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CONTENT

EDITORIAL

Information and cooperation

Heuvel W J A van den

ORIGINAL PAPERS

Medical, psychological and socio-demographic characteristics of patients, enrolling in a palliative home care program in Romania

Dumitrescu L, Heuvel-Olăroiu M van den

Palliative medicine: expertise, cooperation, communication

Erjavec Z

CLINICAL LESSONS

Paraneoplasia Dermatosi

Simionescu L

MANAGEMENT

Volunteers in palliative, terminal care in The Netherlands

1. Backgrounds and principles

Bart H

COMMENTS, DISCUSSION

Paleativ ? Paliativ?

Bogdan C

NEW PUBLICATION

The role of nurses in medical end-of-life decisions

Bruchem-van de Scheur A van

Assessment of pain in patients with dementia

Sandgathe Husebo B

The picture on the cover: *Messenger Angel* from Bogdana Contras, Romania

EDITORIAL

Information and cooperation.

Prof. dr. Wim J.A. van den Heuvel,
Chairman of the International Editorial Board of PALIATIA.

The need for palliative care is evident as well as its shortage in most European countries, especially in Central-Eastern European countries. This volume of PALIATIA shows the enormous need for palliative care in Romania by reporting about the 'health status' of patients enrolling in a palliative care programme at home. In Romania, care at home by family is the rule, institutionalisation is a shame and volunteers are rare in health care.

However, volunteers may play a pivotal role in palliative care as experiences in the Netherlands show, reported in PALIATIA in this volume and the next two. The knowledge in palliative medicine is growing, including pain assessment and treatment of co-morbidity, but once more this knowledge demonstrates the importance of interdisciplinary cooperation and profound communication.

About communication: the next EAPC conference in April 2009 in Vienna, Austria, is held at the right place: the connection between East en West Europe, where further developed arrangements in Western Europe may be compared with Eastern European approaches. We may learn from each other, although colonisation of some 'western' arrangements by 'humanitarian organisations' may endanger the authentic approaches in Eastern Europe.

ORIGINAL PAPERS

Medical, psychological and socio-demographic characteristics of patients, enrolling in a palliative home care program in Romania

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Abstract

Objectives:

Palliative care at home is a new service in Romania. The objectives of this study are to describe the medical and health status of patients who enroll in a palliative care at home program and to analyze which medical, psychological and socio-demographic factors are related with the functional health status of these in Romania.

Methods:

Following the inclusion criteria 129 patients, enrolled in the new service, which was delivered by five teams in specific areas. Data are collected at the intake of the patients by the coordinating general practitioners. Statistics include frequencies, bi-variate analysis and stepwise linear regression analysis.

Outcomes:

The results show that social support is available for most of the patients, that co-morbidity is a problem and even more the number of symptoms: 68% of the patients reported 11 symptoms or more. Pain management is the most frequent problem. Social support is stronger in rural areas as compared to urban. The regression analysis showed a significant relationship between a worse functional health status and living in urban areas and having many symptoms.

Conclusions:

It is concluded that almost all enrolled patients have major medical problems and about half of them have psychological problems. The needs of the patients are not easily met in rural areas.

Keywords: *symptoms, pain, palliative care at home, co-morbidity, urban-rural*

Introduction

The number of patients in need of palliative care in Romania is much larger than the services offered. (1) Especially palliative care at home was until recently a non-existing service.(2) In 2002 an innovative service was started to offer palliative care at home, mainly for cancer patients.(3) Data on patients in need for palliative care are not available yet in Romania. Such data are important because they do not only specify the condition the patients are in and the care and support needed by these patients, but they also show what expertise and skills are needed by the members of the palliative care team.

