

PALLIATIVE CARE IN PULA AND IN THE ISTRIAN REGION

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The principles of palliative care have been known and accepted at WHO level. Palliative care (PC) represents an approach aiming to increase the life quality of patients and their families, in the moments when they face the problems of life-endangering diseases, in the form of prevention, early detection, a high quality pain estimate and treatment, as well as physical, psychosocial and spiritual difficulties connected to the final life stages (WHO 2002). Palliative care (PC) is a problem of public health in Croatia, receiving surprisingly little attention. Although PC is connected with patients suffering from malignant diseases, palliative principles and palliative medicine should be applied more widely (in neurological, and circulatory diseases, in patients with chronic diseases of the heart, lungs and kidneys), and especially with older persons.

A seriously ill person needs a more complex approach in the moment when active medical treatment stops. The body, the soul and the spirit are ill, the family caring about the patient is ill. The patient is suffering pain and having other symptoms related to the final life phase, he is not able to work, he is excluded from most social contacts, he is financially impoverished, and the family is exhausted and often helpless. Help is necessary throughout the course of the disease, and the family members also need support after the patient's death.

This kind of work requires a multidisciplinary team work. Not only doctors and nurses are involved in the work of a palliative team, but also physical therapists, psychologists, psychiatrists, social workers, priests and volunteers. They all need to be specially trained to work in the palliative care. The training should especially include clarifications and elaborations of the personal attitude to life, death, illness and suffering, as well as a series of other bioethical questions.

Health care workers provide a certain form of palliative care, but the specific palliative care is provided by trained professionals, in some countries even specialists of palliative medicine. Palliative care is not sustainable on volunteer organizations, it should be professional, systematically implemented and free.

PC is included in the health care system in 120 countries throughout the world. Our neighbours in Bosnia and Herzegovina, Macedonia, Serbia and Slovenia have organized PC. This was possible due to a significant help from abroad, but a social and political will existed within the countries, making the realization possible. Croatia has no excuse for the lack of an organized palliative care, working on a volunteer basis for 15 years. The founder of palliative care in Croatia is prof. dr. Anica Jušić. After several years of working, writing and persuading, palliative care was included in the Act on health care in 2003. However, the legally guaranteed care has produced little or no results so far and the volunteer work during 15 years has exhausted a large part of the volunteers. Two palliative teams in the Primorsko-goranska region that started working in late

2008 give us hope for the future.

A volunteer palliative team was formed in 2005 within the Anti Cancer League in Pula. Local authorities have shown understanding and finance the team with financial means from the Istrian region and the town of Pula.

PALLIATIVE CARE IN THE ISTRIAN REGION AND IN PULA

The first lecture on palliative/hospice care was held in 1995 by prof. dr. Anica Jušić following the invitation of the then president of the Istrian branch of the Croatian Medical Association, prim.dr. Dubravko Marković. Mr.sc. Gracijela Vretenar and prim.dr. Dubravko Marković have supported the idea of a hospice in Pula (radio show). At that time dr. Josip Ladavac initiated the founding of a hospice in the premises of the old hospital, but the project remained in its initial phase.

Ten years later, on July 22, 2005, a palliative team was founded at the Anti Cancer League in Pula. Dr Julijana Franinović Marković, mr.ph Irena Grahovac, prof Danica Kuzmanović and Milka Radetichio formed the nucleus of palliative care from the very beginning.

Our activities include trainings, work with patients, aids rental, publishing of results on congresses and project applications.

TRAINING

Palliative care or palliative medicine cannot function without trained professionals, and that is why a large part of our activities is focused on training.

Three persons attended the postgraduate studies of PC, realized through international cooperation (Medical school in Zagreb and the University of Kent/Great Britain) in the duration



Picture 1 Visiting hospice in Tuzla

of 2 years. All three have successfully finished their training.

In October 2007 we were introduced to the work of the hospice in Tuzla that functions as a hospital ward. The deputy mayor of Pula Mrs Vesna Petrović and dr. Ksenija Družetić, head of the Emergency ward of the Community health centre in Pula visited the Tuzla hospice with the members of the palliative team.

In November 2008 we attended the conference: „Multiprofessional week in palliative care“ at the St Christopher’s Hospice in London. This training was particularly useful, since not only the palliative care volunteers attended, but also doctors from the Pula General Hospital (dr. Dragan Trivanović, dr. Tomislav Peharda), and heads of the health and social care departments from the town of Pula and the Istrian region (prof Sonja Grozić Živolić and prof Silvija Hrelja).



Picture 2. Marijana Bras, president of the Croatian paliative care society and Zoran Lončar at workshop together with Vesna Petrović, representing city of Pula

Several general practitioners and doctors from the emergency ward have attended training on pain treatment and the communication of bad news. A training workshop has been later organized in Pula with 36 participants.

