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CONTENT

EDITORIAL

Further development is needed

Heuvel van den WJA

ORIGINAL PAPERS

Addressing cancer distress screening in Romania: partners and needs

Degi C, Mild B, Vagasi J

CLINICAL LESSONS

Causes of death in geriatrics

Bogdan C

Palliative care in malignant ulcers

Grigore D

The role of the family in palliative care at home of patients with pressure ulcers

Veria C

Palliative treatment in restless legs syndrome

Focșeneanu B

MANAGEMENT

The importance of multidisciplinary collaboration team: palliative care specialist - epidemiologist- pathologist in the study of specific local aspects of the natural history of HIV-AIDS

Șerban IG, Ghiulendan R, Marcaș C

COMMENTS, DISCUSSION

Palliative surgery and palliative care - partners in incurable diseases

Leșe M

NEW PUBLICATION

Dying at home

NEWS

New project Hospice Emanuel

The picture on the cover: *Herfst* from Ton Dubbeldam, Netherlands (1990)

EDITORIAL

Further development is needed

Prof. Dr. Wim J.A. van den Heuvel, Chairman International Editorial Board PALIAȚIA

In the seventies of the last century – now 40 years ago – the first ideas on ‘psycho-social oncology’ were discussed in the USA. The idea that patients with cancer as well as family members suffered a lot was not so new. New was the idea that more scientific research was needed to develop effective interventions to help patients and families to cope with the psychological and social impact of cancer. Among health care professionals the need for such research and interventions was disputed. Many of these professionals – as the public – had the opinion that disclosure of the diagnosis ‘cancer’ would harm the patient more than benefit. For years, families and health care professionals cared for patients with a secret, which influenced negatively the caring process and the quality of life of patients.

In The Netherlands in 1976, a special institute for research in psycho-social oncology was founded by the Dutch Cancer Society, of which I was appointed as director. This institute developed instruments to assess quality of life in cancer patients and designed interventions to deal with psycho-social problems in patients and families. Communication was one of the key issues: communication between patients/families and professionals, between professionals and between patients. The later resulted in organizations for specific patients groups, where patients could exchange their experiences as well as their ideas about better care and support. In addition, research on the effectiveness of cancer prevention was executed: primary prevention (healthy life style and healthy environment) and secondary prevention (screening to detect preliminary signs of cancer).

These days psycho-social oncology is integrated in cancer research, in the development of new treatments and in the care for patients and their families in most western countries. In Romania, this development is just starting and rather new, as we learn from Csaba Degi et al in this issue of PALIAȚIA. The need for psycho-social intervention in oncology is evident, but it has to be feared that it takes a long time to be part of palliative care practice in Romania.

As we learn from the articles and news in this issue of PALIAȚIA, the comprehensive, interdisciplinary concept of palliative care is well known and accepted among palliative care professionals. By palliative care terminal ill patients are supported, treated, comforted and are allowed to die – even of ‘old age’ as Prof. Bogdan states.

We know most patients want to be care for at home and if not possible in a ‘home-like’ environment, while in between care (day care, respite care) arrangements are also needed. Such a well balanced palliative care facility needs enough manpower with palliative care expertise. We learn that such balanced facility is in development now in Bihor. It will not be easy, but the need is evident all over Romania and other CEE countries.

In Europe, in EU, in Romania various conferences, committees, expert meetings have plead for a national strategy to stimulate the further development palliative care. The ideas how it should be done are available, the people who are willing to work on it are present, but most policy makers do not consider palliative care as a priority. In Romania health care is not a priority at all for policy makers. This does not make the need for the development of better care less urgent, on the contrary. But it urges us to try harder and harder. PALIAȚIA will support and help.

ORIGINAL PAPERS

Addressing cancer distress screening in Romania: partners and needs

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Abstract

Background:

Cancer distress screening is new method in Romania, still in early development and not well-known. Diakonia Christian Foundation and the Romanian Cancer Association are partners in creating new possibilities in this field.

For the first time, we performed a pilot psychosocial screening of cancer patients and their care givers in Transylvania.

Methods:

We interviewed patients (N=100) and used two screening instruments (FACT-G 4.0 and BDI) to assess distress.

Results - conclusions:

Cancer as both a fate and faith-turning experience needs standard psychosocial screening in all its forms and settings. This is our main message. It means that in Romania we need at least a psycho-oncology office in all four regional cancer institutions in Romania.

Key words: *cancer distress, screening, needs, pilot study*

Introduction

Cancer does not appear from one day to another, but rather in a long process, and its causal factors could be followed back to several dysfunctional interactions between the environment and the organism. Still cancer diagnosis hits patients suddenly and mostly unprepared, generating crisis, panic and disorders on many levels (1).

Although cancer morbidity and mortality are not considered incidents of civilization (1), in Europe still each year around 3.2 million new cancer cases are diagnosed and 1.7 million deaths are recorded due to neoplastic diseases (2). According to the World Health Organization, a 50% growth in cancer incidence is expected by 2020, which is 16 million new cancer patients and 10.3 million cancer deaths worldwide over the next decade (3).

Cancer development, pathology and prognosis have multi factor origins and aspects. Based on the psycho-oncologic approach and relevant literature, we can assume that psychosocial

factors have a particular role in cancer diseases, since they contribute to the continuation or exacerbation of this chronic disease (4).

Our previous results show that in Romania 16.9% of cancer patients are not aware of their oncological diagnosis, 47.5% are clinically depressed, 46.7% experience anxiety disorders and 28.1% report critically low quality of life. Among cancer patients suffering from clinical depression 85.4% have some type of malignant disease and 90.7% of those indicate low quality of life; 75.9% of cancer patients who report low quality of life are also facing clinically relevant depressive symptoms. Moreover, almost two-thirds of the cancer patients to whom cancer diagnosis was not disclosed are highly or severely depressed (5,6).