International literature has shown that palliative care at home may result in acceptable quality of care and quality of life, but no data are available from Romania.(4,5,6,7) Symptom management is an issue which is seen as extremely important by patients and family.(8) A lot of studies describe the prevalence of the symptoms of patients during their participation in a palliative care program showing frequently reported symptoms like anorexia, asthenia, dry mouth, confusion, and constipation (9), or dyspnea, pain, delirium, and vomiting.(10)

Less is known about the symptoms on the moment the patients are assessed to enrol in a palliative care program. Potter showed the prevalence of symptoms of patients at first referred to different palliative care services.(11) Heedman and Strang assessed the symptoms of cancer patients admitted to a hospital based home care program.(12) How these symptoms relate to other characteristics like medication, co-morbidity and physical and psychological status is not studied frequently. Such relationships are important to pay attention to when patients enrol into palliative care since they will determine the need for care and support and indicate the risk for complications. Knowledge about the relationship between these characteristics facilitates the assessment of the need for medical, psychological and spiritual support. (10)

Most people want to live as independent as possible together with their beloved ones even if they have a terminal disease. Therefore, the functional health status of the palliative care patient is important not only because dependent patients need more care, but also – and more important – because independency enlarges the autonomy and quality of life of the patient and their families. In this article the question is studied: in what medical and health condition do patients enrol in a palliative home care service and which medical, psychological and socio-demographic factors are related with functional health status of these patients. The specific questions to be answered are:

1. what are the socio-demographic characteristics of the assessed patients?
2. which diagnosis, symptoms and co-morbidity have these patients?
3. how is the physical and psychological condition of the assessed patients?
4. what is the relationship between functional health status on the one hand and medical, psychological and socio-demographic characteristics on the other hand?

By this study it is possible to describe in what 'state' patients enrol in palliative care program at home in Romania as compared to other countries, as far as literature is available and comparable. And it also shows which these patients needs have.

Methods

Enrollment

To deliver palliative care at home five multidisciplinary teams were established in two regions of South Romania. Three teams worked in an urban area and two teams in a rural area. Each team has a general practitioner (GP) as coordinator, an oncologist as consultant, and 2-3 members (nurses and social workers). The way the teams were built and trained is described elsewhere. (3)

The patients to be enrolled in the study were selected using the following criteria:

- patients with cancer in an advanced stages in which curative treatment was no longer possible, or patients in a terminal stage. Later on patients with other diseases (dementia or organ insufficiency) were included because they requested so;
- prognosis forecasting the patient's death in the next nine months;
- patient's domicile is in the team's action area;
- the patients and/or their families give a written informed consent for the palliative care;
- assurance of the cooperation with the curative doctor / patient's family doctor.

In total 157 patients were referred to the palliative care teams by the oncologists meeting the inclusion criteria diagnosis and prognosis, in the project between October 2002 and September 2004. No precise data are available about the total number of patients who could have been enrolled, since reliable cancer registration does not exist in Romania. The palliative care teams, i.e. the coordinator being a general practitioner, applied the additional inclusion criteria. For reasons like distance and workload and while some patients refused the treatment 19 patients could not be included. Informed consent was asked from patient and family. Informed consent was not given in 4 cases because the family did not want that the patient would know the diagnosis/prognosis of the disease. Some families (5 families) were not included because they expected financial help. In this study data of 129 patients are used.

Registration

A registration form was developed to record the basic data from each patient when enrolled in the service. This registration form was developed based on international registration forms and data. The draft registration was discussed and modified to the Romanian situation in a workshop with the members of the five palliative care teams at home. The registration includes: demographic characteristics, medical data (like diagnosis, medication, disease duration) and presence of symptoms and complications (including the duration and severity when it could be reliably assessed), social support given to patients and psychological characteristics.

Additionally the care process and actions taken by the palliative care team were registered after the patient started to participate in the palliative care program. The registration form was completed by the team coordinator (general practitioner) during the assessment, leading to the admission of the patient in the program. In addition, the registration form has two appendices to record the nurses' activity and physiological parameters.

Variables

The dependent variable in this study is 'functional health status'. It is measured on a five point scale varying from 1 'all functional activities are executed by the patient without problems' to 5 'patient is unable to execute any functional activity'. After describing the type of symptoms, diagnosis and metastases, these variables were quantified as number of symptoms and number of metastases for the regression analysis. Psychological / mental status was assessed by the GP scoring whether the patient had signs of severe anxiety, sadness and feelings of depression. Sociodemographic data are measured on standard way and sometimes 'condensed' for statistical analysis.

Statistics

The recorded data were entered in a database and analyzed with SPSS statistical package, version 12.0. Frequencies were described first. After a bi-variate analysis between the variables, step wise linear regression analysis was executed to identify the most powerful variables related with functional health status. Statistical significance was set at $p < .05$.

