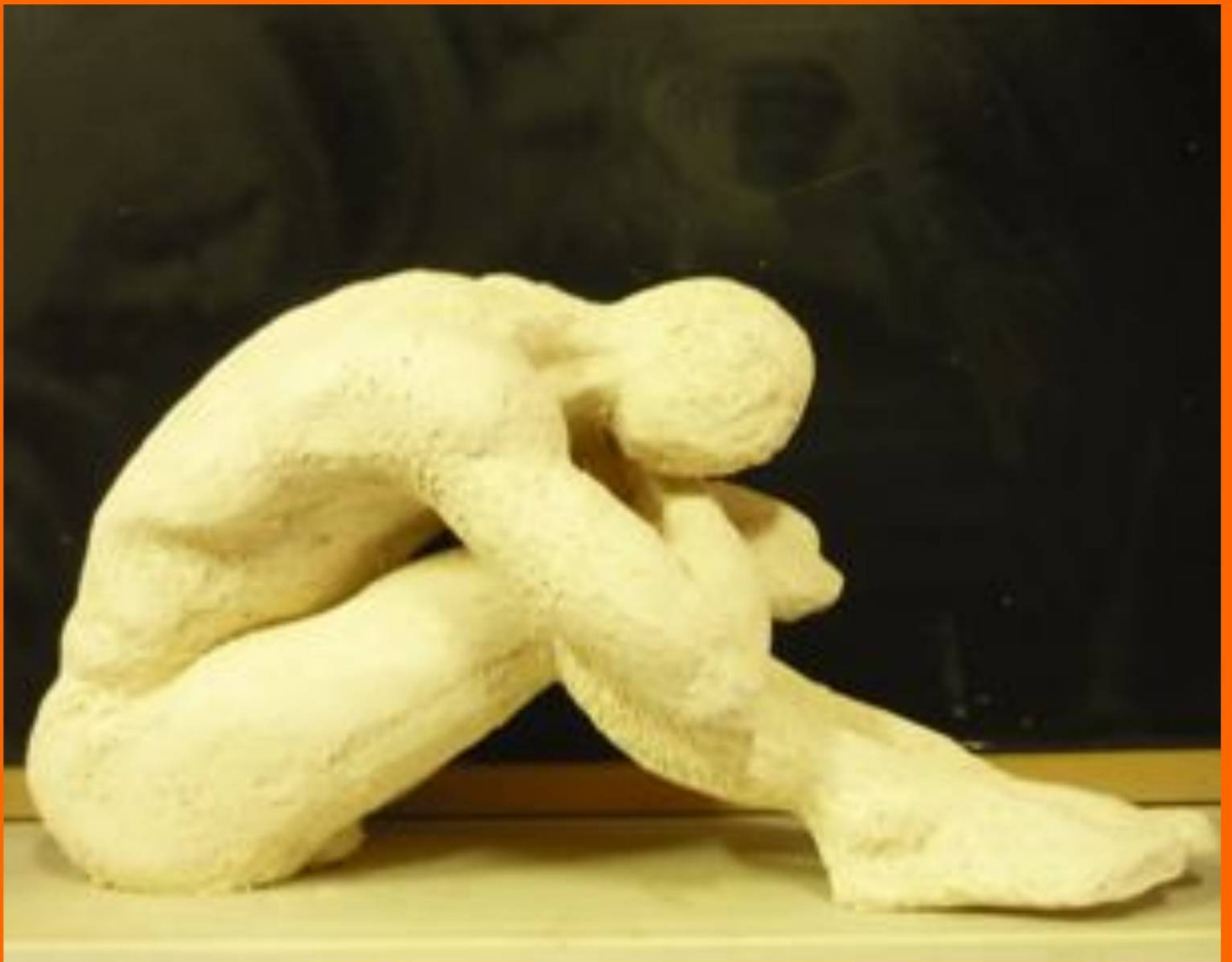


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EDITORIAL

Volunteers and their literary memorial

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In Europe Hospice and Palliative Care have been professionalized and needless to say, to some extent, medicalized. This development has marginalized people working in a honorary capacity. Let's put it another way: volunteers seem to become complements for professionals.