Trainings were organized not only for health care workers, but also for 20 non-health-care volunteers, 7 of which are still



Picture 3 Ljerka Proštenik at volunteer education

active today. We have held lectures on palliative care for doctors, nurses, pharmacists and priests. We have attended several TV and radio shows in order to inform the wider public on the subject matter, articles on palliative care were published in numerous newspapers; we have participated in discussions in Pula and in Zagreb, held lectures to associations, etc.

WORK WITH PATIENTS

The question is often raised, if patients in their final phase of life need palliative house calls at all. The patients in a very severe state are taken care of in hospitals, the others are in the care of family doctors. According to a statistics published in the Croatian health care statistics chronicle from the year 2007, half of the patients die in their homes (52% of approximately 52000 deaths in 2007, 48% in 2008)x. The average number of deceased patients per health care team in the Republic of Croatia totals 22 a year (18 in the Istrian region). Half of these people die in their homes and they should receive a more intensive health care. The number of medical services in the year 2007 totalled 38 million on the level of primary health care, and the total number of services (primary, secondary and tertiary) was more than double. Is there room for house calls in such a huge number of services? Unfortunately, the same statistics shows a decrease of house calls in Croatia of 44% in the year 2006 as compared to the year 1990. Only 1,6% of health care services that doctors provide in Croatia are house calls, in Istria the percentage is even lower – only 1,4%. Who cares for the patient then in the final phase of his life and how are the symptoms controlled? The state is acceptable as long as the patient is mobile, but when the patient becomes bed bound and needs medical attention the most, this assistance is reduced to health care with poor symptoms control. The situation is even harder taking into consideration the insufficient communication between primary and secondary health care levels. We work with the patients in these circumstances and in this time. Although we cannot provide a complete palliative care, we regularly work with the patients and their families, relieving first of all pain, but also other symptoms related to the final phase of life. Patients or their families learn about us from other patients, from the family doctor or the pharmacist. Our work is based on house calls. The prevailing therapies include pain relief, followed by dealing with exhaustion, vomiting, dyspnoea. Very often the patient and his family are not aware of nor informed about the disease’s nature.

Palliative house calls are always a challenge. Here you get the chance to meet not only the patient, but also the care-giver (usually a family member) who is exhausted himself and needs help, too. The situations differ significantly, from households where the whole family is involved in the care, to patients with a cannula and a nasal-gastric probe living in a camping vehicle without running water or electricity.

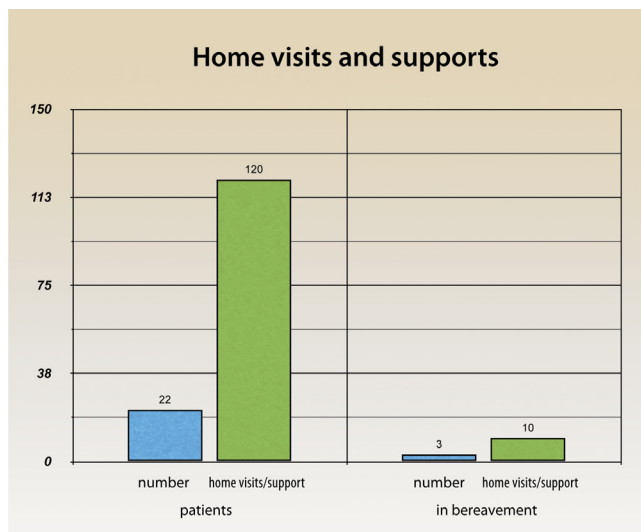
It is sometimes enough just to be there for the patient and his family in these situations no matter how difficult the circumstances are. The first house call usually lasts 1 to 2 hours. Afterwards a programme is drafted (involvement of a nurse, a social worker, a psychologist, a priest...) and the family doctor is notified that we are going to pay visits to the patient. The care-



Picture 4 Patient N. with a wife in their home.

giver can reach us on the phone up to the following visit.

A palliative team consists of a doctor, sometimes a nurse, a psychologist, a social worker, a non-health professional volunteer. We took care of 22 patients during the year 2008 paying a total of 120 house calls, for an average of 5-6 visits per patient. Some of the carers needed support after the patient's death, during the bereavement period.

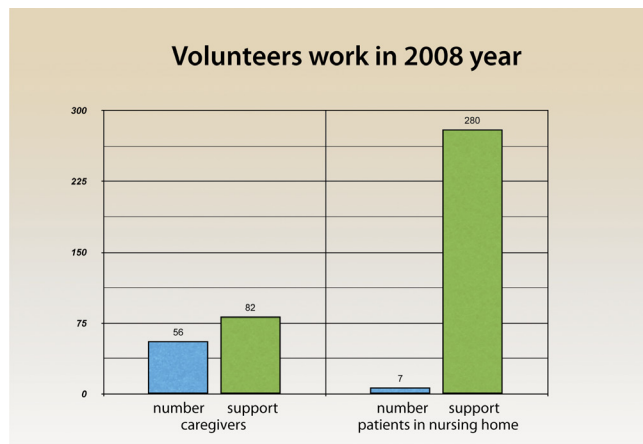


Picture 5 Review of users (patients and families in the bereavement) and a number of home visits and supports u 2008 year.

