QUO VADIS, PALLIATIVE CARE IN CROATIA?

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Summary

Since 1994 in Croatia there have been systematic and continuous activities with the aim of spreading the most actual information about palliative care. In 1999, the practical activity started resulting in the foundation of the Regional Hospice Centre as a civil organization. It has now more than five years of constant activity of volunteers – both health and non-health professionals. The inclusion into the existent health system as recommended by the Committee of EU Ministers failed until now, due to the instability of law and repeated reforms of the reforms... and our old and popular standpoint "we know all about and we do all that". Expertise is not required. And only the quality could be the advantage in our future competitions.

KEY WORDS: palliative care, civil societies, health protection law changes

QUO VADIS, PALIJATIVNA SKRBI U HRVATSKOJ?

Sažetak

Od 1994. godine u Hrvatskoj se neprestano provode razne aktivnosti sa svrhom širenja najnovijih informacija o palijativnoj skbi. Godine 1999., u organizaciji civilnoga društva osnovan je Regionalni hospicijski centar. Već više od pet godina u njemu djeluju dobrovoljci među kojima su podjednako zastupljeni i zdravstveni i nezdravstveni djelatnici. Zasad se nije uključio u postojeći zdravstveni sustav na način na koji to preporučuje Vijeće ministara Europske Unije ponajviše zbog nepostojanosti zakona, neprestalnih reforma već donesenih reforma ... te onog našeg starog i omiljenog stajališta "mi sve to znamo i mi sve to i radimo". Za to nije potrebna stručnost. I samo bi kvaliteta mogla značiti prednost u našim budućim nastojanjima.

KLJUČNE RIJEČI: palijativna skrb, civilna društva, izmjene zakona o zdravstvenoj zaštiti

INTRODUCTION

Modern hospice movement has been accepted in more than 120 countries. The definition that the cultural level of a society may be determined by its sensibility for suffering of its mostly threatened and feeble members is always more widely accepted. According to many statistics, the most neglected group of patients is that of the dying.

EDUCATION / INFORMATION IN PALLIATIVE CARE

At the Institute for Tumors and Allied Diseases, in 1974, director Željko Maričić made a trial to introduce palliative care with no success (1). In 1989, at round table discussions on terminal stages of neuromuscular diseases, Živko Kulčar and Slobodan Lang (from the Public Health School «Andrija Štampar») reported on their unsuccessful trial to organize hospice at the Medical

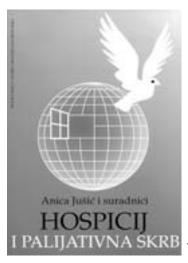


Figure 1. Title page of the first hospice book with the Hospice Movement logo

School level. The argumentation was – we do not need such institution (2).

The organized hospice movement started in 1994 with the First Symposium on Hospice and Palliative Care lasting two days, and with its logo design (Figure 1). In the autumn of the same year, the Croatian Society for Hospice/Palliative Care, CMA was founded in order to ensure continuity of the activity (3). The Society activity involved organization or co-organization of many of symposia, conferences and courses for different healthcare professional profiles (physicians - primary care, neurologists, pediatricians, for staff of homes for the sick and disabled, for nurses, social workers etc.). The lecturers were from Croatia supported by a significant number of foreign guests from England, Canada, Germany, USA, Netherlands, Poland, Czech Republic, Hungary and other countries.

A significant number of those interested were sent to one- to one-month courses held in England (London, Oxford, Rochester-Kent), USA (New York, Buffalo), Poland (Poznan, Puszczykowo, Bydgoszcz, Gdansk, Warsaw), Hungary (OSI seminars),

Single persons or groups were sent to congresses held in London, Palermo, den Hague, Aachen, Berlin, Bucharest and Brussels, often thanks to the financial support of OSI NY (4).

The regular teaching in palliative care as optional subject was organized at the High Nursing School. At the Zagreb University Medical School, postgraduate courses in primary care, chronic malignant pain treatment, and English courses in palliative care were registered. Undergraduate

courses started in 2004 at the English study of the Zagreb University Medical School. As «End-of-life issues» they are given by the Rochester group and Croatian teachers. The leader of the unique enterprise, due to collaboration between the University of Kent, UK and the Medical School, Zagreb, Croatia, is David Oliver (elected guest-professor of the Zagreb University Medical School). The first undergraduate course in English will be held end in June 2006. At the same time, the post-graduate course in palliative care in English will be reorganized, as the first module of «Certificate in Palliative Care» (5).

The publications are rather abundant: seven books were issued as fundamental professional literature for palliative care/medicine studies in the Croatian language. BILTEN as the official journal of the Croatian Society for Hospice/Palliative Care was issued eleven times (with 40 pages and color photos), and afterwards changed, for financial reasons, to www:hospicij-hrvatska.hr

A huge number of single papers were published in Liječničke novine, Liječnički vjesnik, Acta Medica Croatica, Medicus, Medix and other journals and as chapters in different textbooks. Some papers were published in foreign journals or textbooks as well.

PRACTICAL ACTIVITIES

Practical activities started with the foundation of the civil association «Friends of Hope» in 1997 as logistics support to the Croatian Society for Hospice/Palliative Care, CMA at the city of Zagreb level. In 1999, the civil society «Croatian Association of Hospice Friends» acting at the Republic level was founded. In 2002, the Regional Hospice Centre was opened at Hirčeva 1 in Zagreb. The owners are those Associations, receiving only verbal support by the Ministry of Health.

