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## EDITORIAL

### The non-oncological palliative care

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For a long time palliative care was thought to be exclusively for cancer patients in terminal stages. This idea is evidently changed in the last years because of the aging “boom” and the related (co)morbidities as dementia, AIDS, diabetes, chronic heart failure etc. Modern medicine has often no solution for the cure in frail old but can delay the inevitable end. Cicely Saunders recognised the ‘non oncological dimension’ of palliative care about half century ago, when she designed a department in St. Christopher’s Hospice for “dying people and frail old”. She understood the need for palliative care in old patients.

Meanwhile international organizations – UN, WHO, Council of Europe, EURAG – have focused on the development of the non oncological palliative care, specially the geriatric palliative care. The International Plan of Action on Ageing (UN, Madrid 2002) was the strategy in Europe adopted at the Ministerial Conference on Aging, Berlin, September 2002 for elderly. A special paragraph stipulates palliative care for older people in the document "Berlin Ministerial Declaration - A society for all ages".

Various epidemiological arguments (ageing of the population, increase of chronic diseases, the pattern of co-morbidities, mortality) underlined the need to widen palliative care.

About future aging in Romania we can say that in 2050 there will be two billion old people (1 person of 5 will be old). In only a few years – 2020 – about three quarter of all deaths will be due to aging in developing countries, most elderly people will die because of a chronic (vascular, neurological, endocrinological) disease, which terminal stages will require specific adaptations in palliative care.

Related to aging, the late-onset of Alzheimer's dementia (60-70% of all cases of dementia) requires in the final stages of evolution (5,6,7 Reisberg) appropriate palliative care. This also applies to many neurological diseases that requires specific palliative care in the terminal stages. Finally, another disease developing in variable time after onset, without curative therapeutic solutions till now, is AIDS; in the terminal stage these patients have diverse and intense symptoms. The palliative care in the last phase has a specific character because of the young age of these patients, which requires the presence and intervention of psychological care.

In conclusion, palliative care has common principles and content that must be adjusted to the specific disease: cancer, dementia, AIDS and other diseases as well as to specific age groups: elderly, adults, children.

Key words: *non oncological palliative care, geriatrics, dementia, AIDS*

## ORIGINAL PAPERS

### Quality of dying and death: concept and measurement. An analysis

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#### Abstract

##### *Objectives:*

This paper describes the meaning of the concept of quality of dying and death. It presents the most common instruments to measure quality of dying and death. It reports about an international index on quality of death.

##### *Methods:*

The descriptions are based on a literature search, followed by an analysis of the findings in the literature.

##### *Results:*

The concept of quality of dying and death is often not well defined. Most definitions combine aspects as patient's preferences, including time of dying, with reducing suffering and dying with dignity.

Two instruments are frequently used and well validated, i.e. the Quality of Dying and Death (QODD) and the Quality of Dying and death in Long-Term Care (QOD-LTC).

Recently a Quality of Death Index is developed, which compares 40 countries on quality of dying and death provisions.

##### *Conclusions:*

Quality of dying and death becomes an increasing important concept in health care. More research is needed to develop instruments to measure the concept more precisely. The available Quality of Death Index lacks proper indicators to measure quality of dying.

*Keywords:* quality of dying, death, measurement, quality of death index, end-of-life care

#### Introduction

Quality of life has been introduced in the seventies of the last century as an objective for health care outcome. Quality of life was measured through the assessment of physical functions by an 'external' rater (mostly a medical doctor). In the eighties the concept was widened in health care, following social science research (1). Quality of life is considered as a 'subjective' concept since then. Quality of life refers to an individual's wellbeing, i.e. emotional, social, and physical aspects of life. In health care quality of life is also called health related quality of life, referring to the individual's wellbeing in relation to disease, a disability, or a disorder. Quality of life, i.e. basically the patient's view, has become legally a significant factor to initiate or not a medical treatment/intervention. The patient's quality of life has become an important indicator for treatment and quality of health care, especially in patients with chronic illnesses and in frail old. Quality of life may have a special meaning in end-of-life care (2).

In the last decades medical knowledge, technology and public health policies have changed life expectancy, morbidity patterns and the range of medical interventions. Life expectancy is increased enormously (and will do), the number of chronic ill people has increased too as

well as the number of frail old. This is especially the case in developed countries. New medical specialities have been developed around care for chronic ill people, frail old and dying patients (geriatrics, palliative care specialists, nursing home physicians). So, 'end-of-life-care' has become a new speciality in health care in most developed countries. Other concepts, besides the concept of quality of life, have become more important, i.e. quality of care and quality of dying and death (3). With 'end-of-life-care' not only quality of life has to be taken in account but also quality of dying. For health care professionals the Hippocratic 'duty to cure and not to harm' is shifting to 'not to harm and relief suffering'. Besides quality of life quality of dying has to be considered as an important indicator of quality of care since health care may have a greater effect during the dying process (2).

In the last decade various studies have described quality of dying and death and some instruments are developed to measure it (4). Otherwise than the concept of quality of life, where the person himself is the main 'assessor', quality of dying and death can largely be assessed after the person has died. This raises the question who should/could be the assessor of quality of dying and death and what criteria have to be used.

Medical knowledge and welfare make it possible to minimise suffering as death approaches. However, provisions for end-of-life care are often not available. Over 100 million people would benefit from such provisions world wide, but less than 8% of those in need have access to such provisions (5). End-of-life-care and the growing interest in quality of dying and death (in some developed countries) may become another indicator to assess the quality of care. Indeed a 'quality of death index' has been developed to compare the quality of end-of-life-care in countries.

These developments raise several questions, which will be explored in this article:

1. What is meant by quality of dying and death?
2. How to assess quality of dying and death;
3. How do various countries score on quality of dying and death?