Our data demonstrate the widespread negative effects of cancer diagnosis non-disclosure, of clinical depression and of low quality of life on psychosocial functioning of hospitalized cancer patients in Romania. This prevalence, on the one hand, significantly increases hopelessness, illness intrusiveness, anxiety, vital exhaustion, depression, emotion-focused coping, lacking of the family support, behaviour inhibition and external locus of control and, on the other hand, decreases problem-focused coping, physical-, emotional-, social/familial- and functional well-being, sense of coherence and self-efficacy in cancer patients. Cancer diagnosis non-disclosure, clinically significant depression and seriously decreased quality of life are more prevalent among persons with malignant tumours and among older, undereducated, widowed and socioeconomically deprived cancer patients (6).

Romania still has to adapt and develop psychosocial assessment protocols which would allow appropriate screening for cancer distress in cancer patients, specifically depression, anxiety and quality of life. Lack of psycho-oncology specialists and services in state-financed oncology hospitals is partly counterbalanced by the most accessible private or non-profit community facilities, namely the palliative and supportive care groups. The Diakonia Christian Foundation's, home nursing and a palliative care program and the Romanian Cancer Association's, "Common Destiny" groups represent best practices in this field in Transylvania.

Palliative home care service

The Christian Foundation Diakonia from Cluj Napoca, Romania is a non-profit organization with the mission of supporting those with illnesses, diseases and social problems, offering the beneficiaries equal chances regardless of certain specific differences (e.g., nationality, religion, ethnicity, sex, political beliefs), thus contributing to the strengthening of an individual and his / her responsibility based on the Christian value system.

The Diakonia began its activity in 1992 and since then it has developed and offers its services in several areas of socio-medical work. Our activities evolved around four major areas: 1. Home care: medical care (1992), palliative care since 2007, social care „Adopt a Granny”; 2. Social, educational and community development activities in the village of Mera; 3. Elderly homes “Good Brother” and “Mother,” and 4. National and international volunteering.

After numerous medical investigations, the diagnosis of an incurable disease, the run from one hospital to the other, the patient's family becomes helpless, vulnerable and hopeless. The patient does not respond to any curative treatment. This is where palliative care helps to enable the patient to live with dignity and without unbearable physical and mental pain in the last period of their life.

After 17 years of experience in home care services and a preparation period in the field of palliative care, 2008 marked the truthful starting point for delivering palliative care services in Cluj Napoca. This service is financed by the organization “Something for Romania” from

Scotland since 2007. The palliative care services are free of charge both for the patient and his / her family. The care is provided by a multi-disciplinary team which consists of a doctor, nurse, care givers, a social worker and on voluntary basis, pastors and psychologists are involved.

The objective of the multi-disciplinary group is to improve the quality of life of the patient through controlling the symptoms (pain, nausea, depression etc.), counselling and educating the family regarding the day to day care of the patient. The team works together closely with the family or other relatives, the treating specialist doctor and the family doctor. As a first step our multi-disciplinary team develops a multi-disciplinary care plan.

The care plan

Standard 1. The care plan is based on a comprehensive and interdisciplinary evaluation of the patient and family.

Criteria: The evaluations are realized through interviews with the patient and the family, revision of medical records, as well as examinations and evaluations, both clinical and paraclinical. The first visit for initial evaluation is done by the doctor and/or the medical assistant. This evaluation includes the documentation of a complete diagnostic, stage of disease, prognosis, associated conditions, physical and psychological symptoms, functional status, socio-cultural environment and spiritual background. The evaluation of children is done, taking into consideration their age and the stage of neuro-cognitive development.

The demands of the family and of the patient concerning the objectives of the care service, their understanding of the diagnostic and prognosis, and their preferences regarding the place of care giving are documented and evaluated.

Standard 2. The care plan is based on needs, objectives and values expressed by patient and family.

Criteria: The care plan is implemented in discussion with members of the interdisciplinary team, the patient and family. It identifies the problems, the objectives and advised interventions as well as the professionals involved, the date of evaluation and the frequency of visits. There is a designated case coordinator who monitors the implementation of the care plan. This plan is reassessed after a maximum of seven days from the first visit by at least three representatives of three different areas of expertise within our team. The plan is revised according to the needs or at least once a month during the usual multi-disciplinary team meetings (these take place once a week).

Standard 3. The care plan is signed by the patient or by the relative in case the patient is not competent.

Standards concerning the process of care giving - principle: palliative care aims to improve the quality of life of patient and their family through a holistic approach, i.e. the physical, psychological-emotional, social and spiritual domains.

The physical domain

Standard 1. Relieve of pain and other distressing symptoms for all patients.

Standard 2. The medical personnel, assesses, plans and implements a plan for pain control and other symptoms associated with the disease.

Criteria: The pain and the other symptoms are being assessed and monitored regularly according to the care plan and the care plan is completed. The symptoms are initially assessed using the Edmonton Symptom Assessment System - ESAS. The reassessment of the symptoms is made by using the same tool, after at least three days and documented in the care plan. The pain is assessed initially using the validated Brief Pain Inventory - BPI. The performance status is assessed using ECOG / WHO performance status and documented in the care plan. Other validated tools are being used for assessing the symptoms such as the Mini-Mental State Exam - MMSE, for cognitive functionality and Hospital Anxiety and Depression Scale - HADS, Beck Depression Inventory - BDI for anxiety and depression. The tools can be adapted for use with children and patients with cognitive disorders.

Pain management and other symptom control are considered effective when the symptoms cease or are brought to an acceptable level for the patient. The barriers to effective treatment of the pain must be recognized and discussed including terms related to side effects, addiction, respiratory depression, and opioid toxicity. Interdisciplinary consultation and intervention of other specialists are being asked for if required.

Nursing

Standard 1. The nurses assess the mobility and self-care capacity of the patient and collaborate in goals achievement and appropriate interventions as part of the care plan.

Criteria: The nurse identifies the level of self-care in activities, eating and mobility, as well as the risk of developing pressure sores, using standardized tools – such as the Waterlow Pressure Risk Assessment Tool.

The nurse implements and documents the established intervention in the care plan and reassess it periodically. She or he educates the patient and family regarding the prevention of pressure sores using the available equipment. The nurse assesses and documents the nutritional needs of the patient and recommends the adequate diet and its method of administration. The patient and the family will be educated regarding the needs of specific nutrition depending of the stage of the disease.

Standard 2. The palliative care service encourages that patients have as much oral nutrition and hydration as is possible.