Results

The acceptance of the patients in the program was decided after the initial consultation by the coordinator. Next a care plan was developed and accordingly delivered by the palliative care at home team. The initial consultation was made at the patient's domicile in 91% (117) of the cases. 4%(5) of the patients were initially consulted in a hospital and 5% (7) at the coordinator's office.

Socio-demographic data

The gender distribution was about equal in the enrolled patients (see table 1). As might be expected more elderly patients enrolled in the service (86% over 50 years). The average age was 66,7 years. Less than half (40%) of the patients were living in a rural area. Most patients lived at home and not alone (74%). Almost one quarter of the patients were widowed; this number was significantly high in urban areas as compared to rural. The majority of the patients was very poor (67%) with a budget under the average wage (i.e. 50 euro per month in 2002).

Table 1 – Demographic data of the participating patients.

Characteristic	Number of patients (%)
<i>Gender</i>	
Man	62(48%)
Woman	67(52%)
<i>Age</i>	
< 50 years	19(15%)
51 – 65 years	41(32%)
> 65 years	69(54%)
<i>Place of living</i>	
Patients in rural area	51(40%)
Patients in urban area	78(60%)
<i>Living situation</i>	
Lives alone, at home	18(14%)
Lives at home, not alone	96(74%)
Lives at another place (friends, family)	15(12%)
<i>Marital status</i>	
Married	87(67%)
Widowed	29(23%)
Other situation	13(10%)
<i>Monthly income</i>	
Income - < 25 euro	19(15%)
Income – 25 – 50 euro	67(52%)
Income – 50 – 75 euro	30(23%)
Income - > 75 euro	13(10%)

Functional health status

Three quarters of the patients were restricted in most activities; over half of these patients needed permanent care. Only a few patients declared that they could do all activities (table 2). Ten percent of the patients were able to do easy work.

Table 2 – Functional level/need help of the patients, when they enrolled in the palliative care program.

Level of activities	Number of patients (%)
can do all activities, without restriction	2 (2%)
restrictions for hard activities, but capable to do easy works	12 (10%)
capable to care for himself, but not to do activities, more than half of a day	20 (16%)
very difficult to take care for himself and for more than half a day in bed or wheelchair	41 (32%)
need permanent care, is immobilized in bed or wheelchair	54 (42%)

Social support

The majority of patients (90%) had social support: 62 (48%) patients from children, 25 (19%) from one of family member, and 29 (23%) from more relatives. Only 10% (13 patients) did not receive social support. When asked what kind of help the patients (and their family members) hoped for 77 patients (60%) indicated professional (i.e. medical, nursing, care) help, 41 (32%) psychological help and 54 (42%) spiritual help.

Medical data

The illnesses treated by the teams represent in most of the cases (92%) oncologic diseases and only 10 patients were diagnosed with other disorder (organ insufficiency and dementia) (see table 3). For men, first place in diagnostics was pulmonary cancer (13x) and the second place, the colon cancer (10x) and for women breast cancer (15x) and uterin col / uterus cancer (14x) were most frequent .

Metastasis was found in 83 (64%) patients. Most frequent metastases were peritoneal (11x), hepatic (10x) and bone metastases (7x). Metastasis were most often found in patients with ovary cancer, stomach cancer and breast cancer. Of 29 patients local recidives were identified (see table 3). Other diseases included organ insufiency or dementia.

Table 3 – The diagnosis at the moment patients enrolled in the palliative care program, absolute and percentages.

Diagnosis	Number of patients (%)	Patient with metastasis (%)
Lung / bronchia cancer	20 (15%)	13 (65%)
Colon / sigmoid / rectum cancer	16 (12%)	11 (69%)
Breast cancer	15 (12%)	13 (87%)
Uterus / uterine cols cancer	14 (11%)	8 (57%)
Pancreas / liver / liver bladder cancer	12 (9%)	8 (67%)
Esophagi / stomach cancer	11 (9%)	10 (91%)
Head / neck cancer	6 (5%)	2 (33%)
Brain cancer	5 (4%)	2 (40%)
Other localizations	5 (4%)	4 (80%)
Unknown primary tumor	4 (3%)	3 (75%)
Leukemia	3 (2%)	2 (67%)
Ovary cancer	3 (2%)	3 (100%)
Mieloma	2 (2%)	1 (50%)
Genito-urinary tract cancer	2 (2%)	1 (50%)
Melanoma	1 (1%)	0
Non oncological diseases	10 (8%)	

Co-morbidity was registered in 91% (117) of the patients (see table 4); cardiac problems were most frequently mentioned (40 patients).