### **The meaning of quality of dying and death**

Generally, from the patient's perspective, quality of dying will be associated with being free of discomfort as far as possible, surrounded by beloved ones and receiving qualified care. Dying in such a situation may be described as 'good death' (6) or 'high quality of death' (7). A "good death" also encompasses important social, psychological, and existential elements and not feeling a burden. A "good death" is characterized by physical comfort, social support, acceptance, and appropriate medical care, and should minimize psychological distress for the dying and his family (8).

A precise definition of quality of dying and death is not easy. The definition does not only depend from the patient's preferences and the disease process, but is also related to availability of and accessibility to qualified care.

In a systematic review on measures on quality of dying and death Hales et al. (4) show that most authors do not provide a 'formal' definition. Of the 31 studies they present 21 did not provide such a definition.

Various authors (9,10) define quality of dying and death as the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others. Tsai et al (11) refer to 'good death', i.e. when patients suffering is reduced as much as possible, death is accompanied with dignity, and time of death is appropriate.

Bridge et al. (12) present a quite different approach. They consider quality of death as the quality of life of the client in the last two days. This approach is in line with Wallston et al.

(13), who describe quality of death as feelings and events that terminally ill patients reported they desired during the last three days of life.

Most definitions combine aspects as patient's preferences, including time of dying, with reducing suffering and dying with dignity. However, what dignity means is less clear. The concept of quality of dying and death is seen as a multidimensional concept. The most common dimensions include: physical experience, psychological experience, social experience, spiritual/existential experience, nature of health care, death preparation, and circumstances of death (3).

### Measuring quality of death and dying

Various instruments have been developed to measure quality of dying and death. In almost all instruments, by definition, others than the dead person have to assess the quality of dying and death. Family members are the most obvious source, especially in those countries where dying in the presence of family is common practice. This is the case in most countries in the world but not so in North America and Western European countries. Quality of dying and death is measured mostly by written questionnaires to be filled in by family members and/or care providers, sometimes completed with qualitative interviews.

The number of validated instruments published in international literature is limited. We present here the most used ones.

The most common instrument is the Quality of Dying and Death (QODD) questionnaire. This instrument is developed in the USA (10). It rates the patient's dying experience on various domains.

The QODD contains originally 31 items; each item had to be scored between zero (terrible experience) and ten 10 (almost perfect experience). In older studies the *total score* is used to assess the quality of dying and death. More recent validation studies show four empirical (latent) dimensions, reducing the total number of items from 31 to 12 (14). In overview 1 the latent dimensions and measured indicators are shown.

Table 1- Overview 1: (latent) dimensions of QODD and their indicators (14)

Dimensions of QODD	Indicators
Symptom control	Having pain under control. Having control over what was going on. Being able to breathe comfortably.
Preparation	Having the means to hasten death, if desired. Visiting with spiritual advisor. Having funeral arrangements in order. Having health care costs covered.
Connectedness	Sharing physical expressions of affection. Spending time with family and friends.
Transcendence	Feeling unafraid of dying. Feeling at peace with dying. Feeling untroubled about strain on loved ones.

Other versions of the QODD have been developed, based on the original one. There is a special version for health professional, combining patient's experiences to be rated by the health care professional (15 items), completed with questions about the medical care patients received and how the patient experienced this care (4 items), with questions about experiences at the moment of death (3 items) and with a overall rating of quality of care (2 items).

A special instrument is developed to measure quality of dying and death in long-term care facilities (QOD-LTC) (15,16). Specific versions are available for patients with dementia or with cognitive impairments. The dimensions and validity of the various versions is different. The QOD-LTC distinguishes three dimensions: personhood, closure, and preparatory tasks. The psychometric quality is seen as acceptable.

In the Good Death Inventory (GDI) the perspective of the bereaved family is the central issue. This instrument is developed and validated in East Asia (11,17,18). Eighteen dimensions have been distinguished. Each domain is measured with at least three questions. The dimensions are: environmental comfort, life completion, dying in a favourite place, maintaining hope and pleasure, independence, physical and psychological comfort, good relationship with medical staff, not being a burden to others, good relationship with family, being respected as an individual, religious and spiritual comfort, receiving enough treatment, control over the future, feeling that one's life is worth living, unawareness of death, pride and beauty, natural death, preparation for death.

The Good Death Scale (GDS) is used in the USA and in some Asian studies (8,19,20), but less is known about its validity. Three dimensions, measured by 11 indicators, are distinguished: psychosocial/spiritual, physical and clinical.

The overview of instruments to measure quality of dying and death shows a large variety in dimensions. Individual preferences, social relationship, availability of expertise and facilities may all play a role in the assessment. No wonder, since the same variation could be observed in the description of the concept of quality of dying and death.

### **Provisions for qualified care for dying and death**

Given the (possible) role of environmental factors in assessing quality of dying and death, the question is raised how do various countries and health care systems score on quality of dying and death. A recent study (5) has developed a Quality of Death Index. Twenty four items are used to measure Quality of Death. Each item is weighted. Four dimensions are used in this Index and also each dimension is weighted:

- Basic end-of-life health care environment (10 items) (weight 20%),
- Availability of End of Life care (4 items) (weight 25%),
- Cost of End of Life care (3 items) (weight 15%),
- Quality of End of Life care (7) (weight 40%).

The most important dimension is quality of End of Life care, having a weight of 40%; the least weight (15%) has cost of End of Life care. Items in quality of End of Life care include: public awareness of end-of-life care, availability of pain killers, doctor-patient transparency and accreditation for end-of-care providers. Basic end-of-life care environment deals primarily with life expectancy, number of doctors, and gross national income and percentage spend to health care. Theoretically the highest score could be 10 and the lowest 0.

Based on these four weighted dimensions 40 countries are scored with a maximum of 7,9 and a minimum of 1,9. A score of 5,0 means the quality of end-of-life care is far from perfect. About half of the 40 countries score a 5,0 or more. The top five countries are: United Kingdom, Australia, New Zealand, Ireland and Belgium. The last five countries are: Mexico, China, Brazil, Uganda and India. Remarkable is the absence of South Eastern European countries, except Greece and all African countries, except Uganda.