The Regional Hospice Centre is the center of interdisciplinary home care visits (performed by active volunteer health professionals) and the center for education of volunteers who are not health professionals (very important in the modern hospice movement). The Centre has started to develop the bereavement service as well as an outpatient department for pain and palliative treatment. It is the place where different types of health professional courses have been organized.

Once a week, there is a consulting meeting of interdisciplinary team members and supervision meetings for volunteers who are not health professionals. During the five years, these volunteers took care of 725 patients. The majority of the patients suffered from malignant diseases.

INCLUSION INTO THE EXISTENT HEALTH SYSTEM

Thanks to the activity of the Ministerial Committee for palliative care, the paragraph 81 was included in the Health Protection Act (2003) allowing the foundation of the Institution for palliative care to include hospice home care visits, outpatient department for pain and palliative care and daily hospice. The proposal for a special hospital-hospice was not accepted. The law has actually been revised. What will be the end result and how long will it take nobody knows.

The inclusion into the existent health system should be our priority, also in compliance with the instructions given by the Ministerial Committee of the Council of Europe to member states about the palliative care organization. The same year (2003), the Croatian Society for Hospice/Palliative care produced a Croatian translation of «Recommendations» (Fig. 2), with emphasis on the following: the right to get palliative care is one of the basic human rights; palliative care units should be included into the existent health system, as responsibility of the government; any health professional should have some education in palliative care; those dealing with the dying should have a higher level of knowledge; those leading the hospice units should have, if possible, the specialization in palliative care (6).

WHAT HAS BEEN ACHIEVED IN CROATIA?

In the expertise on the Health Reform Project in Croatia funded by the MMF, a very realistic design of the palliative care network, based on local needs, was given. The proposal was discarded. In 2001, the Mayor of the City of Zagreb promised a piece of land for a hospice building and all required permits free of charge. The initial document for building was made along with a financial estimate, but the piece of land has not been granted to date. We elaborated the project



Figure 2. Title page of «Recommendations»

entitled «Palliative Care in the Community» with the proposal of two interdisciplinary teams to be paid by the Croatian Institute for Health Insurance. The proposal was also directed towards the Ministry of Health and Social Welfare. In spite of the letters in support of the activity of the Ministerial Committee for Palliative Care and its president Anica Jušić addressed by the Minister of Health and Social Welfare to the Government and State Presidency, nothing happened, no answer at all. The health professionals volunteering for six consecutive years are getting into «the burn out syndrome». The material expenses of hospice home care visits have been covered through projects alone.

During the January 2006 meeting at Šubićeva 9, representatives from different Croatian cities reached a sad conclusion that many already developed and promising initiatives had actually failed.

PALLIATIVE CARE INSTITUTIONS IN CROATIA'S NEIGHBORING COUNTRIES

We are in contact with many of our colleagues from Croatia's neighboring countries for years. They attended our courses or symposia in Zagreb. We met abroad at congresses and courses and remained in touch by correspondence and publication exchange. We in Croatia cannot of course compare with member countries of the Council of Europe, but we are afraid we may not be able to match with non-members, very soon.

Macedonia. In 1998 already, they opened the first hospice as specialized institution for palliative care in Skopje, through collaboration of the Ministry of Health, Phar program and Sue Ryder foundation. They have four specialized multiprofessional and interdisciplinary teams. Until September 2005, they took care of about 1,860 patients (80% with malignant diseases -60% dying at hospice and 40% at home). In 2005, another hospice was opened at Bitola. In 2003, due to their Health Protection Act, palliative care was integrated into the existent health system and health insurance.

Bosnia and Herzegovina. The hospice home care service «Njega» at Sarajevo started with an interdisciplinary team, full time paid by the Health Home and conducted by two Irish hospice nurses. Now, they have beds, too. At the Tuzla General Hospital, the Palliative Care Department was opened few years ago and the Daily Hospice during the autumn 2005.

Serbia and Montenegro. During the autumn 2005, the Belhospice was opened chaired by a medical oncologist whom I met many times at different courses abroad. Nowadays, she has the diploma in palliative care. At the Institute of Oncology, Belgrade there is a clinical pharmacologist with extensive education in palliative care, involved in many international palliative care research projects, and engaged many times as visiting professor. The already mentioned «Recommendations» by the Committee of Council of Europe ministers (2003) were translated into the Serbian language. On this occasion in autumn 2005, the Ministry of Health organized the European Conference on Palliative Care in Belgrade, with some sessions chaired either by the Serbian Health Minister or the Health Minister of Monte Negro.

Hungary. In 2005, the Hungarian Government defined the National Program of Cancer Control as the part of their National Development Strategy. At the suggestion of the Hungarian Hospice – Palliative Care Association, the National Cancer Control Program involved the strategy of hospice network development. Until 2010, at least one stationary hospice center per health insurance region should be organized. Concerning hospice home care services, the first stage should be organized until 2007, the second until 2008 and the third until 2011.

CONCLUSIONS

The Hospice Movement in Croatia has been supported only by the vice-president of the Croatian Government, Mrs Jadranka Kosor. She used to be the patron of our Fifth Symposium on Hospice and Palliative Care in 2005, and she told us there, we should consider her as our volunteer. She asked the Minister of Health and Social Welfare to report to the Government what has been done for palliative care in Croatia. Her support was financial, too. She agreed to be the patron of the First Congress on Hospice and Palliative Care in October 2006 to mark the World Hospice and Palliative Care Day (7).

Let us hope that law revisions will help the realization of all these institutions already approved by EU members as well as some non-member European states. We hope that the realization of the institution, which, sooner or later, must be effected (due to the general trend of globalization), should not be stopped or postponed.

As we often say – hope dies last.

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