Table 4 – Co-morbidity at the moment the patients enrolled in the palliative care program, absolute and percentages.

Co-morbidity	Number of patients (%)
Oncological	22 (17)
HIV / AIDS	3 (2)
COPD	17 (13)
Neurology	14 (11)
Cardiac	40 (31)
Sugar diabetes	11 (9)
Others comorbidities	62 (38)

The most frequently recorded symptoms are presented in table 5. The percentage of symptoms is rather high. At the first consultation were most frequently pain, loss of weight, fatigue and loss of appetite (all over 80%). Given the high percentage on each symptom, it is expected that most patients had a high number of symptoms. Indeed, it was found that 31% reported more than 15 symptoms while 37% reported 11-15 symptoms.

Table 5 – Top 10 symptoms of the patients at the moment the enrolled in the palliative care program, absolute and percentages.

	Symptoms	Number of patients (%)
1	Pain	116 (90%)
2	Loss of weight	115 (89%)
3	Fatigue	110 (85%)
4	Loss of appetite	107 (83%)
5	Dry skin	85 (66%)
6	Dry mouth	81 (63%)
7	Nausea	80 (62%)
8	Difficulty with breath	75 (58%)
9	Dizziness	72 (56%)
10	Urinary problems	53 (41%)

The medication used by the patient when he started to participate in the programme was prescribed by the oncologist in most cases (73%) and only 5% by the family doctor. About one quarter (23%) were curative prescriptions. The symptomatic medication was high as might be expected given the high number of symptoms (table 6). Most medications were prescribed for pain treatment. The percentage of morphine is rather low due to difficulties in prescribing it.

Table 6 – Type of medication and pain medication of the patients when they enrolled in the palliative care program, absolute and percentages.

Medications	Number of prescriptions
Curative medications	30
Symptomatic medications	116
Adjuvant medications	90
Medications prescribed for pain	Number of prescriptions
Analgetics medications	70
Antiinflammatory medications	36
Morphine derivations medications	61
Morphine	4
Combinations of medications	20

Psychological status

At the first consultation 53%(69 patients) of the patients reported psychological problems (anxiety and depression symptoms), 47%(60 patients) did not express such problems or stated explicitly to have no psychological problems (8 patients).

Relations between medical data, functional level, psychological and socio-demographic characteristics.

Bi-variate analysis of the variables showed significant associations (chi square or Pearson correlations) between the following socio-demographic data: urban-rural living and social support (chi square=7.86, df=3), indicating more social support for the patients in rural areas;

monthly income (chi square=2.52, df=3), gender (chi square=7.28, df=1) and marital status (chi square=11.69, df=2), meaning that women and unmarried patients had a lower income.

The associations between medical data, functional level and psychological data showed significant relations between number of symptoms and number of metastasis ($r = 0.31$), functional level ($r=0.25$) and psychological health status ($r= -0.30$). Patients with many symptoms also have more reported metastases; have a worse functional health status and more frequent psychological problems.

The following socio-demographic variables were related with medical and psychological data:
 - urban-rural living with number of metastases (chi-square=8.65, df=2), number of symptoms (chi-square 24.60, df=2), functional health status (chi-square=10.22, df=2) and psychological problems (chi-square=26.58, df=1) indicating that patients living in the rural areas had less (known) metastasis, showed less symptoms, showed a better functional and psychological health status.

- social support with psychological problems (chi-square=9.78, df=3), which shows that those patients, who received support from children have a better psychological health status.

Linear regression analysis

Linear stepwise regression analysis with functional health status as dependent variable showed that number of symptoms is the strongest associated with functional health status, followed by living in a rural-urban area (see table 7). First introducing socio-demographic data living in a rural-urban area had a significant impact; in the second step no significant contribution was found. In the third step medical variables were added, only number of symptoms contributed significantly to functional health status. The total explained variance is rather low, i.e. 8%.