Nevertheless this is an inaccurate logic to follow. Psychosocial and spiritual attendance and counselling, the presence and attention of involved fellow men are the core and the heart of human and ethical tasks in hospice movement.

The original mission and purpose of Hospice and Palliative Care was to integrate death and dying people into society. Professionals are not to be integrated - their main interest lies in self-preservation and self-assertion. Only neighbours, relatives, beloved ones and citizens are truly able to integrate dying people into the social community. Professionals on the other hand tend to disintegrate dying people.

Taking these considerations seriously volunteers have to regain their vested right within Palliative Care and modern Hospice Movement.

In his prodigious novella *The Death of Ivan Ilyich*, Leo Tolstoy memorialized the volunteer's role literary: the servant Gerasim stays with his dying Master. He sits beside his bed and warms his feet with bare hands. His Master moves him to pity. He says: "We all have to die once so why shouldn't I do something for you." (Tolstoy, 1988). To do something for others is taken for granted, a momentum of care which sustains the Hospice Movement. That may in the very first place be an empathic feeling as well as the experience of solidarity or the advocacy on someone's behalf. Consequently a second step is needed to provide professional, inter-professional and organisational knowledge, skills and competencies. In fact the reverse is not possible.

Ivan Ilyich knew that nobody felt pity for him and nobody would understand his condition. Only Gerasim did and had pity on him. Hence, Ivan only felt at ease with Gerasim. He felt comfortable if Gerasim held his legs all night long and didn't want to leave him but only said: "Don't worry about me." Or all of a sudden added in an informal manner: "It is you who is ill, I do have to care for you."

Only Gerasim told the truth. Altogether one could realize that he was the only person to comprehend what it was all about and he alone decided not to tell an untruth. Thus he only felt pity with his exhausted and sick Master.

As he said: "We all once have to die so why shouldn't I do something for you." he expressed that he was not feeling annoyed or bothered because he did something for a dying person but implied that he hoped one day when his time had come a human being would do the same for him.

In general the idea of voluntary work within the field of Palliative Care and Hospice Care has slightly changed. The main point is not only to accompany strangers but to promote and utilize the concept of hospitality within the own profession. Apart from that, education plays an inevitable role in preparing people to work in consideration of sensitive belongings of dying people, their relatives and friends.

Volunteer work differs from full-time professional work to the effect of the scientific consensus that volunteers are the main experts for everyday occurrences. They bridge the gap to normality, to society and to the general public sphere. Furthermore they bring along compassion in different roles they play, being friends, partners, fellow men or companions. However relationships vary widely between giving and taking, not only in a symmetric or balanced manner.

Thinking of volunteer work in Hospice and Palliative Care, the attitude is most important. What matters is being able to listen and to support people with human, social and temporary presence. In fact the Hospice movement as well as Palliative Care and Palliative Medicine are undergoing profound changes also as far as the pressure of professionalization is concerned. Due to this reason volunteer work within the field is changing and has to find new shapes. On grounds of what has been said so far, it can be anticipated that volunteer work is going to get caught up in the maelstrom of professionalization and is going to change accordingly.

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ORIGINAL PAPERS

Development of the palliative care in Croatia: the first National Survey

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Abstract

The need for palliative care in Croatia is evident as in most ageing societies. Knowledge about the exact need and health care professionals experience is lacking. Therefore a survey was executed among 1564 citizens and 789 health care professionals.

The results show that citizens and health care workers recognise the need for palliative care. Health care workers report, that 30% of their patients need palliative care.

The majority of health care workers and citizens states that palliative care services should be set up, including hospices. Also the majority recognises the lack of services for terminal patients in hospitals.

It is concluded that palliative care is largely absent yet in Croatia.

Keywords: *palliative medicine, palliative care, hospice, Croatia*

Introduction

At the beginning of this century, Croatia entered a new phase of its development in terms of socio-economic and health affairs. Today, the country faces the challenges of transition, and economic and social changes also determine the changes in the health sector. As transition country stepped almost two decade ago into a process without precedent in economic history- the process of transition from non – private ownership to a private form.