Psychological and psychiatric aspects

Standard 1. Due to the diagnosis of an incurable disease there is psychological suffering causing stress, anxiety, depression and anticipatory grief, this challenges the patient and family's coping mechanisms and their ability to adapt to their changing circumstances. The members of the interdisciplinary team assess the emotional needs of the patient and family and a plan is implemented to provide support and address psychosocial needs.

Criteria: The level of understanding and acceptance of the diagnosis, prognosis, therapeutic options and compliance with the treatment are identified along with their emotional reaction to the disease and the willingness to communicate openly with the team members. The key members of the family involved in care-giving are assessed regarding any need of additional emotional or psychological support.

Referrals to the psychological or psychiatric services are made for cases which exceed the medical team's competence.

In the plan of caring goals and actions are agreed on regarding the psycho-emotional aspects, and the efficiency of the interventions and the appropriate modifications of the plan

of care according to the phases of the disease which the patient and the family are going through.

Standard 2. The entire clinic staff is trained in ways of emphatic communication and emotional support and can build a therapeutic relationship with the patient and care givers and can manage the daily situations.

Criteria: At the initial training, each member of the clinic team follows a course of communication and approach of the psycho-emotional aspects. The course has a minimum of 30 hours. During the professional activity, the clinic staff benefits from each training day in communication and self development, but also in recognizing and managing the emotional reactions to loss and death.

Standard 3. In order to obtain good quality communication, during the caring process there are organized meetings with the family, patient and members of the interdisciplinary team in order to clarify the need for information, fears, the aims of the caring process, plan of referral to other services, etc.

Social aspects

Standard 1. The social needs of the patient and his family are identified in the interdisciplinary evaluation, and a solution is found as quickly as possible to meet those needs.

Criteria: The patient's file contains the following documentation: the structure of the family, interfamilial relationships, existing social supports, and the key person involved in caring of the patient / primary care giver, living conditions, financial status, need for equipment, other available community resources, and legal aspects.

Standard 2. The social worker defends/protects the rights of the patient and his family, assures the relationship with other social services, other institutions in order to promote access to the care for the patient: help given at home, access to school and workplace, transport, medication and support in organizing funeral services.

Standard 3. The social worker offers the family psycho-emotional counseling and help before, and during the period of mourning.

Criteria: The interventions are recorded/noted in the patient's file.

Spiritual aspects

Standard 1. The spiritual/religious support services are essential in the patients and their families' caring process in order to be able to face the effect of the incurable disease, death and mourning.

Criteria: The exploration of the religious and spiritual dimensions starts with caring, and continues throughout the whole caring time, and it is documented.

Within the spiritual evaluation we identify: religious denomination, preferences, faith, along with the patient's and his family's religious rituals and practices.

Spiritual care services are provided by priests, pastors, clerics belonging to their own religion.

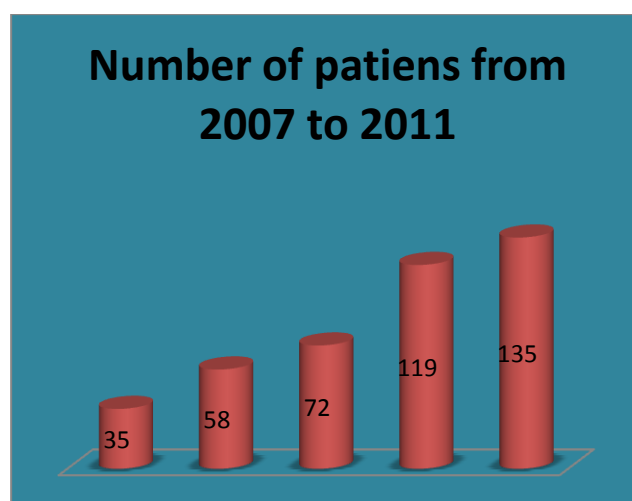
The home care service team of Christian Foundation Diakonia usually participates at the funerals and if the family needs it they offer support in the process of mourning, too.

The development of palliative home care service

In 2007, the first year of palliative care, we looked after 35 patients with incurable diseases, most of them suffering from cancer. Since then, the number of patients have increased steadily to 135 in 2011 (see overview 1).

The personalized therapy plan is set up within 72 hours, which means, that all members of the team evaluated the patient's condition and agreed upon the necessary socio-medical steps that were to be taken. The first as well as the intermediate evaluations are set up based upon standardized criteria, which are set by the National Assembly of the Palliative Care.

The pain which was the main symptom was relieved in 93% of the patients three days after the first visit. All families appraised their overall situation as less burdened and less fearful ten days after our initial evaluation.



Development does not refer only to the increase of the number of clients, but also to the contribution to the qualitative improvement of palliative care on national level in Romania. There is a qualification course in palliative care for doctors and some regional training centres in the country.

Future plans

One of our priorities is to organize and set up palliative care services not only in Cluj-Napoca city, but also in the countryside, because in smaller communities where there are no hospitals and there is only minimal or no access to health care people, patients do need help.

The "Common Destiny" group

Above we presented the Diakonia organization from Cluj-Napoca, next the rehabilitation group called the "Common Destiny" will be introduced from the Romanian Cancer Association in Tirgu Mures. This association was established in 2000, with the general goal of helping the physical and psychological recovery of people with cancer, and also implementation and promotion of their rights.

The association was created based on the experience of the founding members, being patients with breast cancer, all of them facing the devastating impact of the cancer diagnosis, and having been encountered the physical and psychosocial burdens related to cancer.

Firstly, they identified the needs of patients diagnosed with cancer diseases. Its results oriented their initial goals which were to offer support to cancer survivors in the psychical recovery, to help the reintegration into society, and to improve their quality of life.

Furthermore, they initiated educational programs for the general and patient population, with the goal to prevent the occurrence of cancer, and to increase awareness of a healthy lifestyle. They also assist patients in the treatment of the lymphatic oedema.