The data show a worldwide lack of end-of-life care. One may question what factors are causing this lack of end-of-life care. Looking at the countries with a relatively high score indicates that end-of-life care is given in rich countries. They are able to incorporate palliative care strategies into their overall healthcare policy. Training for palliative care is still rarely

included in healthcare education curricula in most countries and palliative and end-of-life care often have to rely on volunteers or charity.

Also, death maybe seen as a taboo among the general public and among health care professionals. Therefore building public awareness on dying and death is important together with expertise in end-of-life care, especially in primary health care. The availability and use of painkilling drugs is another important cause why end-of-life care is not given (properly).

## **Discussion and conclusions**

This paper started with the concept of quality of life, which has become important in health care outcomes during the last 20 years. The last decade the concept 'quality of dying and death' is receiving more and more attention. Although the definition of this new concept is far from clear, instruments are developed and validated to measure quality of dying and death. So various instruments are available to measure the quality of dying and death in end-of-life care. Nevertheless, as the study of Downey et al. (14) shows, additional developments are needed.

These developments concern primarily the theoretical basis of the concept. One issue is the balance between the assessment of the dying person himself, the experiences of family members and the experiences of health care professionals. Another issue is how the quality of dying and death is related to quality of life, i.e. how do the 'objective assessment' by family and health care professionals relate to patients' wishes and perceptions about his life. By what methods should the patients' wishes and perceptions be assessed is another issue for further study. In some studies questionnaire are supplemented with qualitative interviews which will present a more complete picture on the quality of dying and death. More attention should be given to the feelings and experiences that terminally ill patients reported during the last weeks/days of life.

Inclusion of end-of-life care into broader health policy is important. A great concern is that only a few, rich' countries score high on the Quality of Death index (5). End-of-life care is not expensive per se. Probably the taboo of death in many societies and the 'curing task' of health care professionals may prohibit the development of proper end-of-life care. Training in nursing and medical schools on end-of-life care is a prerequisite. The General Assembly of the European Council has adopted a resolution asking each country to develop a proper policy in end-of-life care. Training in schools of health care professionals and developing expertise in palliative care have to be an essential part of such a policy.

The outcomes of the Quality of Death index may also be questioned for two reasons. It is remarkable that the United Kingdom and Ireland score highest with Australia and New Zealand. Of the 22 interviewed experts half are from the Australia, United Kingdom, and the United States of America (5). In the index quality of dying and death is strongly associated with palliative care provisions, and especially with hospices. For most countries in the world, however, end-of-life care means care at home. Therefore, the expertise in primary health care to support end-of-life care should be an important indicator for quality of dying and death.

Also the emphasis on general health care data (like life expectancy, number of old people and number of doctors) and economic data (like gross domestic product and costs of health care) show that the index is a measure of health care development generally and does not really focus on quality of dying and death, i.e. the feelings and experiences of terminally ill patients.

Due to medical knowledge and technology and to the demographic development the importance and need for end-of-life care will increase. The presence of end-of-life-care indicates the interest policy makers and health care professionals have in the wellbeing of their citizens and patients. So far, we may conclude that this interest is largely lacking.



Inclusion of end-of-life care into broader health policy, and the improvement of standards of end-of-life care will significantly contribute to the quality of life of citizens. Policy makers in health care should pay more attention to end-of-life care.

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## On the issue of palliative care education of physicians in Russia

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### Abstract

The importance of education of medical specialists and primary care physicians in palliative care has been highlighted in a number of International and Federal documents, declarations and guidelines.

Palliative care started 20 years ago in the cancer field in the Russian Federation and has been actively developed since then. The Russian Cancer Palliative Care Centre was established by the Health Ministry of Russian Federation Order № 222 (dated 27.06.2001) embedded in the Moscow Research Cancer Institute.

The Federal Postgraduate Cancer Palliative Care Training Program for physicians was developed and approved by the Russian Health Ministry in 2000. The program addresses all aspects of palliative care: physical, psychological, social and spiritual. Today this palliative care training programme is considered to be the best specialist state certificate course in palliative care.

In Russia like in most countries of the world palliative care genesis occurred at the junction of oncology and anaesthesiology. Cancer palliative care was born to meet the need of patients with advanced cancer to be released from unbearable pain.

Palliative care provides treatment and support not only for patients with advanced cancer. We know that patients with non-cancer life threatening diseases and children with life threatening and life limiting diagnoses are under its umbrella and “pallium”. Therefore, palliative care issues are included not only in the educational cancer programmes, but are taught in other university departments such as the Department of Medical Bioethics, the Department of Health and Health care, the Department of Pediatrics, the Department of Infectious diseases.

Also, specific palliative care clinical guidelines, for example in HIV/AIDS, have been developed and published.

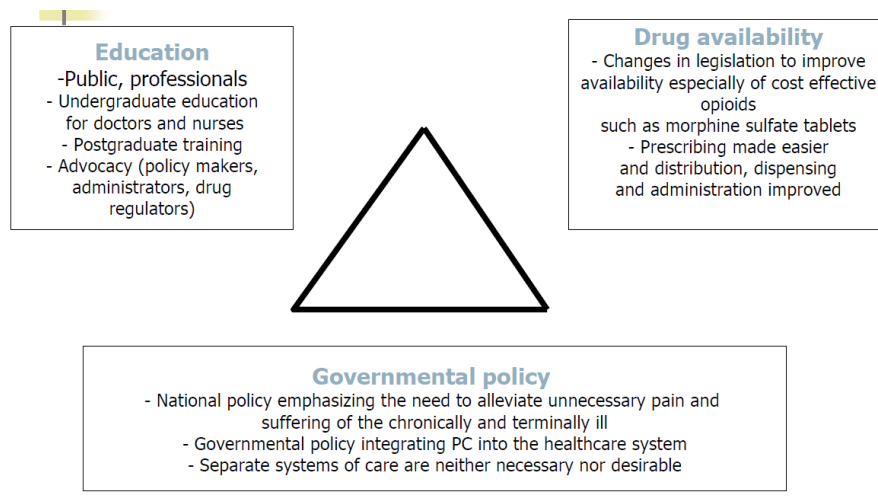
We assessed district doctors' self-confidence in performance of 17 different end-of-life clinical skills. It shows that most of district doctors were competent to perform patient management at the end of life only with close (50%) and minimal (32%) supervision/coaching. Almost all respondents (98%) noted that such issues, as symptom control, communication and ethics at the end of life should be included in the Medical Universities Graduate and Postgraduate Curriculums.