Table 7: Linear step-wise regression analysis with functional health status as dependent variable at the moment the patients enrolled in the palliative care program.

Model	Unstandardized coefficients		Standardized coefficients	t	Sig.	95% Confidence Interval for B	
	B	Std. Error	Beta			Lower Bound	Upper Bound
Constant	1.640	.242		6.76	.000	1.160	2.119
Place of patients	.321	.144	.194	2.22	.028	.035	.607
Constant	1.830	.500		3.65	.000	.839	2.820
Place of patients	.288	.164	.174	1.76	.080	-.035	.612
Age	-.060	.098	-.054	1.76	.541	-.253	.134
Marital status	.071	.107	.059	3	.507	-.140	.282
Psychological status	-.065	.160	-.040	-.614	.684	-.383	.252
Constant	1.597	.518		3.08	.003	.571	2.623
Place of patients	.180	.174	.109	1	.301	-.164	.525
Age	-.060	.097	-.053	1.03	.540	-.251	.132
Marital status	.076	.106	.062	8	.478	-.135	.286
Psychological status	-.010	.160	.006	-.615	.951	-.327	.307
Number of symptoms	.231	.102	.226	.712	.026	.028	.434
Number of metastasis	-.073	.092	-.074	-.061	.427	-.255	.109
				2.25			
				6			
				-.797			

Discussion

Most studies in palliative care analyse the evolution and treatment of the disease and care process after the palliative care has started.(11,13,14,15) Only a few studies have made an assessment of the health status of the patient before palliative care started.(12,16) Such an assessment is considered to be very essential to offer appropriate care. And this study shows that such an assessment uncovers various problems needed to be taken care of.

The advanced cancer stages imply a complex symptomatology and indeed this is shown by this study. The average number of symptoms per patient was 12.8, the majority (94%) due to neoplastic illness and a minority (6%) to the comorbidity which is reported also in the literature.(9,10,14,17) However, an other study on patients referred to the palliative care services (11) the average was lower (7,1). An explanation could be the absence of palliative care services in Romania. At the same time, it should be noted that the estimated incidence of cancer has increased with 3.6% during the last decades in Romania, while most European countries have an estimated increase of approximately 0.5-1% per year.(18) Additionally, most Romanians contact their doctor in a late (terminal) stage of the disease, when healing is almost impossible, and interventions imply very high costs. The late call for care is due to the lack of information about this type of care, the absence of such services in many areas, especially on the rural side, and to the belief that cancer is an incurable disease and nothing can be done.

There exists a significant difference between the average number of symptoms for patients in urban (14,3) and rural areas (10,4). Also a large difference is registered for the number of metastases between urban and rural areas (in urban areas 74% of the patients report metastases and in the rural areas 49%. Probably, in reality this difference does not exist. The patients in the rural areas have only one option for medical service, i.e. the GP practice. So, diagnostic facilities are limited. Additionally, insufficient knowledge about a disease like cancer and limited material resources make patients' delays in rural areas a common pattern. So, the data reflect the lack of diagnostic facilities and expertise in rural areas. No differences in number of symptoms were observed between women and men which is in line with other studies. Only the respiratory symptoms were more prevalent in men as compared to women as found by others.(13,14)

As expected pain is the most reported symptom, which seriously affects the functioning of the patient and which is hard to treat as shown in other studies. (9,10,19,20) Adequate treatment and control for pain is found in most western studies.(12) For pain control only a small proportion of the patients (about 16%) follows a treatment scheme recommended by international palliative medicine protocols, indicating a variety of different proportions of analgesics or anti-inflammatory drugs or another medication.(21) Pain management is a major problem in Romania. This is related with the restrictive opioid law on the one hand and with "old fashion" specialists who do not adopt the WHO's recommendation about analgesics on the other hand.(2,22) Also the interest of a small group of specialists who are allowed to prescribe analgesics prohibits pain management as well as the attitude of the patient, who considers morphine to be synonym for death.