The aim was creation of the market economy and parliament democracy. Its government has introduced policies and undertaken reforms to remove macroeconomic imbalances to establish market economy framework and to re-integrate the national economy into the

European Union and the global economies.(1). That economic process has been reflected on the healthcare system, too. Namely, from habitual social healthcare services, with the costs completely covered by state, today there is possibilities that citizens can choose between private and non-private services. But, the hospitals are still in state ownership.

The innovation is in third type of insurances. Along with basic and old –age insurance there is also the additional insurance. According mentioned healthcare system pass trough very turbulent phase and changes of transition. Some of these changes apply to the implementation of palliative care within the health service of the Republic of Croatia, which at the moment does not possess the resources required to satisfy the needs of palliative care. In addition, Croatia still lacks scientific, professional and practical training with respect to palliative medicine and palliative care. These are required to establish an acceptable level of palliative care.

The necessity to organize palliative care in Croatia might be more than obvious. According to the last census 17 % of population in Croatia are older than 65 years. However, it is not known what people know about palliative care neither data on the need are inventoried. Therefore a research was carried out with the participation of citizens and healthcare givers.

The objective of the study was to establish the level of informativeness of citizens about palliative care generally, and a need of the citizens for palliative care.

Participants and Methods

The survey was conducted through two anonymous questionnaires. One questionnaire was intended for the survey of non-health professionals, In total a randomised sample of 1564 persons received the questionnaire. The other questionnaire aimed to evaluate the attitudes of health professionals. This questionnaire was send to 789 health care professionals, selected at random in 7 Croatian cities. The introductory part of the questionnaire included information about the anonymity of the survey and its objectives. Next the questionnaire asked for socio-demographic data like sex, age, education, employment, the number of generations who lived in the household of surveyed persons, and specifically for health care professionals the length of work as health care professional.

For citizens (questionnaire one) the questionnaire continued with statements about satisfaction with the current organization of health care and about the provision of care for palliative care.

For health care professionals the questionnaire asked for the number of patients in need for palliative care and for the experiences in palliative care, including the number of patients cared for and continued with statements about the need of interdisciplinary teams for palliative care and which disciplines should be involved.

In each statement, the attitudes were measured by a Likert scale comprised of five levels: 1. strongly disagree, 2. disagree, 3. undecided, 4. agree, 5. strongly agree. The obtained data were analyzed by SPSS and adequate statistical methods depending on the type of data.

Results

The *health care professionals* answered the questionnaire overwhelming (97%) indicating the interest in and need for palliative care in Croatia. Indeed, based on their everyday work with the patients, the health care professionals stated, that 30 % of their patients need

palliative care. Of these patients in need for palliative care 20 % needed institutional care like hospice.

The need for organizing a system of palliative care is underlined by the opinion of the *citizens*, that little attention is given to terminal patients. Over 43% believe that little attention is given to terminal patients, while 13% of them considers that such patients are not given any attention at all. On the other hand, 2% of the respondents think that plenty of attention is given to terminal patients in their towns.

Over one third (36%) of the citizens express the opinion that Croatian state hospitals take very little care of terminally ill patients, while 16% of the respondents think that these hospitals take no care at all of terminally ill patients. On the other hand, 3% of the citizens answered that Croatian state hospitals take the utmost possible care.

The other results will be presented *combining* the answers of the citizens (non health care professionals) and the health care professionals in 7 Croatian towns, because the differences between the two groups were statistically not significant.

The need to establish a system of palliative care is recognised as 'strongly agree' by 53% of the citizens and health workers questioned. The total percentage of all participants, who are in favour of implementation of a palliative care system in Croatia is needed, exceeds 91%. Over 54% of responders completely agree that hospices need to be set up in their town, while 34% of them mostly agree with that. So a total of 88% of the citizens and health care workers consider the establishing of hospices in their town or county to be necessary.

Related to the sociodemographic characteristics, the study in rural places would probably reveal attitudes more in favour of a bigger role for the family rather than state hospitals in the care of terminal patients.