Although education in palliative care has made progress, it has still to be incorporated fully into the medical curricula.

*Keywords: palliative education, doctors' skills in palliative care, Russia*

### Introduction

Palliative care education is one of the three core components of the WHO Public Health Strategy alongside with appropriate policies, adequate drug availability and implementation of services at all levels throughout the society (Stjernswärd J, 2002).



The importance of education of medical specialists and primary care physicians has been highlighted in a number of International and Federal official documents, declarations and guidelines. This also should apply to palliative care.

### **Palliative care development the Russian Federation**

Palliative care is a relatively new service approach in the Russian Federation. It started 20 years ago in the cancer field and has been actively developed since then as well as the effective curative cancer treatment. Its aim is to improve the incurable cancer patients' quality of life. The number of those in need for such palliative care is more than 300 thousand people annually in the Russian Federation.

Palliative care started with the establishment of small pain clinics/rooms at some leading Cancer Research Institutes - the All-Union Cancer Research Centre, the Medical Sciences Academy, the USSR, Leningrad Cancer Research Institute named after professor NN Petrov; the Rostov Cancer Research Institute, and Moscow Research Cancer Institute named after PA Herzen, in the late 1980s. The first hospice for cancer patients was organised in St. Petersburg in 1990. The Russian scientific, methodological and educational centre for chronic cancer pain control was set up in 1991 and the Expert Council for Cancer Palliative Care Organization was opened in 1993. The first cancer palliative care department was founded in Moscow city clinic № 11 in 1994.

The research medical journal "Palliative Medicine and Rehabilitation" has been published in the country since 1996. Later palliative care articles became available in the medical journal "Health and Quality of Life".

### **Palliative care education**

Palliative care education for physicians first started at the First Moscow Sechenov State Medical University Cancer Department Palliative Care Course in 1999 (led by professor GA Novikov). The Federal Postgraduate Cancer Palliative Care Training Program for physicians was developed and approved by the Russian Health Ministry in 2000. The evidence-based program addresses all aspects of palliative care: physical, psychological, social and spiritual. Today this palliative care course is considered to be the best specialist state certificate course among palliative care educational units in the country and physicians from different cities attend it.

The course tutors are well-known experts in the field, with great clinical experience and unique personal qualities that are so important in the field of specialist palliative care. The

tutors also provide participants with the opportunity to explore ethical issues for patients approaching the end of life and to develop their communication skills in palliative care. The training is provided for clinicians with different background.

The core course curriculum modules are the following:

- cancer palliative care organizational and methodological approaches;
- chronic cancer pain diagnostics and treatment;
- homeostasis disorders in cancer patients' diagnostics and management;
- psychological and social aspects in palliative care.

Clinical hand-on training of physicians is conducted in Moscow City Clinical Hospital № 11 and at the 5th Hospice in Moscow South-West Administrative District. Course participants have the opportunity to take part in clinical meetings/discussions which are held twice a week.

This course is not the only one in the country. At St. Petersburg Postgraduate Medical Academy (the Federal Mechnikov Agency for Health and Social Development) palliative care issues are included in full in a postgraduate course for physicians "Cancer Prevention and Diagnostics, Palliative Care for Cancer Patients."

The Russian Cancer Palliative Care Centre was established by the Health Ministry of Russian Federation Order № 222 (dated 27.06.2001) embedded in the Moscow Research Cancer Institute named after PA Herzen. It works in close collaboration with clinical, academic and other units of the Institute. Clinicians working for the Centre see and provide advice to cancer patients with severe pain admitted to the Institute. They also provide clinical analysis of complicated and difficult cases and provide counselling for specialists - oncologists and therapists. The leading specialists in pain control and researches are employed by the Centre and most innovative scientific ideas and research articles are coming from its staff. Therefore the Centre is also considered to be the leading educational institution for physicians.

Special attention should be paid to the city of Ulyanovsk where palliative care development was initiated by the Medical Faculty of Moscow Lomonosov State University branch in 1992. The academic staff of the Cancer Department developed the University curriculum "Hospice and palliative medicine" for teaching 4, 5 and 6 year medical students of universities and medical colleges in 1995. Additionally (according to our data), 7 other palliative care courses exist at the medical universities of Tumen', St. Petersburg, Ufa, Yaroslavl', Chelya-binsk, Arkhangel'sk, and Moscow (the Russian Medical Postgraduate Academy).

In Russia like in most countries of the world palliative care genesis occurred at the junction of oncology and anaesthesiology. Cancer palliative care was born to meet the need of patients with advanced cancer to be released from unbearable pain. Palliative care provides treatment and support not only for patients with advanced cancer. We know that patients with non-cancer life threatening diseases and children with life threatening and life limiting diagnoses are under its umbrella and "pallium".

Therefore, palliative care issues are included not only in the educational cancer programmes, but are taught in other university departments such as the Department of Medical Bioethics, the Department of Health and Health care, the Department of Pediatrics, the Department of Infectious diseases.

