the field of palliative care
2. lack of organizational motivation to reach better health and satisfaction outcomes
3. lack of common standards in palliative care
4. lack of understanding of team work and continuity of care

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[9] Zdravstveni statistični letopis 1997-2001, Inštitut za varovanje zdravja R Slovenije.

[10] Statistični urad Republike Slovenije. http://www.sigov.si/zrs/slo

5. lack of governmental recognition of the growing needs of patients with chronic and progressive diseases in the past, and therefore lack of financial incentives;

Possible strategy to solve these problems:

to introduce a common protocol on the basis of evolving standards of palliative care for patients in their last phase of life, together with an financial evaluation of services in palliative care. All these in order to propose policy recommendations to Ministry of health and a practical model of organized palliative care for all settings.

Common protocol - clinical pathway can:

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

Classifying of palliative care – some options:

Some considerations are to be taken in the potential basis for classification of palliative care in the immediate future in Slovenia[11]:

- ➢ 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 categorise palliative care: 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 Utilisation Groups (RUG) was designed mainly to categorise inpatient days in specialised nursing and intermediate care facilities in the United States. The main variables are level of dependence for activities of daily living, broad categorises 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 the specific care needs of palliative care patients, except in terms of activities of daily living.

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[11] Hindle D. A background paper: Classifying and paying for palliative care. An occassional paper, Ministry of Health of Slovenia, 2003.

- ➢ The most widely used classification in Australia is called Sub-acute and non-acute inpatient (SNAP) classification, which is designed to categorise 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 specific organization of non-acute inpatient and mobile outpatient services in palliative care[12].

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

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

II. Methodology

II. 1. Research design:

Experimental group of patients and their families following the criteria of admission to palliative care terminal phase[13] will receive palliative care supported by a clinical pathway and a control group will be treated in the non-pathway manner.

II. 2. Aim and objectives of the research project

Aim

To introduce a common protocol for palliative care terminal stage in order to introduce common standards into practice and to develop basics for building classifying system in palliative care for the management and payment purposes on the national level.

Objectives

- To create and organize a pilot study of introduction of modified palliative care clinical pathway.

- To develop basics for classifying in palliative care for managing, planning and funding purposes. The purpose is to classify the patients and not the service or the ward in which they are treated: classification will be based on the characteristics of the patient and on the goal of intervention.

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[12] Gomez-Batiste X, Porta J. Tuca A, et all. 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.

[13] Ellershaw J, Foster A, Murphy D, Shea T, Overill S. Developing an integrated care pathway for the dying patient. *European Journal of Palliative Care,* 1997;4 (6):203-7.

- To clarify what constitute a good clinical practice: define basis for national clinical standards in palliative care.
- To establish ways of empowering individual initiatives for palliative care teamwork.
- To measure satisfaction of patients, their families and staff in comparison with those without the intervention.
- To propose an implementation and financial model for palliative care in Slovene health care system.
- To produce a policy paper for experts in the field and for Slovene Ministry of Health.

II. 3. The research hypothesis to be tested

➢ Clinical pathways for palliative care offer better clinical practice measured by patient and family satisfaction.

➢ Appropriate education and introduction of clinical pathway can offer more satisfaction to the staff and better subjective opinion on teamwork.

➢ It is possible to make a basis for classification of palliative care in the frame of clinical pathway.

II. 4. Methods

II. 4.1. After exploratory stage first step involve a review of current practice in Slovenia to identify opportunities for improvement of palliative care.

II. 4.2. Next step is to compare Slovenia and selected other countries in terms of organization, clinical practice, networking, standards, common protocols, data systems and payment systems. Organization of palliative care in United Kingdom, Australia and Catalonia will is being explored. The aim is to develop an understanding of the strengths and weaknesses of current arrangements, and build an agreement on what might be done in short and long terms.

II. 4.3. Three palliative care teams (physician, two nurses, social worker) in three hospitals (Golnik, Oncology Institute, Ljubljana and Teachinf Hospital Maribor) together with corresponding three ambulatory counselling teams in primary care (Primary care Kranj, Primary care Maribor, Hospice-home care Ljubljana) are identified and educated. Education includes workshops on palliative clinical knowledge (with possible evolution of basics for standards design in palliative care) and education for palliative care clinical pathway implementation.

II. 4.4. Production of

- common symptom control guidelines (translated and modified from Ellershaw[14]),

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[14] Ellershaw J, Wilkinson S. Care of the dying. A pathway to excellence, Oxford University Press, London, 2003.

- a leaflet of information on the research for the patients, their families and the staff,
- bereavement leaflet for family members.

II. 4.5. Questionnaires for satisfaction of patients, their families and staff involved in the project, and for the control group without the intervention, are developed.

II. 4.6. The form of protocol (The Liverpool Clinical Pathway) is translated, copied and activated for period of 3 months: Sept – Oct – Nov 2004. It is planned to support 50 patients with this protocol. At time of first assessment, every patient is assigned to care using pathway with the criteria of the Liverpool Clinical Pathway, which predict, that the patient is: bed bound, semicomatose, only able to take sips of fluid, and no longer able to take tablets. When at least two from the four criteria are true, pathway for the patient can start. There is a form of clinical pathway separate for hospital and separate for community (ambulatory) available.

II. 4.7. If the pathway is not followed at any point, the health care professional records the reason for the deviation as a "variance". Analysis of the variances provides a mechanism for analysing the reasons for not achieving the desired outcomes of the care. This, in turn, directs educational initiatives and resources utilization in order to achieve maximum impact in the provision of clinical care. Variances are recorded and discussed once per month in meetings with each team. As weaknesses are noted in the pathway form, the form design should be modified.

II. 4.8. Consultation among the teams and a coordinator is available on line.

II. 4.9. Classification basis is proposed and tested along with the protocol for each patient.

II. 4.10. Data collection

II. 4.11. Statistics on number of variances by type and data analyses of the research results from the questionnaires are produced.

III.Research Results

will follow

IV. Discussion

will follow

V. Conclusions

will follow