Discussion and conclusions

This Croatian National Survey is the first questionnaire about the need of implementation of palliative care in Croatian health care system which can be compared with other researches already conducted in many countries worldwide, which have adopted the universal questionnaire entitled: "The European Organisation for Research and Treatment of Cancer QLQ-C30: A Quality of Life Instrument for Use in International Clinical Trials in Oncology", (2) as well as the questionnaires developed by the Research Steering Committee of the European Association of Palliative Care.

The data confirm the need amongst Croatian citizens and health care workers for the organization of a palliative care system and the establishment of hospices.

There is also a significant number of papers on the assessment of the public's attitude on care at the end of life (3).

This study focuses on palliative care in end of life situations. It is evident, also from the international literature, that the need for palliative care is larger (4). Palliative care is not limited to end of life care.

A study among general practitioners in another Balkan country also showed the need for improvement of palliative care and their wish to learn more about it (5). But this applies also to other parts of the world, especially in rural areas (6) Therefore, the opinion of the health care professionals may be not representative for all areas of Croatia, since the sample was taken from cities.

The answers of citizens and health care professionals in Croatia regarding the organization and establishment of palliative care system, justify the conclusion is that the organization of palliative care is largely absent and has to be extended. Also establishment of a hospice in the regions in Croatia is seen as a need.

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CLINICAL LESSONS

Unusual reaction of rejection from the mother of a patient diagnosed with lung cancer, mediastinal nodes and pleural effusion

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Abstract

We present the case of a young male patient, 40 years old, unmarried, without children, diagnosed with lung cancer, mediastinal nodes and pleural effusion.

The patient was admitted several times at St. Luke Hospital in Bucharest and lastly stayed at Palliative Oncology Ward. He died after one year and 6 months after the disease was diagnosed. This case is presented because of the unusual and rare relationship with his family.

Usually, the death of younger family members is a reason for more bereavement and for parents the death of one of their children is very traumatic. The family offers support to the patient and is supported by and integrated in the palliative care team. This happens in the majority of cases.

In this case we try to support and assist the mother of the patient during the last part of life of her son. The relationship with her son was very strong, which is part of the culture of the rural county they were living before. The mother had an unusual attitude: she was aggressive to the team and rejected any attempt for support. We tried to inform her and to comfort her and we tried to understand her psychological, mental state. However, she did not allow us on any way. So we felt, we could not give the care as we wanted to.

Keywords: *cancer patient, family relationship, aggression, rejection of care*

MANAGEMENT

Volunteers in palliative terminal care in the Netherlands

3. Volunteers: selection, training and counselling

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Abstract

Volunteers play an important role in delivering palliative terminal care in the Netherlands. Volunteering is defined as the whole of activities done without payment by a volunteer for another person, group (without any blood ties), or the society as a whole within an organisation and without any obligation. However, it is important to recruit the right volunteers; therefore several procedures have to be followed, including detailed information about the role of the volunteer. Training of volunteers is necessary as well as continuous support and motivation. Another issue to consider is the relation between volunteers and professionals in the field of care.

Personal involvement and compassion are the most important qualities of volunteers, not expertise.

Keywords: volunteering, terminal care, palliative care, role of volunteer, role of care professional.

About being volunteer in Romania

1. Brief history, semantic meaning and legal aspects

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Abstract

This article is the first of two articles which describe the development and organisation of volunteering in Romania. This first one presents information about the beginning of volunteering in Europe, the semantic meaning of volunteering and legal aspects. The second article will deal with regulations on supporting volunteer activities in care at home for elder persons and aspects of volunteering in palliative care in Romania.

Objective:

The aim is to describe the legal aspects of Voluntary Law no. 195/20.04.2001 with the latest modifications and completions. These are placed within a historical context.

Material and methods:

The Romanian legislation on volunteers is inventoried and analyzed. The analysis is placed within the European and Romanian voluntary movement history.