HIV/AIDS palliative care issues are included in the certification HIV training course within the specialty "Infectious Diseases" which is held by the Federal Scientific and Methodological Center for AIDS Prevention and Control (Head, Academician Vladimir Pokrovsky). The course is designed primarily for professionals working in the field of HIV prevention and control - infectious disease physicians working for district, republican, territorial, regional and

urban centres for AIDS control, as well as the physicians from the penitentiary system medical service, TB services, etc. The course also provides training for physicians - infectious diseases specialists from different kinds of polyclinics and hospitals and all physicians who wish to improve their skills in HIV infection.

HIV/AIDS palliative care clinical guidelines have been developed and published. A lot of HIV/AIDS palliative care educational activities were organised in the framework of GLOBUS project during the period of 2005 – 2009 and later in the framework of “The Priority National Project on Health” when numerous palliative care workshops, seminars and conferences were held and the leading Russian experts were invited to teach the participants. During this project period many specialist books and brochures were published and distributed among the people involved.

There are fewer educational programmes in palliative care for children. Some seminars and conferences were organized in 2004-2008 by the Federal Research and Clinical Centre of Paediatric Haematology, Oncology and Medical Immunopathology”. It is known that palliative care education of paediatricians is provided by Professor EV Polevichenko, Head of Department of Paediatrics Faculty Dean, Rostov State Medical University. The existing children’s hospices are places for professional education.

The “places of hospice excellence” in Moscow and St. Petersburg, the first Moscow hospice and the hospice in Lakhta, provide hand-on training for physicians on demand which is a really unique and very valuable experience.

Physicians have an opportunity to improve their knowledge in palliative care attending research conferences that often take place not only in the “capitals” but in other cities of the country.

### **Doctors’ skills in palliative care**

We conducted a study with the aim to assess district doctors’ self-confidence in performance of 17 different end-of-life clinical skills; comfort with difficult end-of-life clinical decisions (e.g. treatment and hydration withdrawing, shifting in treatment approach from curative to comfort care) and also their interest in learning about end-of-life clinical and ethical topics. We translated into Russian and used a tool “A Survey Instrument to Measure Physician Self-Confidence and Concerns about End-Of-Life Clinical Skills and Decision-Making” designed by David E. Weissman and Bruce Ambuel (Waukesha Family Medicine Program; Medical College of Wisconsin).

The results of our study showed that most of district doctors were competent to perform patient management at the end of life only with close (50%) and minimal (32%) supervision/coaching. Almost all respondents (98%) noted that such issues, as symptom control, communication and ethics at the end of life should be included in the Medical Universities Graduate and Postgraduate Curriculums.

### **Professional information on palliative care**

Existing palliative care books, handbooks, professional guidelines are also the source of professional education for physicians. The information about training opportunities, internships, new instruments and programs in palliative care is a regular contributor to the Internet for news site [www.pallcare.ru](http://www.pallcare.ru) ; the web-site activity has been supported by Nizhny Novgorod Initiative for the development of palliative care since 2006.

## Conclusion

Although education in palliative care has made progress, it has still to be incorporated fully into the medical curricula. The main objectives for the development of education and training for doctors are the following:

- organization of palliative care educational departments and/or regular courses at the medical high education institutions for providing education and training for medical students as well as for postgraduates
- development of national palliative educational standards
- establishment of a system of palliative care education and training in the country
- legalise regulations for licensing palliative care department as well as hospices, including the prerequisite that the facility staff is certificated, i.e. confirmed training in palliative care at the state recognized educational Institution.

All these measures could be taken regardless the fact whether the new medical specialty/subspecialty “palliative care” is approved or not.

**Conflict of interest:** none

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## Palliative care in terminal AIDS cases

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### Abstract

The advances in the treatment of HIV infection significantly improved the life expectancy of these patients, but we are still unable to cure them.

#### *Material and method:*

The Regional HIV Centre in Iasi did a follow-up of 1031 HIV infected patients from 9 counties of Nord-Eastern Romania. We retrospectively studied the charts of the patients who died of AIDS in the last five years (2007-2011).

#### *Results:*

In that five years 43 death patients were recorded (median 9 years). Eighteen deceased patients had a progressive and irreversible respiratory failure due to pneumocystosis pneumonia or tuberculosis, 15 patients had a multi-organ failure and 10 patients had a meningeal coma. The palliative therapy was conducted throughout the hospitalization of the terminal stage.

The patients who survived longer required psychological support from admission until they lost their state of consciousness. These were 23 patients with a duration of psychological palliation from 2 to 32 days.

The following disciplines were involved in the palliative care of the deceased patients: infectious disease specialist, intensive care specialist, psychologist, priest, nurses, friends and family of the patient.

#### *Conclusion:*

Palliative care of terminal AIDS patients involves a multidisciplinary team who has to cope with the medical, psychological and religious needs of the dying patient.

Key words: *AIDS, pneumocystosis, psychological palliation, terminal care.*

(Full text in Romanian)

## CLINICAL LESSONS

### Particular aspects of opioid treatment in patients with chronic kidney disease

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#### Abstract

The number of patients dying with end-stage renal disease (ESRD) on renal replacement therapies or on conservative treatment is continually increasing. Therefore, the necessity for effective symptom control becomes a pressing issue.

Pain has been reported to be a common problem in the general population and ESRD patients. The high prevalence of pain in the chronic kidney disease (CKD) population is particularly a matter of concern because pain has been shown to be associated with poor quality of life and with poor survival. Some studies demonstrated a reduced pain control in CKD patients by analgesics, especially opioids under prescription. Pain could appear in ESRD patients, as well as in cancer patients that develop renal insufficiency.

The use of opioids for chronic non-malignant pain has become increasingly accepted. Based on the World Health Organization analgesic ladder for pain, opioids should be prescribed and used for pain that is classified as moderate to severe or when non-opioid analgesics have failed to achieve optimal pain control. Opioids must be carefully managed for all patients to effectively control pain while minimizing adverse effects. It is recommended that meperidine and codeine are avoided in renal failure/dialysis patients; morphine, hydromorphone or oxycodone are used with caution and close monitoring; and that methadone and fentanyl/sufentanyl appear to be safe to use.