Activities of the association are carried out exclusively with the help of trained and lay volunteers and consist of the following programs:

- Psychological counselling of the patients;
- Physical recovery of the patients;
- Prevention and treatment of the lymphatic oedema;
- Providing information about the disease and treatment alternatives;
- Informing, educating and raising public awareness about the factors that increase risk of breast cancer and the importance of time at diagnosis;
- Lobby and advocacy both for the rights of the breast cancer patients and for the improvement of the medical care in general; support for the introduction of modern methods of screening and treatment of breast cancer;
- Early diagnosis of the breast cancer;
- Support for the national and local breast cancer screening programs;
- Pre and post-cure counselling for breast cancer patients;
- Training for the medical personnel about breast cancer;
- Projects aimed at screening and treatment of breast cancer;
- Research projects about breast cancer, and support for scientific events, activities in this field;
- Development and maintenance of a breast cancer patient database, and support on creating a National Registry of Breast Cancer;
- Collaboration with other national and international organizations in fighting breast cancer;
- Physiotherapeutic recovery of patients with disabilities and post-therapeutic complications;
- The breast prosthesis program, obtaining breast prostheses free of charge from the National Health Insurance House;
- Fund-raising (sponsorships, donation, etc.) in order to achieve objectives;
- Donation of medical, physiotherapeutic and informative products, means;
- Creation of the Mammary Center in the Mures County Hospital, under the aegis of University of Medicine and Pharmacy of Targu-Mures.

Screening needs and results

In an experimental pilot-study we have screened for the bio-psycho-social and communication needs in cancer patients.

Sample and instruments

Cancer patients were interviewed at the Diakonia Christian Foundation in Cluj-Napoca and at the Romanian Cancer Association in Tirgu Mures. The Diakonia Christian Foundation takes care mostly of those cancer patients who are in the last stage of the disease, their life (the palliative group). The association Romanian Cancer Association in Tirgu Mures is a self-help rehabilitation group (the supportive group), in which most patients survived cancer. We screened both groups.

At the Diakonia Christian Foundation 72 questionnaires were completed, and at the Romanian Cancer Association 38. In total we analyzed 110 questionnaires; out which 10 were excluded (cancer patients were in a critical state, unable to answer, we obtained information only from the relatives). Also, in depth interviews were made, depending on the state of the patient. We carried make five interviews. Before tape-recording we asked for the

informed consent of the patient. Data were used confidentially, according to the agreement signed with the involved cancer care organizations, before we started the pilot screening.

We used two standardized instruments: the FACT-G 4.0 (Functional Assessment of Cancer Therapy - General) quality of life register, and the shortened version of BDI (Beck Depression Inventory) depression scale. The FACT-G 4.0 covers four dimensions of well-being: physical well-being, social and family well-being, emotional well-being and functional well-being. The shortened version of the BDI scale has nine items, with 0-3 scoring (0: not characteristic at all, 1: scarcely characteristic, 2: characteristic, 3: fully characteristic). Depression categories were defined as follows: 0-9 points: no or minimal depression, 10-18 mild depression, 19-25 moderate depression, and above 26 points indicates severe depression.

Semi-structured questions for in-depth interviews were adapted from the School of Social Work, The University of Alabama, U.S.

Data were analyzed in the SPSS 17.0 statistical program.

First results

- Demographics

Mean age in the palliative care group was 67.5 years, while in the supportive group it was 59.9. For the total sample mean age was 65 years, the youngest patient 38 and the oldest 97 years. No differences were found in marital status between the two groups.

Regarding church affiliation we didn't find any significant differences between the two groups, but we did find significant differences in religion practice between the two groups. Those in the records of the Romanian Cancer Association from Tirgu Mures go to church more often, while those from Diakonia Foundation practice their religion in their own way. This might be because their chronic medical condition is a barrier in going and attending to church services, while the other group is made of cancer survivors, with better medical condition.

- Health status

With respect to medical condition we found a statistically significant difference. In the palliative group, bad or very bad medical condition was reported more frequently, while in the supportive group more than the half reported their medical condition to be satisfactory or good.

- Depressive symptoms

We assessed depression with the shortened BDI (Beck Depression Inventory) depressive scale. We analyzed depressive symptoms in patients with cancer, controlling for the following variables: age, gender, education, religion, self-rated health, tumor site, and whether he or she would be open to speak about his / her disease.

Our results show that the two groups are equally depressive as there is no statistically significant difference between them. The psycho-oncological literature does not support the fact that every patient suffering from cancer is depressive, but research seems to agree that depression symptoms are present in the majority of cancer patients. According to Greer one third of the patients with cancer are clinically depressive (7).

- Quality of life

Both groups were asked to rate the services, they had received so far, on a Likert scale of zero to 10, The respondents were highly satisfied; most of them gave 10's.

We analyzed the quality of life scores of the two groups in order to compare their physical (PWB), social (SWB), emotional (EWB) and functional (FWB) well-being. After controlling for the confounding variables we have found statistically significant difference between the supportive group having a high positive average score (17.72), while the palliative care group

scored much lower score (9.36). In this case we can talk not only about statistically but also about clinically significance (8).

In case of the practice of religion we found that those who practice religion in their own ways have the worst physical well-being against those who practice it rarely but in the church community. We found significant differences between the social well-being and the practice of religion too.

Those patients, who practice religion in the church, have much higher emotional well-being.

In analyzing the question "Would you be open to talk more about your disease?" we established its influence on the quality of life. We have found that those who would be open to talk more about cancer have a weaker physical well-being. For social workers in oncology, it gives an "open door message," meaning that the patient welcomes the psychosocial support.

Conclusions

Hopelessness, the burden of disease, anxiety, depression, loneliness are all factors which influence the outlook on life of the cancer patients. Social support becomes very important, because those who have a critical health status are living separated and isolated from the outside world, which brings different symptoms of depression by. The palliative group seems to be more pessimistic, while the supportive group more active (they communicate a lot with one another), but depression and low quality of life is typical for both groups.