Results:

The voluntary movement in Europe after the First World War was started with the 'godfather' the German sociologist and historian Eugen Rosenstock-Huussy. Besides Romanian milestones are presented. The International Year of Volunteers in 2001 declared by the United Nations, was also the year when Romanian Volunteer Law was adopted in its new and modern form.

Next the semantic meanings of volunteering in Romania is described. Legislative aspects start with the volunteer definition, establishing the beneficiary and the principles the law is laying on. Besides the volunteer's rights and obligations, the regulations on volunteering in the "Youth" program are presented.

Conclusions:

Romanian legislation which regulated volunteering work and responsibilities of volunteers was adopted with delay, as compared to western European countries because the hackneyed "voluntary work" in the communist propaganda. But also the mentality to obtain a material advantage from any 'volunteering' activity was another impediment to attract volunteers in actions of public interest.

After 2000 the number of volunteers is increasing, as are the nature and proportion of actions which volunteers are involved in.

Keywords: volunteering history, volunteering legislation in Romania, medical volunteering and volunteer organizations.

COMMENTS, DISCUSSION

Morphine use in severe pain-un justified fear

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Motto: "Pain is an oppressor of human kind. May terrible than even death itself."

Dr. Schweitzer Albert

Motto: "Pain is an absolute mess."

Milton

One of the most frequent human affections is pain, a symptom present in many diseases, accidents and present even in physiological states.

It may sound like a paradox, that even if there are available a wide variety of very effective pain-killers, in many cases pain can not be treated. It is a fact that many people are affected by pain and the quality of life is *damaged* by it. The quality of life is even more affected by this condition when this symptom is not only incompatible with a normal life but also can determine the person to end his life.

Hippocrates with his genius intuition has recognized the importance of the pain in human life and the duty to fight it. He has stated: "*Sedare dolorem divinum est*".

In the last decades WHO has published many studies regarding prevention of pain and the use of available drugs in various countries. We found, based on these publications, that pain is mistreated in many cases or is not treated at all. Pharmacological discoveries and solutions are not used.

Based on these studies, new recommendation are made, for the medical personal, for the education of the population and new study groups and workshop groups were formed. It was noticed that doctors are not used to prescribe the best pain-killers which are the opioids (morphine), the best treatment for sever pain. In studies made by specialized division of WHO, Romania is placed among the countries with the lowest use of opioids. This means that a large number of seriously ill and dying people are deprived of the best treatment against pain and they are condemned to meaningless suffering.

How we can explain this situation in Romania? First, the morphine is best known as a very good pain-killer, very effective against severe pain. Second, its use can cause addictedness, and it can be use by some people for no medical purposes (as drug addicts). Although this is true it must not prevent us from using correctly the opioids. The abuse in non-medical purposes is not linked with the medical use of morphine.

Possible (side)effects of using opioids (and also other drugs) are physic addiction (the sudden stop of using the drug leads to abstinence syndrome), tolerance (the usage and the need to rise the doses for the same effect), psychological addiction (behavior altering which leads to non-medical use of opioids). These effects can be prevented or controlled if the treatment it's held under medical supervision. Some side effects of morphine, like slow breathing or constipation, should not worry, because the diminishing of pain is more important, and these side effects can be treated separately.

It is noticed that even doctors are concerned regarding the use of opioids which made the WHO to recommend training doctors in this field. The idea of preparing doctors specialized in pain treatment, "pain-doctors" , is starting to become a fact.

There is another aspect, i.e. the fear of patients who associate the use of morphine with the (carcinogenic) diseases in the last stage. Here WHO has made also some recommendations about the education of the population. Actually, opioids are not prescribed due to the diseases, or the stage of the diseases, but they are prescribed, no matter the diagnostic, to relieve severe pain, which do not react to others painkillers.

The Romanian Health Ministry has taken the initiative of gathering a group of experts in the field of pain therapy, which lead to the modification of "drugs" law (30 years old) , which didn't fit anymore with the progress in pain killing therapy .The new law allows us to join the international practice of the developed countries, and also to follow the WHO recommendations.