Note that there are no "safe" drugs in renal failure; titer and careful monitoring is mandatory.

Key words: *chronic kidney disease, opioids, pain*

(Full text in Romanian)



## **Palliative care for patients with congestive heart failure**

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### **Abstract**

Provision of palliative care based on the needs of the patient and not on diagnosis will extend the content and quality of palliative care for patients with advanced heart failure. The guidelines advice palliative care (IP) for patients with congestive heart failure (CHF) describes the classic treatment of the disease and underlines the importance to give the needs of the patient a central place in the care plan. However, we still do not know exactly the content and extent of patients needs and there are no clear criteria for selection of these patients neither how to meet their needs.

*Key words: heart failure, end of life, palliative care, care plan*

(Full text in Romanian)

## **Principles and particularities of palliative care in Alzheimer disease**

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Patients with Alzheimer disease are a very special group in palliative care. Some particularities, as communication difficulties, profound changes of personality, disorientation etc. put special task on the palliative care team. The team needs to elaborate a special intervention strategic plan: adaptive, flexible, anticipatory, multidisciplinary, securing and profoundly ethical. Understanding the patient and his life is an absolute prerequisite.

Professional interventions should be, at every moment, the right solutions to deal with multiple problems of the patient and, at the same time, the most suitable answer to simple questions or difficult dilemmas. The intervention plan includes also the family of the patient. The common goal for family and professionals is to take care for the dignity, the comfort and the quality of the end of life of the patient.

*Key words: Alzheimer disease, end-of-life, palliative care, intervention plan*

(Full text in Romanian)

## MANAGEMENT

### The importance of HIV-AIDS Palliative Care Team in a Clinical Hospital for Infectious Diseases

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#### Abstract

Health care is a basic human right. Sick and suffering people are deeply vulnerable. They are searching for treatment and if possible cure, but also for answers to the meaning of their suffering, the meaning of their life, their relationship to God, and what happens after they die. Some patients may go abroad for medical treatment.

In the Clinical Hospital for Infectious Diseases, Constanta, the HIV-AIDS Palliative Care team offer a wide range of therapies and support (pain therapy, infectious surveillance, psychotherapy, psychological and religious support, law consultancy on care abroad). It is essential that all activities take into account medical confidentiality, ethical aspects, human dignity, and compensation of vulnerability. We offer consultancy on HIV-AIDS patients, terminal patients too, including care and treatment abroad. Last year, nine HIV – AIDS patients from our hospital travelled to West Europe. Before travelling they ask palliative care and treatment consultation.

The HIV Palliative Care team offers medical, nursing, psychological, ethical and pastoral care to persons living with AIDS in the local congregation, integrating the well-being of our patients, caregivers, family and friends, enhancing the course of treatment, healing process and end of life care.

Key words: *terminal patient, HIV/AIDS Palliative Care Team*

#### Introduction

Health care is a basic human right. Sick and suffering people are deeply vulnerable. They are searching for treatment and if possible cure, but also for answers to the meaning of their suffering, the meaning of their life, their relationship to God, and what happens after they die. For patients looking for treatment and cure may have high priority. Therefore, they want to go abroad for medical treatment.

When patients are confronted with AIDS their emotions and reactions are often intense, including dangerous ones like panic. Their emotions and reactions may create behavioural and relational problems, which are difficult to control by care providers and family members. They show the (potential) conflict between the rights of the individual and the rights of society in perspective. The long latency period which is very different from one individual to another creates uncertainty, vulnerability and strong emotional reactions. AIDS involves two extremely important taboos for mankind – sex and death and gets the impression that is an

equation – sex equals death. Regardless the taboo, patients should always be informed about the disease. Patients may react against the permissiveness practised, interpret these as punishment from God etc.. Besides, the diagnosis brings restrictions on travel, on education, on employment. It is important to provide accurate information, to explain that AIDS is not a highly contagious disease. In Romania, we need funds for research, for education, but also for screening and treatment. At the same time the disease give rise to serious ethical questions.

### **International recommendations**

Support of NGOs to fight against AIDS must be carried out in conjunction with the health care programmes already set up by the countries concerned, by the World Health Organisation and also with the various local or national organisations in different countries which all play a role in the fight against AIDS:

- informing the population (Given the popularity of the radio in African countries, it could be used to great effect. Brochures should use illustrations and not printed texts);
- training of medical personnel;
- the foundation of detection centres and the improvement of blood transfusion conditions (the prevention of HIV by blood transmission, the prevention of mother-child vertical transmission);
- care and support of the sick and their families;
- the prevention of HIV by sexual transmission by informing people about the disease, its modes of transmission and the simple ways of protecting themselves, by alerting the population of the danger represented by this infection for the population as a whole so that they would adopt a more responsible attitude, by reassuring the general public to situate the disease in its true place within the general pathology (1).

*The AIDS Control consists of:*

- surveillance to promote, support and coordinate data collection and analysis in order to identify trends in HIV infection, considering its social, demographic and economic implications;
- health promotion, i.e. developing, promoting and evaluating educational activities to change perceptions, attitudes, behaviours;
- research and technological development in the clinical, epidemiological, operational, psychological, and ethical field;
- diagnostic laboratory tests, the control of blood;
- human resources: coordinating, promoting, supporting the formation of professionals in all relevant areas;
- planning, supervision, evaluation;
- medical assistance: recognition, diagnosis of HIV infection in all phases focusing on the home, ambulatory and hospital, prison;
- specific prevention is recommended for the control of HIV infection in pregnant women, the use of infectious and other skin piercing instruments, recommendations for the control of HIV injections in prisons, instructions for the use of condoms (1).