Being social workers, we think psychosocial counselling would be the best option for the cancer patient and his / her family, relatives. We need to give space and time for the patients, so they can speak openly in front of us and ask for help. Nourishing of the soul is a complex process, in which the social worker has to show compassion, warmth, empathy, caring, reliable experience and acceptance, unconditional positive regard. In individual counseling we are qualified to improve their quality of life, for example in helping them how to have a healthy life, physical activity, proper nutrition, relaxation, and stress managing methods. At the same time, we are opened to talk about questions related to cancer disease, like: causes and courses of the disease, treatment options, and side effects and how to handle them. Similar topics might be discussed over with the care givers. Family members and relatives need to be strengthened to stay next to the cancer patient, help him / her through in the cancer struggle, accept the situation and stimulate hopefulness in patients. They need to be taken care of too, as to avoid burn-out and giving up the fight, because these states, processes might negatively impact the patient.

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CLINICAL LESSONS

Causes of death in geriatrics

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Abstract

Pierre Delore observed over five decades ago: "It is a fact found that doctors do not like to talk about death." There are doctors who accept sufferings because it is related to life, but cannot stand death, which is not generally regarded as a natural phenomenon, but as a professional failure.

Due to changes in the evolution of society today death is perceived and managed differently than a century ago, when it was caused by transmittable diseases. Later in developed societies, death is caused by degenerative diseases - caused by body ageing, lifestyle and environmental changes.

Today, the majority of deaths (all ages) takes place in hospitals and nursing-homes - 60-70% or even more, as the country is more developed. A process of breaking the band with the family is gaining ground, death is transferred to specialized professionals in terminal care and dying to perform rituals that previously belonged to the families- body corpse preparation, ritual washing, dressing (in another time love gestures and respect), other customs appropriate to culture, traditions, religion.

The causes of death in the elderly remains still poorly elucidated, with plenty of unknowns. The elderly tend to be medicalized due to statistical requirements, because (inter)national bodies (WHO) require a diagnosis coded. A natural end "of old age" does not fit in the coding system and so is 'not existing'.

A rather neglected problem in medical practice, but also in education, is training in morbidity risk of death, and in morbidity by cause of death.

Ageing will have a major impact in the 21st century as well on the ageing society as on the causes of death and morbidity will be, in order: cerebrovascular pathology, the cardiovascular, chronic respiratory diseases and lung cancer. Currently, most authors ranked first cardiovascular diseases, but given the age of increasingly advanced cerebrovascular death prevails, in addition, there is a tendency in physician to prefer a cardiovascular disease as a diagnosis for death, especially if patients are not well investigated and for patients in rural areas. Also the diagnosis of Alzheimer's dementia is avoided as a cause of death.

Keywords: *death, elderly, causes of death, gerosuicid*

(Full text in Romanian)

Palliative care in malignant ulcers

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Abstract

Although they appear in a rather small number of neoplasms and seem easy to take care of, malignant ulcers need mostly specialized nursing, mainly due to compromising the viability of the tissues altered and because they are the outward show of a primary or secondary malignant tumor.

The therapeutic approach varies with the patient mentioning that the debridement and the dressing of the wounds get really advantages for the patient especially by avoiding the overfester. It is very important to pay particular attention to the emotional impact of these wounds on the patient and family.

Key words: *malignant ulcers, debridement, dressing*

(Full text in Romanian)

The role of the family in palliative care at home of patients with pressure ulcers

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Abstract

Pressure ulcer prevalence in the general population varies depending on the reference group between 15-25%. Bedsores (or pressure ulcers) is common in elderly with lack of physical activities and multiple pathology.

We present the case of a 85 years old women with multiple pathology and sacroiliac infected pressure ulcer treated successfully at home. Under the guidance of a family physician with competence in palliative care, and who taught the family members how prevent and care this injury.

The prognosis in this case is reserved, given multiple pathology, age, but the involvement of the family in the treatment and evaluation improve the quality of life of the patient.

Describing this case brings into focus the need for family education in making preventive measures and treatment of pressure ulcers at home.

Key words: pressure ulcer, multiple pathology, palliative care, quality of life

(Full text in Romanian)

Palliative treatment in restless legs syndrome

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Abstract

Restless legs syndrome (RLS) is a neurological disorder that can occur at any age, characterized by unpleasant sensations in the legs frequently manifested in rest that causes an urge to move them to temporarily relieve these sensations. The symptoms are generally worse in the evening and for some people, symptoms may cause severe nightly sleep disruption that can significantly affect a person's quality of life.

This syndrome is more common in end-stage renal disease patients undergoing hemodialysis (up to 60% of cases) and patients with Parkinson's disease (up to 20% of cases). In most cases, doctors do not know the cause of restless legs syndrome; however, they suspect that genes play a role. About half of people also have a family member with the condition.

The diagnosis is based on a patient's symptoms and answers to questions concerning family history of similar symptoms, medication use, the presence of other symptoms or medical conditions, or problems with daytime sleepiness. Treatment for RLS is targeted at easing symptoms. In people with mild to moderate restless legs syndrome, lifestyle changes, such as beginning a regular exercise program, establishing regular sleep patterns, and eliminating or decreasing the use of caffeine, alcohol, and tobacco, may be helpful. Drugs are useful in patients who do not benefit by conservative means or who present lack of comfort and persistent symptoms.

This syndrome is frequently associated with insomnia, day time sleepiness and fatigue and untreated reduce the quality of life in people with chronic diseases in palliative stages.

Keywords: *restless legs syndrome, palliative care, sleep disturbances, quality of life*

(Full text in Romanian)

MANAGEMENT

The importance of multidisciplinary collaboration team: palliative care specialist - epidemiologist- pathologist in the study of specific local aspects of the natural history of HIV-AIDS

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Abstract

Even if enormous progress has been made in understanding the natural history of HIV infection, as well as in the development of effective antiretroviral therapies, the AIDS epidemic continues to evolve dramatically, in the last stages palliative care is needed towards death.

Anathomopathology contributes to the collection of epidemiological data. Data collection needs a multidisciplinary team. In a hospital for infectious diseases the team exists out of: infectious doctors, infectious nurses, vaccinologist, epidemiologist, laboratory virologist, immunologist, biologist, psychologist, psychiatrist, sociologist, social worker assistant, hygienist, family doctor, general practitioner, dietician, physiotherapist, specialist in palliative care, nursing, neonatologist, paediatrician, gynaecologist and obstetrician in maternity cares, midwives, pharmacists, oncologist, physio-occupational therapist, NGO representative, lawyer, judge, attorney, mediator, spiritual worker – priest, volunteers, paramedics, anestezist, surgeon, pathologist.