About half of the patients are identified to have psychological problems. This is based on an assessment by the GP. Probably this is an underestimation since the GP did not fill in problems in the checklist if the patient was not explicitly mentioning such problems. In another small study in this population we found the percentage of self reported psychological problems significantly higher (results not published). The patients' psychological status has a great impact on quality of life. The latter is indicated by the relationship between psychological status and social support. Psychological problems are understandable related with number of symptoms. No difference was found between psychological status and

gender in contrast to some other studies where male patients showed an aggressive response as compared to female patients.(22) However, we found a difference in psychological problems between rural patients (25%) and urban patients (71%) in line with other studies.(10) In Romania, this difference may be explained by the described lack of facilities in rural areas and beliefs about cancer ('one has to accept') and by the strong family support in these areas, which affects the coping with lifethreatening situations.

This study shows that the patients enrolling in a palliative care service are already taken care for by their family members, as is usual in Romania. That is not to say that these patients do not need professional care. And indeed they want such professional care. This study shows the multitude of problems these patients encounter and that the last months of life are characterized by a lot of needs. Palliative care at home is rather new in Romania and continuously developing by building mobile, multidisciplinary teams. Such teams may provide the care, which is and needed and accepted and acceptable in terms of quality and costs. In Romania, institutions for dying people are not common; the Romanian custom is to care for the dying person at home.(2,23)

Developing and providing palliative care at home is an alternative for institutional care. Primary health care facilities have an important role in supporting and developing this kind of service. Today in Romania the legislation is available to develop the care at home services, including palliative care, and the possibility to be reimbursed by the Health Insurance House.

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Palliative medicine: expertise, cooperation, communication.

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Abstract

Palliative care services are directed to patients, who suffer from life-threatening diseases without a chance for cure, and their families. Palliative medicine is a part of this service and asks for specific expertise. In palliative medicine three phases may be distinguished: early palliative phase, late palliative phase and terminal phase.

In each phase diagnosis of co-morbidity and complications are necessary, which needs specialised expertise, and decisions about treatment have to be taken in cooperation with patients, their families and members of the palliative care team.

The article presents examples about pitfalls in diagnosis and how complications could be treated. Besides expertise a well-organised service is needed. Communication is an essential part of that organisation.

Keywords: *palliative medicine, expertise, cooperation, communication*

CLINICAL LESSONS

Paraneoplasia dermatosis

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Abstract

Skin para-neoplasia syndromes are non-malignant pathological processes, but which are associated with significant frequency and psychopathological close relations with strict malignant tumors in the body and whose evolution is similar to that of neoplasia. They reappear every new relapse.

These paraneoplasia dermatosis are three categories:

- mandatory Paraneoplasia Dermatosi which are associated constantly with neoplasia
- voluntary Paraneoplasia Dermatosi which are associated with increased frequency with cancers

- occasionally Paraneoplasia Dermatosi which are sometimes associated with cancer

Most important for medical practice are the ones mandatory Paraneoplasia . If mandatory Paraneoplasia Dermatosi is present, a systematic search for a cancer is indicated with all the necessary examinations: clinical, biological, radiological, endoscopic because they are almost constantly associated with a cancer.

Keywords: *dermatosis, neoplasia, combination with cancer*

MANAGEMENT

Volunteers in palliative terminal care in the Netherlands

1. History and principles

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Abstract

This is the first of three articles on the development of volunteering in palliative care in the Netherlands. Organisation of volunteers started at local level based on direct experience with the need for palliative care at home 25 years ago. Later volunteering in hospice related care was developed.

A national foundation, called Volunteers in Palliative Terminal Care (VPTZ), includes 140 local/regional volunteer organisations for terminal care at home and 70 organisations of volunteers, who deliver terminal care in a hospice context. The local volunteer organisations have each their own policy, organisation, personnel and financing. The national foundation represents their interests at the national level and offers activities, like courses, training and information, to support quality, knowledge and continuity of volunteer work in terminal care.

Keywords: *terminal care, volunteers, quality of care, palliative care.*

COMMENTS, DISCUSSION

Palliative? Palleative?

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Abstract

Palliative (palleative) is an adjective or noun depending on how it is used. It is derived from the Latin word *pallium (manta)*, which means a 'Greek robe' and the adjective 'palliatius'. Later it was established in the common language and its meaning became metaphorical: "solution that temporarily solves a problem, a situation or its effects", and, in medical language: "solution that improves the health, temporary removing the symptoms without eliminating the cause".