### **Risks for HIV-AIDS**

AIDS remains a leading cause of serious illness and death for young adults. The disease course is not uniform nor predictable. Risk factors vary from sexual intercourse and drugs use to blood transfusion. Using survey data nationwide projections estimate that 540,000 people die after ICU admission each year in the USA. The age-specific rate of ICU use at the end of life was highest for infants (43%), ranged from 18% to 26% among older children and adults, and fell to 14% for those >85 years (2).

The highly active antiretroviral therapy (HAART) transform HIV into a manageable chronic disease. Need for psychosocial, family and care planning support, for comprehensive symptom management is fundamental (3). HIV has profound psychosocial effects on the HIV infected person, the family, the community and the society (4).

### HIV-AIDS Palliative Care team

Constanta is one of the important towns in Romania and the “Clinical Hospital for Infectious Diseases” is well-known. In this centre the HIV-AIDS Palliative Care team offers a wide range of therapies and support (pain therapy, infectious surveillance, psychotherapy, psychological and religious support, law consultancy on care abroad). It is essential that all activities take into account medical confidentiality, ethical aspects, human dignity, and compensation of vulnerability. We offer consultancy on HIV-AIDS patients, terminal patients too, including on care and treatment abroad.

Currently activities are focused on infectious disease treatments. A patients history is not only a physical history but also a “spiritual history”. Treating patients is “like reading a biography”. Our centre is the interface of medicine, palliative care, religion, spirituality, law, psychology, epidemiology and public health (5).

HIV-AIDS patients are local and international travelling for medical care - “medical tourism”, from poor countries to prestigious medical centres, from EU and USA abroad to find lower cost care, or even procedures that may not be available domestically. Costa Rica, India and Thailand were the most frequented destinations for care, orthopaedic, cardiac, cosmetic and infertility procedures, for HIV – AIDS Americans. Debates are focused over the dangers and ethics of medical tourism, over the use of procedures that have not been rigorously tested, over the potential for citizens of poor nations to be neglected in favour of serving the “tourists”.

Last year, nine HIV – AIDS patients from our hospital travelled to West Europe. Before travelling they ask palliative care and treatment consultation. The travel context and pilgrimages ask to analyse special health risks, food and water hygiene, problems of sanitation, occupational infections involved by interpersonal relations, but also for a intense cooperation between doctors, psychiatrists, priests, social workers, psychologists, and palliative care experts (4).

Before explaining the way we work, we will first present some statistical data about our centre. The number of HIV – AIDS patients receiving treatment in our hospital, between January 2008 and June 2011 is presented in Table 1, showing we are treating over 500 patients per year. Most patients are between 15 and 24 years old and most patients are living in cities.

Table 1 - Clinical Hospital for Infectious Diseases, Constanța, HIV Patients between January 2008 and June 2011

HIV Patients		Total	Men	Death	Rural	Hospital days	< 1 year	1-4	5-14	15-24	25-34	35-44	45-54	55-64	65>
2008	Acute	525	208	13	162	5254	1	2	11	378	44	52	26	9	2
	Chronic	84	21	2	-	4410	-	-	4	80	-	-	-	-	-
2009	Acute	352	163	4	117	2653	-	-	12	236	34	26	26	14	4
	Chronic	201	107	9	60	5060	-	-	-	191	10	-	-	-	-
2010	Acute	396	197	8	122	4966	-	-	2	263	37	37	28	26	3
	Chronic	162	88	2	54	2442	-	-	-	111	10	6	20	15	-
2011 half	Acute	334	147	5	122	3744	19	16	11	210	26	27	12	12	1
	Chronic	30	2	-	4	585	-	-	-	29	-	-	-	1	1

Number of hospital beds, admissions and discharge of HIV-AIDS department in the period January - June 2011 are presented in Table 2.

Table 2 - Number of hospital beds, admissions, and discharge in the HIV-AIDS department January-June 2011

		Number of beds	Already in hospital	Admitted	Discharge hospital
HIV AIDS ACUT	Child	5	4	51	47
	Adult	15	37	284	287
HIV AIDS CHRONIC	All	24	30	29	30
PALLIATIVE CARE	All	5	4	15	13

The HIV Palliative Care Team offers ethical and pastoral care to persons living with AIDS in the local congregation, integrating the spiritual and emotional well-being of our patients, caregivers, family and friends, enhancing the course of treatment, healing process and end of life care.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, psychosocial and spiritual. Top-quality palliative care can make the difference between a gentle death and one in which suffering is so terrible and prolonged (6,7,8).

Psychological support and psychotherapy are used to treat behaviour disorders like anxiety, phobia, depression. Such disorders affect attention, memory, emotional equilibrium, interpersonal relations, performance at work, quality of living. Psychological support may counteract the neuropsychological and psychosomatic diseases (9). Psychotherapy is a conscious and planned interactional process that aims to influence the behaviour disorders. Its treatment is offered by consensus and with well defined aims. Psychological methods and techniques, to be learned and based on theories about the normal and pathological behaviour, are applied in common and implies a reliable emotional relationship (9). Cognitive behaviour techniques combine elements of action, learning and support, including mental self programming, cognitive restructuring, correction of mental automatisms, the rational-emotive method, assertiveness, psychical self regulation. These techniques optimise correct behaviour and solve the difficulties of everyday living and stimulate self control.

The psychotherapeutic and formative theological message is meant to contribute to the acceptance of the theologian's authenticity. Positive relationships are stimulating feelings of safety, therapeutic alliances, collective catharsis, assimilation of problematical experiences, modification of expectations, realisation of insights, creativity, adaptation. (10,11,12,13,14). We apply hypnosis and self-hypnosis to regulate behaviour and to control and stimulate therapeutic efforts. We are working in respect and with empathy. Faith is considered as a resource, a way for resilience, supporting the cooperation between doctors, psychiatrists, priests, social workers, psychologists, on AIDS - support (15,16,17).