The data collected and analysed by such a team may contribute to understand the last stages of the disease and support palliative care with this new knowledge.

Collaboration between epidemiologist - specialist palliative care services - anathomopathologist on presentation of the HIV AIDS patients necropsy records, many of them with palliative care, contribute to a better understanding of the local phenomenon of HIV-AIDS.

Additionally, epidemiological surveillance of HIV-AIDS is certainly a major factor in the spread of HIV.

Key words: natural history, HIV – AIDS infection, collaboration between epidemiologist - specialist palliative care services – anathomopathologist

(Full text in Romanian)

COMMENTS, DISCUSSION

Palliative surgery and palliative care - partners in incurable diseases

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Connection between oncology and palliative care seems, to most of us, normally and even joyfully, and we see that patients with advance oncological disease are well cared for when all others medical specialities are not able to do so. But surgery and palliative care seem to be, at least at first glance, contradictory, and the connection has to be explained. Actually, this relation is rather strong.

Curative medicine eradicates or at least controls the disease, prolonging life, goals which are not founded in palliative care. However, in surgery the objectives are very similar to palliative care, targeting cancer effects and complications of the disease, not always healing. Surgery is integrated in both curative and palliative treatment. Palliative surgery is accounting for a large enough number of surgical procedures and operations in cancer patients. The surgery in palliative patients can address benign pathology such as evacuation of collections or correcting the stoma as part of a palliative treatment. Last but not least, it should be noted that many patients with a diagnosis of cancer are surgically by definition because, in their lifetime, sooner or later, they will need a surgical intervention greater or a lesser.

Palliative surgical indications should be well weighted considering the life expectancy of the patient, the benefits it brings, risks and possible complications.

Key words: *palliative surgery, palliative surgically care, palliative care*

(Full text in Romanian)

NEW PUBLICATION

Dying at home

The German Journal '*Praxis Palliative Care*' publishes four times a year an issue, focusing on a specific aspects in palliative care. The leading philosophy of the journal is that palliative care may contribute to quality of life till the end. Its target group is individuals who work with patients and families in palliative care. The journal pays attention to all aspects in palliative care and includes all disciplines, including volunteers.

The last issue of '*Praxis Palliative Care*' focuses on dying at home. Dying at home is a wish of many terminally ill patients, but in various European countries, like in Germany, Sweden or The Netherlands, the majority of these patients do not die at home. This is quite different from European countries like Poland, Romania or Slovakia.

Why do many patients not die at home, although they wish so? Is it because of lack of resources, a shortage of qualified personnel, a failure in organization of continuity is care or is dying at home a taboo in society? The journal indicates that these factors and others play a role why patients in Germany may not die at home. However, of all these factors the most important are the culture of care, social support and societal solidarity. Once, these conditions are present – like at least the culture of care and social support are in Romania – still expertise, resources and care organization are conditions to deliver qualitative palliative care for patients dying at home. The articles in the journal deal with these important, more practically oriented 'problems'.

If patients in hospitals or institutional care want to die at home, the discharge of patients has to be prepared in time. First of all professionals in hospitals and institutional care should be alert to observe and ask about the wishes of the patient and family. If the patient wants to die at home the health care professionals, taking care for the patient at that moment, have co-responsibility to prepare a proper discharge.

Discharge is possible if all necessary steps are clarified: who take care for the patient and is continuity in care guaranteed (number of people involved, responsibility), which professional are involved and do they have the proper means (medicines, assistive technology), is anticipated on the situation at home and stressful conditions, which may occur at home (facilities, complications, action after death).

Another aspect which is dealt with in the journal is the time of the dying process may take. This requires that informal and formal caregivers are prepared to take care for a long period, are able to cope with stressful situations and are supported in coping with these situations.

The journal gives practical tips and present cases which show how dying at home may be realized in such a way that efforts are taken to ensure the quality of life and dying of the patients and to support the quality of care.

NEWS



EMANUEL HOSPICE PROJECT: A palliative care center for adults and children with advanced incurable diseases

“You matter because you are you, and you matter until the last day of your life. We at hospice will do everything we can not only to help you to die peacefully, but to help you live until you die.” Dame Cicely Saunders, founder of the hospice movement

THE NEED FOR HOSPICE SERVICES IN ROMANIA

- 50,000 Romanians die of cancer every year.
- 1,300 people in Bihor die of cancer every year.
- The majority of these suffer severe pain in their last months.
- Less than 5% of Romanians who need palliative care receive it.

HOSPICE CONCEPT: « history and development around the world »

Hospice provides a familiar environment and atmosphere in which the patients feel at home, as well as caring and compassionate staff to help them achieve peace and comfort, and be treated with respect and dignity until their last moment.

The dying people are valued and appreciated and they benefit of a specialized care in order to keep their dignity, to support their freedom (independence), to control their symptoms and to comfort them.

The evolution of the modern hospice and of the specialized palliative care needs a lot to the vision, courage and dedication as of Ms. Dame Cicely Saunders, who is considered to be the pioneer of the modern hospice movement.

In 1967, Cicely Saunders founded St. Christopher's Hospice in London. This has become a centre of excellence regarding the quality of services which were provided to terminally ill patients. From St. Christopher's, the principles of palliative care were promoted in all the health care facilities from Great Britain, and gradually the enthusiasm for the dissemination of the knowledge and the competencies in this field, crossed the border. Health care professionals studied the care of terminally ill patients at St. Christopher's Hospice Education Centre, and after this, they applied their knowledge in their countries, first in America and Europe and then, in the whole world. Currently, there are hospices in over 120 countries, from each continent.

EMANUEL HOSPICE FOUNDATION

Emanuel Hospice is a non-profit charity that has as its main activity to offer palliative care to adults and children in Oradea and its surrounding areas. These patients are diagnosed with advanced incurable diseases and receive services for their medical, psychosocial and spiritual needs. Emanuel Hospice also seeks to influence the local practices by promoting the hospice concept and palliative care principles among health care professionals and the public.

The mission is to provide an optimal quality of life to the patients with advanced incurable diseases from our community in the spirit of Christian love.