Thus, the term is ambivalent, being used both in the medical and in common language; the later like: "the government offered only palliative solutions in the fiscal field". As a matter of fact, the term has penetrated the medical language, being taken over from the common language, along with the apparition of palliative care concept and practice.

In the Romanian language both forms, palliative and palleative, may be used. We consider that "palliative medicine" can remain in the word family of "palliative". We proposed and argued for the use of *palliatology* that will eventually replace palliative care, having the following advantages: including of palliative care in the other than medical disciplines and specialties. It combines *palliatius and logos*. Palliatius in the meaning of 'solution that improves the health, temporary removing the symptoms without eliminating the cause'. 'Logos' in Greek means: speak, account, think, and 'logicos': accordingly to the human ratio.

Keywords: *palliative care, palliative medicine.*

NEW PUBLICATION

The role of nurses in medical end-of-life decisions

Ada van Bruchem-van de Scheur,
Universitaire Pers Maastricht 2008
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This thesis investigates the role of nurses in euthanasia/physician assisted suicide. It studies the role, perceptions, responsibilities, and problems of nurses in medical end-of-life decisions. It is a combination of a quantitative and qualitative study.

The dissertation starts with an overview of the role of nurses during the period 1985-2001 and is followed by empirical analysis, based on in-depth interviews and focus group interviews and a questionnaire among 1509 nurses working in various health care settings.

The role of nurses in euthanasia/physician assisted suicide needs specification. There were considerable differences between the role of nurses working in hospitals and nursing homes on the one hand and those working in home care organisations on the other hand. In the later the nurses are less involved. Overall in 23% of the cases nurses disagreed with the physician's decision to hasten the patient's death and in 27% of the cases, the physician did not inform nurses about the aim of the medication (to hasten the patient's death).

Also the role of nurses varied within the process of euthanasia/physician assisted suicide. Nurses are not frequently (enough) involved in the decision making process, although they are involved in the preparation of the euthanasia/physician assisted suicide. However, 63% did not see it the task of nurses to do such preparation.

Nurses think quite differently themselves about their roles in reviewing the euthanasia/physician assisted suicide process, in decision making of it and in preparatory activities.

The study concludes that communication between physicians and nurses needs improvement, especially in the home care situation. Also, it is concluded that the knowledge of nurses with regard to euthanasia law and regulations is lacking as is their interest to participate in decision-making in euthanasia/physician assisted suicide. Therefore, the study advises that nurses are educated in laws and legislation and that communication is an important part of nurses' education.

From an international point of view, the study is relevant because it brings up new issues in the discussion concerning the role of nurses, such as their role in preparing euthanatics and inserting an infusion needle to administer euthanatics.

Assessment of Pain in Patients with Dementia

Bettina Sandgathe Husebo
University of Bergen 2008
ISBN 978-82-308-0601-2

The aim of this thesis is to develop a staff-administered behavioural pain assessment tool for older persons with dementia, to test the instrument with respect to reliability and validity, and to use it in the clinical setting of an entire nursing home population. The multi-morbidity and lack of communication of people with dementia require a comprehensive approach to pain assessment and treatment.

Step by step an assessment tool is developed and tested using indicators during standard movements and video taped demonstrations and evaluations. The indicators are based on patients' pain behaviour/expressions. Most frequent and painful was mobilising of the legs and arms, Pain in the pelvis and/or genital organs was also frequently observed.

The Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale proved to be reliable (interrater and test-retest reliability) with a high internal consistency. Validity testing of a behavioural assessment tool is difficult, because the pain scores are indirectly observed and inferred by nurses. So concurrent validity testing is recommended.

Patients with severe dementia have similar intensity, diagnoses and locations of pain as compared to patients in other stages of dementia. Patients with dementia who received opioids were more likely to demonstrate higher pain intensity scores than mentally healthy controls receiving opioid.

A reliable, tested instrument to assess pain in dementia patients is available now, MOBID-2 Pain Scale. Future research should explore the prevalence of pain in these patients as well as treatment modalities.