## Conclusions

AIDS is a social, medical and public health problem. Confidentiality, from the perspective of the health of the public as a whole, is an imperative placed on doctors, not to disclose information about their patients. First time described in the Hippocratic Oath, modern time

included in the Declaration of Geneva of the World Medical Association, confidentiality occupies a central position in a medical ethics.

The arguments for maintaining medical secrecy, the concept of medical confidentiality are so highly valued in certain countries that they were included in laws as an almost absolute privilege. Medical confidentiality has a close relationship with principles that we greatly esteem: personal privacy, individual autonomy, trust, truthfulness, honesty, operating both in the interests of the individual and of the public in general. Doctors will be in a much better position to safeguard patients health if they are informed about the relevant facts of the patient's illness and personal life. Patients are much less willing to disclose sensitive information about themselves if they believe it may be passed on to others.

Actually, it has to be considered that medical confidentiality may deprive others of the information needed to protect themselves from HIV - AIDS infection and may prevent society from discovering the extent of the infection within it. The efforts to overcome the threat of AIDS are, in fact, essential to the success. There are circumstances when it may be proper in the public interest to disclose confidential information about an AIDS patient or HIV carrier without that patient's consent – to public health authorities whose responsibility it is to control the spread of infectious diseases (1).

Let us hope that with AIDS, the entire world will unite its forces until such time as the disease is wiped out, whatever the country, whatever the colour, because is a problem which affects the entire planet.

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## COMMENTS, DISCUSSION

### Palliative care in 2011

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Palliative care comes with a new philosophy of care bringing the patient as a suffering person with all his/her needs in the centre of care. In ex-communist countries (and outside) this model is a challenge for the existing disease orientated health care system and, as a result, resistance is occurring in the process of integrating palliative care.

On the other hand palliative care is resonating with deep human values, is addressing a real need and is extremely important for that period in the person's life when vulnerability and need of support is huge. Fortunately, palliative care is continuously gaining supporters among health care professionals, communities, medical authorities and policy makers. Despite economic crisis and poverty palliative care is steadily spreading in the Central and Eastern Europe. The recent conference, supported by the Open Society Institute, in Bucharest (see Paliatia 2011, 3) has highlighted the recent achievements in the region without claiming to be exhaustive.

When moving forward palliative care there are several ways to push for decisions: the human rights arguments, economic arguments, research data, collaborative work and praising, "shaming and blaming", etc. Now recent examples of success and pitfalls are presented, we may expect further action from policymakers in Central and Eastern European countries.

Key words: *palliative care, Central Eastern Europe, achievements, advocacy modalities*

(Full text in Romanian)



## NEW PUBLICATION

### **Care in the last months of life. End-of-Life Care registration in the Netherlands by a Network of General Practitioners**

Abarshi EAB

PhD Free University Amsterdam, the Netherlands 2011

This study analysis data on patient care in the last months of life. The data are derived from registrations of a representative network of general practitioners in the Netherlands. Within one week after death the GP fills in the data of non-sudden death. The registered data include socio-demographic characteristics, place of death, nature and purpose of care, and various aspects of end-of-life care. The analysed data were registered in 2005-2008.

The data show that most patients died at home or in a care home (twice as many as died in hospital). If expected death by the GP was recognised before a patient's last week of life GPs had more patient contacts and death often occurred in the patients' preferred place. In these cases, GPs also discussed specific end-of-life issues with the patient like possible complications, physical problems, psychosocial problems, and palliative care options. Ten end-of-life issues are considered in the research: primary diagnosis, incurability of illness, life expectancy or prognosis, possible medical complications, physical symptoms, psychological problems, social problems, spiritual or existential problems, palliative care options and treatment burdens with terminally ill patients.

Being younger and educated, having cancer, and mental ability were related to discussing the ten issues with their patients. Physical and psychological problems were discussed most frequently; while social and spiritual problems were least discussed by/with GPs.

Almost half of the GPs were not aware of the preferred places of death of their patient. Of those GPs that were aware were mostly informed by the patients themselves.

Transition of care setting in the last three month of life by the patient is also studied: 690 patients made 709 transitions in the last 3 months. The most frequent transition was home-hospital (48%). Two out of every three transitions involved hospital at some point. Terminal hospitalisation (i.e. in the last 7 days of life) was associated with age ( $\leq 85$  years), infection, and absent palliative care treatment goal.

Special attention is given to end-of-life care to the oldest old. Comparison is made between the oldest old ( $> 85$  year) and the old (65-84 years). Comparatively, fewer oldest old patients received palliative care, and more preferred to die in a residential care home as compared to the old. Although the GPs did recognise the "palliative phase" in the oldest old, they received less palliative care.

The study also compared the frequency of GP visits and palliative care service utilisation in Belgium and the Netherlands. The average GP visits in the last week of life were 5,1 at home and 4.4 in the care home in the Netherlands; in Belgium the averages were 3.2 (home) and 2.3 (care home). In Belgium palliative care services were more often used in the last three months of life compared to the Netherlands: 78% vs. 41% (home) and 39% vs. 5% (care home). The differences between the two countries are probably due to differences in existing policies and the organisation of healthcare.

This study shows, that awareness among GPs of patient wishes could be improved. If the GP recognises the dying phase early more desirable end-of-life care outcomes may be expected. A tool could support the GP in recognising the dying process is time. Such a tool is the Gold Standards Framework (GSF).

## **NEWS**

### **Advance Directives Related To Use Of Palliative Care, Lower Medicare End-Of-Life Spending**

A recent study at the University of Michigan indicates that advanced directives do have an impact on health care at the end of life, especially in regions of the country with high spending on end-of-life care. This might be a strong argument for policy makers to prioritize palliative care, although the 'human argument' should be more important.

### **Survival Rates Unaffected By End-Of-Life Discussions**

A new study published in the Journal of Hospital Medicine shows that discussing and documenting patients' preferences for care at the end of life does not cause them any harm, contrary to recent claims.