Our beneficiaries

Palliative care services are offered to adults with a confirmed diagnosis of advanced cancer who live in Oradea or up to 15 km around Oradea and to children (0-18yrs) diagnosed with a life threatening or life limiting condition that live in Oradea or up to 50 km away.

Services we provide

The services are free of charge and they are provided without discrimination to the eligible patients regardless of age, race or religion.

The Emanuel Hospice team consists of specially trained physicians, nurses, and social workers that have received specialist palliative care training from the Hospice Education Centre in Brasov and also from professionals from Poland, Great Britain and the USA. The Hospice team provides:

Medical and nursing services – providing comfort care, including medications to relieve pain & symptom control; providing the patient and his family with the needed information or education regarding the diagnosis, prognosis and treatment; provision of medications, disposable medical /nursing supplies (dressings, incontinence pads) and medical equipment (oxygen machine); preparing the family for the death of the patient (in the last 48 hours)

Social services - helping the patients in obtaining social rights and important documents; providing financial and material support for the patients with small income; recreation activities for the children who are patients such as camps and special outings.

Spiritual and emotional support services - Offering emotional support using appropriate techniques (for individuals or groups) for the patients and their families and spiritual counseling.

Bereavement support - which may include, but not be limited to bereavement visits, personal contact, counseling, as well as opportunities to share experiences in organized support groups and offering information on the grieving process.

Volunteering services - doing in-home visits; repairs and renovation, going shopping for the patients, chopping wood, offering respite care, providing patients with transportation between hospital and home

Our objectives are:

1. To provide nondiscriminatory palliative care services to the eligible patients in need of hospice care.

Achievements. Emanuel Hospice was started in 1996, as the second palliative home care service in Romania. So far, Emanuel Hospice has provided care for 1,400 adults confronted with advanced or terminal cancer. In 1999, we extended our services to children and have cared for 188 children with life-threatening illnesses since then.

In 2011, Emanuel Hospice provided palliative care at home for 258 patients (218 adults and 40 children), helping them live their last days with less pain and more dignity. The hospice team made over 7,000 medical and social visits at the homes of the patients or in the hospital, bringing them comfort. Our usual caseload is about 75 adults and 30 children at a time (see overview).

Number of patients / visits	Children	Adults
Total number of patients (rural)	40 (24)	218 (65)
Number of bereaved families	7 (5)	28 (8)
Number of new patients	11 (6)	145 (11)
Number of deceased	2 (2)	137 (13)
Number of patients discharged	5 (3)	14 (1)
Medical visits: home hospital bereavement	613 (309) 249 41 (35)	4853 (875) 28 (8) 137 (13)
Psycho-social visits: home hospital other institutions bereavement	190 (94) 138 49 17 (6)	472 (28) 19 52 49 (3)

2. To promote the “hospice” and “palliative care” concepts among the medical professionals and in the community.

Achievements. Starting in 2004, the members of the Hospicie team with specialized education in how to train professionals were involved in a educational program for medical doctors, nurses, social workers, and volunteers. This was organized in collaboration with the Medical College of Bihor County and the The Hospice Education Center in Brasov. Over 120 medical professionals from Oradea and 60 volunteers benefited from this introductory course on palliative and hospice care. We also promote this palliative & hospice care concept to the community through the publication of brochures, newspaper and magazine articles, mass media interviews, and special events open to the public.

3. To advocate for the rights of the terminally ill patients, to assure that their pain control needs are provided for.

Achievements. Emanuel Hospice was represented in:

- The committee of the National Association of Palliative Care that developed the National Standards of Palliative Care (officially issued by the Minister of Health in Bucharest in 2002).
- The committee of experts in the area of palliative care of the European Council (France, Strasburg) which elaborated the *Recommendation 24 (2003)* regarding the organization of palliative care services in the members states of the European Union (officially launched in Belgrade in 2005).
- Subcommittee on Palliative and Pain Therapy of the Health Minister who proposed modifications in the legislation regarding the homeopathic medicine regulations, psychotropic drugs, and the facilitating of opiate medication to be made available to the patients for pain control. (Law Nr. 339 passed on November 29, 2005).
- The committee of the National Coalition of Palliative Care, which elaborated the minimum standards regarding the insurance services for palliative care in Romania and proposed legislation in this respect (proposals that are found in the framework agreement regarding the

conditions of providing medical care in the health insurance system in Romania for the year 2010, published on April 1, 2010).

PROJECT FOR A HOSPICE UNIT WITH BEDS IN ORADEA

According to the „Territorial Cancer Register” there are 1,300 cancer related deaths each year in the Bihor county. But palliative care should not be limited only to the patients with oncological illness but it should expand also to patients with non-malignant illnesses such as cardiovascular or neurological diseases.

According to the Recommendations made by the Council of Europe (Rec 24 from 2003) – the terminally ill patients should have unlimited access to palliative care services according to their needs and the preferred place of care: at home, in a day care center, in a hospital or in a hospice facility.

The plan of Emanuel Hospice is to develop our activity further by building an in-patient hospice in Oradea, according to the recognized standards for specialist palliative care units, where people facing incurable illness and their families can have free access to specialized and high quality palliative care services while receiving physical, psychological, social and spiritual support.

The Local Council of Oradea allocated a plot of land with a surface of 5000 square meters freely to Emanuel Hospice. With the support of the City Hall of Oradea, we plan to build a hospice facility made of: an out-patient clinic; a bed-unit with 20 beds for patients (15 for adults and 5 for children); a day care center for adults and children; facilities for the home healthcare teams; space for training and education; and storage rooms.

The out-patient clinic. It will represent the first contact of the patient or his family with the hospice services. The access to the out-patient clinic will be allowed to those patients who are eligible and of course, whose condition allow periodical trips to the clinic for consultations and establishing the treatment plan. In the doctor’s office, the patient receives consultations and medical advice from professionals in palliative care; through the collaboration with a pharmacy from the hospice facility, the patient also receives medication and medical supplies. Here, the patient and his family are also provided with the needed information or education regarding the diagnosis, prognosis and treatment. The patient will also be provided with the needed emotional/ psychological support and counseling. The patients who come to the day care centre will also have access to the specially trained doctor in palliative care and also to the nurses for consultations, re-assessments and recommendations.