NEW PUBLICATON

Praxis Palliative Care

At the end of 2008 a new journal started in the field of palliative care, called '*Praxis Palliative Care*'. The subtitle of the journal is '*For a good life until the end*'. This journal is with 6000 printed pieces the most wide-spread journal on palliative care in the *German language*. The journal offers a wide variety of information, directed to those who are working in the field of palliative care. The journal analyses problems on decision making and making choices in everyday palliative care praxis, but it also offers methods how to deal with such situations and it give (options for) solutions.

The quality of life of persons, receiving palliative care, is the central focus of the journal, but it recognizes that the role of families, volunteers and professionals is as much at stake and that their quality of life also needs attention. So contributions cover a variety of relevant subjects like 'Better nursing for body and mind', 'Possibilities to reach the patient', 'Between love, responsibility and duty', 'Bereavement support for families with a member, suffering from dementia'.

In Germany many palliative care organisations exist, strongly based in charity and volunteering. The journal services these organisations with the wide range of practical information. With the journal work documents are spread which enables workers in the field of palliative care to 'train themselves'. These work documents deal with important topics like 'Supporting death and bereavement' and 'How to deal with difficult, challenging situation in institutional care'.

This journal is recommended for all working in the field of palliative care. Policy makers, responsible for palliative care, would understand better what to do, when they read this journal. There is one draw back for most of the readers of PALIATIA: one has to understand German.

Care and quality of life in the dying phase. The contribution of the Liverpool Care Pathway for the Dying Patient

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This thesis studies the effect of introducing the Liverpool Care Pathway for the Dying Patient (LCP) on the content of care and the quality of life of the dying patient was studied. The Liverpool Care Pathway for the Dying Patient (LCP) provides care goals to ensure that dying patients and their family receive the best possible comfort care.

The research questions concerned the effect of LCP use on 1.the quality of life of patients in the last three days of life, 2.the content of care for patients in the last three days of life, 3.the communication in the last three days of life and the level of bereavement of relatives.

Data were collected asking a nurse, a physician and a bereaved relative to fill in questionnaires over time. The patients' physical symptoms, the content of care to patients and families, as well as some subjective aspects, such as the patients' psychological symptoms, and spirituality were assessed. Measurements included 3 periods: before the intervention when care was given as usual, during the intervention, i.e. using FCP when the dying phase started and after the patient died. In the baseline period, 219 nurses and 130 relatives filled in a questionnaire for 220 deceased patients. In the intervention period, 253 nurses and 139 relatives filled in a questionnaire for 255 deceased patients. The LCP was used for 197 of them (77%).

Concerning research question 1 in the intervention period, the average total symptom burden was significantly lower. For research question 2 the dying phase was considered as being recognized when the patient's record contained any written documentation concerning the start of the dying phase. Caregivers recognized the dying phase of 380 patients (78%). The number of patients receiving diagnostic interventions was significantly lower when the dying phase was recognized (39%), as compared to when it was not (57%). Significantly more patients with a recognized dying phase were routinely turned (46%) and had a syringe driver set up (36%), as compared to patients without a recognized dying phase (25% and 12% respectively). Significantly fewer patients with a recognized dying phase underwent lab tests (15%), radiology or ECG (12%), blood pressure measurements (21%), and body temperature measurements (26%), as compared to patients without a recognized dying phase (39%, 22%, 48%, and 50% respectively).

For research question 3 bereaved relatives filled in a questionnaire for 57% of the patients, on average four months after death. In the intervention period, relatives had lower bereavement levels as compared to relatives of the baseline period. Communication was evaluated similarly for both periods. LCP use during the dying phase seems to contribute to lower levels of bereavement in relatives.

The main conclusion of the study is that the use of the LCP can be recommended for the care for dying patients. It is a noteworthy result that, according to the nurses and the relatives, LCP use contributes to better symptom control in dying patients.

Keywords: communication, end-of-life care, LCP, symptoms

NEWS

International Day of Palliative Care

The *International day of Palliative Care* is held on Saturday 10th October 2009.

4th International Trondheim Conference on Palliative Care

Trondheim, Norway - October 15 - 16, 2009:

“Palliative care: Treatment, research and organizational issues in a multidisciplinary perspective”