During these years, we provided for more than 100 patients and their family members. Unfortunately, the team is often included in the process in a late phase when it is extremely difficult to act (the patient is not known to us, the pain syndrome is very strong, the family desperate...).

NON-HEALTH PROFESSIONAL VOLUNTEERS

Our seven non-health professional volunteers work in the homes for the elder and frail or, more rarely, work with the house call team. Their work consists of support visits to the ill, assistance in the procurement of medicines, company for walks. Each volunteer has one patient under his care. The work



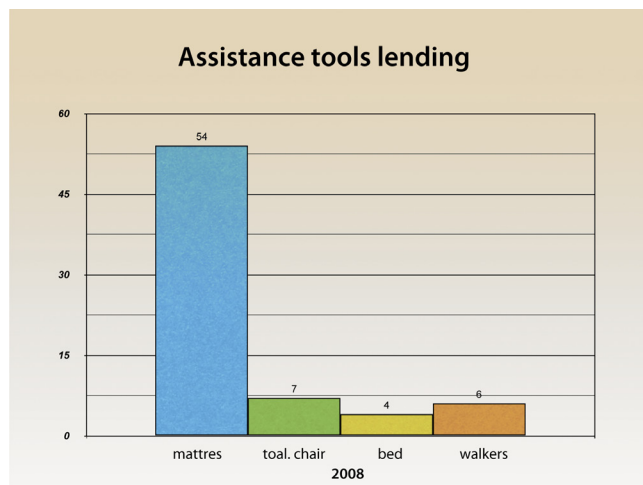
Picture 6 Review of volunteer work with caregivers and nursinghome patients in 2008 year.

of the palliative team and the work of all volunteers are supervised by the project manager.

The persistence and the accountability of our trained volunteers is recognized and highly esteemed by both the patients and the professional institution managers.



Picture 7 Volunteer Tea u visiting Mrs. A.V.



Picture 8 Rewiev of lending assistance tools in 2008 year.

Aids rental

A terminally ill patient needs a number of aids in his final phase of life, which are often hard to obtain, sometimes even after the patient's death. We have organized an aids rental in order to help our patients, solving thus the problem quickly until the aid is obtained by an approval of a medical committee. The most frequently used aid is the antidecubital mattress, preventing the consequences of immobility and long term lying of patients. Most carers receive assistance from volunteers at that point.

Presence at congresses

We are active within the Croatian association for hospice/palliative care. Our works are regularly published in Proceedings, and the model of our work was published in the first book on palliative care in Croatia.

We led a discussion round at the Second congress on palliative care in Zagreb under the title: "Quo vadis palliative care in Croatia", the conclusions were published as guidance for further activities of the promoters of palliative care.



Picture 9 IInd. congress on Palliative care in Croatia, 2008 Zagreb.



Picture 10 Is there a greater reward for our work. Volunteer Branka and mr. T.

Projects in course

According to the Health Care Act, palliative care is a health care measure at the primary level of health care, meaning that hospices cannot be founded without a supplement to the Act, since the legislation says that a Palliative Care Institution cannot be private. The volunteer work has limited activity possibilities which cannot be wider than they already are.

We are currently engaged in 3 projects:

1. Data analysis in cooperation with the Croatian Institute for Public Health of the Istrian region, regarding the need of patients for palliative care. A cost-benefit analysis should be produced based on the data and in cooperation with the association for pharmacoeconomics.
2. The project of determining the grade of anxiety and depression in nurses working with seriously ill and dying patients in its second phase.
3. Work with patients and the cooperation with the Clinical Research Network of the PRIZMA project and the King's College in the application of a questionnaire for the estimate of the quality of life of patients and carers.
4. The training of volunteers is continued as well as the presentation of our work.
5. The most acceptable form of providing palliative care is to be defined (as palliative stationary care or in the patient's home).
 - Palliative teams at the primary health care level.
 - Hospital palliative beds (4-6 beds in hospitals over 400 beds)
 - Founding of a hospice

Any form of palliative care will be defined by a good cooperation with other segments of the health care system and team work within and outside of palliative care.

The Istrian region and the town of Pula have financed so far our training projects and the work of the palliative team alongside with a selfless huge work of our volunteers. However, without a systematic financing of palliative care from the national budget, palliative care cannot be realized. This is no longer matter of our volunteer work, but a strategic and political decision of the Health Ministry and our national government.