The in-home palliative care. Many of the patients express their wish to be cared at home or in places that have become their home such as: nursing homes, fosterhome, or orphanages. This way, the patient will be cared for in his private environment, where he feels safe and he enjoys the intimacy of family relations and the convenience of his possessions. There, surrounded by family and dear ones, the interdisciplinary team from hospice will offer the patient the specialized care he needs. The family, friends, relatives and neighbors they can all be closer to the patient if he is cared for at home. In-home care is usually preferred by the family members because this way, the caregiver can fulfill his other duties in the family, he is less exhausted than if he had to care for the patient over nights in the hospital. In-home palliative care allows the patient to die where he wants to be – at home.

There are situations when patients require short-term hospitalization in bed units in for the treatment of complex problems. After their condition stabilizes, the patients go back to their homes where the care continues until they die. It has been noticed that they prefer to receive the care at home and die at home, in their familiar environment, surrounded by people who love them.

The day care centre represents a care model of the patients whose families are caring for them at home or in specialized social care centers such as nursing homes or orphanages. Patients in day care centers are paying attention to all aspects of disease and suffering; they have access to physiotherapy, occupational therapy, music therapy, art therapy; they also have the opportunity to meet other people in similar situations, in a friendly environment. Here are some of the benefits of having a day care center: the patient has access to specialized palliative care (nurse or doctor who work in the day care center); he is encouraged to report any matter concerning the disease or suffering; he can ask questions and receive competent advice; he is provided with nursing care, physiotherapy, occupational therapy, music or art therapy specialized in palliative care. Family caregivers can have a respite break (for several hours / days) to rest or to solve problems due to delayed patient care. In parallel with the patient, caregiver may spend time with palliative care team members to ask questions, or to receive advice and support. Experience shows that patients in day care centers discover new hobbies and interests, become more positive about their looks, and consequently experience fewer symptoms. It was also found that patients who are cared in day care center, remain at home longer, without requiring hospitalization in patient units, compared with those who are not receiving these services. The fact that they can attend one or two days a week the activities at the day care center results in patients less depressed, coping better with the disease and becoming even more optimistic.

The unit with beds. Although most of the patients and families prefer that the patient is cared for and die at home, there are situations in which it is necessary to get a better control of symptoms, to continuously monitor the patient for a certain period of time, until the effective scheme treatment is set. In other situations, psychosocial issues/problems (severe depression and anxiety, lack of a caregiver for the patient, family conflict) are the cause for admission into the patient's bed. Hospice units with beds (free-standing, unattached to a hospital) usually have a small number of beds (15 - 25). However, size does not distinguish them from a hospital ward, but rather a holistic customized and flexible care program, the attitude of staff and the warm atmosphere that surrounds the patient and family.

Some of the benefits of patient care units with beds are: patient receives specialized and comprehensive care for 24 hours, provided by an interdisciplinary team with expertise in palliative care; the patient is cared for in an environment where he feels safe, enjoying a warm atmosphere where family members, relatives and friends are welcome and encouraged to spend time with the patient; gives the family a break in patient care while having the assurance that the patient is well taken care of according to his needs; the patient receives specialized care in the terminal stage and when the death occurs choose death as the end to take place in the hospice, allowing family support near death.

The patient will be admitted into the bed unit on average for 14 days (until their condition is stabilized) after which he will be released and then followed by home care service or will be offered attendance at the day care center. (In case of deterioration of the patient's condition or at request, the hospitalization may be extended). In the bed unit, the patient will receive complete palliative care services provided by interdisciplinary team members (the same services offered to them at home, the only difference being that in the bed unit they will have access to permanent care). In addition, patients may benefit from the day care center services (physiotherapy, aromatherapy, participation in creative activities).

Center of education in palliative care. Because it is mandatory for all professionals and other personnel involved in palliative care to receive training in the field, we found it necessary to have in the new hospice rooms for training and education facilities for the hospice staff and volunteers but also for professionals from other institutions (doctors, nurses, social workers, psychologists, chaplains) interested in palliative care field. The new hospice facility will be built on three levels, in a style and design that is different from the "institutional" model in which patients feel rather they come "home" than in the

hospital, the built area totaling approx. 4900 square meters. Roadside parking will be arranged for vehicles and a green space for the hospitalized patients and for those attending the day care center. We estimate that the hospice unit will be completed and operational in the provision of palliative services in a period of 3-5 years.

It is encouraging that the hospice project is supported by the local authorities and businesses. Beside donating 5000 square meters of land for the hospice, the City Hall of Oradea initiated a local fundraising campaign *"With all your soul, Oradea"* to raise funds for two projects from health field, which are considered a priority for our town: the building of the hospice center and of the Oncology center.

Until present more than 100.000 EUR were raised through this campaign for the two projects. Other 50.000 EUR were directed straight to the Bank account of Emanuel Hospice from churches, individuals and companies, for the new hospice building. The project of the hospice building was elaborated by a team of 12 Romanian architects and engineers who offered their services voluntary. Encouraging is also the generosity of a local businessman who agreed to build from his own materials the hospice free and offer the building to our organization with windows and doors, so that we will continue with decorations and equipment. His company, Repcon, will invest appreciatively 1 million EUR in the new hospice building, We hope that through the generosity of people, businesses and churches from Romania and from abroad, we will be able to raise in the next two years the other 3 millions EUR, so that the new hospice facility will be functional as soon as possible.

The new hospice center will enable us to provide patients with a complex, and specialized care, according to the individual needs of patients and family members. This center would be a complementary service to existing health services from the community, especially to the new cancer center which is in the process to be built at the Municipal Hospital of Oradea. It aims to improve the quality of life that remains to live for the dying patients so that they would enjoy a dignified life, lived to the end.

Having a clinic-educational profile, the new hospice facility beside providing palliative care to the eligible patients, will promote education and research in palliative care field, in partnership with the High Performance Medical Research Center, from the Faculty of Medicine and Pharmacy, University of Oradea.

If you would like more information about Emanuel Hospice or would like to help further the development of the hospice please you may contact us (see below).

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