



## **Massive open online courses with videos for palliative clinical field and intercultural and multilingual medical communication**

### **National research about the procedures on palliative medicine in Romania**

**Gr.T.Popa University of Medicine and Pharmacy Iasi, Romania**

**Transilvania University, Brasov, Romania**

**Fundatia EuroEd, Iasi Romania**

**Iasi Regional Oncology Institute, Romania**

## **Contents**

1. Introduction .....	1
Aim of the report .....	1
Objectives of the national research .....	1
2. Theoretical research.....	1
Definitions of essential concepts in palliative care.....	1
Provision of statistical data, at national level .....	2
Is the palliative medicine/care supported by legislation? .....	2
Identification of National Strategies in palliative care.....	2
Identification of specialized services in palliative care .....	3
Identification of support specialized literature or organizations.....	3
Is the palliative care visible/debated at national level? .....	3
Best practices/ projects on innovative solutions in palliative care .....	4
3. Practical research.....	4
Decision makers - Interpretation of the questionnaire results .....	4
Providers - Interpretation of the questionnaire results .....	4
Students - Interpretation of the questionnaire results .....	6
Patients - Interpretation of the questionnaire results .....	7
Families - Interpretation of the questionnaire results .....	9

## 1. Introduction

### Aim of the report

The aim of the report is to research and evaluate the medical literature talking about the procedures on palliative medicine, reflect on the palliative medicine and strategies and on the current procedures used in the training of the students enrolled in EU medical universities or used by the professionals & volunteers active in the medical world of work.

Through a consensus process our experts in the project have shortlisted a number of 20 procedures and through the input of trainees, practitioners, patients and families we have highlighted the relevance of these procedures for the academic world and direct care of patients. The aim of the practical research is to understand the feasibility of introducing these procedures and related courses, once they are finalized by our national and international experts, in the academic programs.

### Objectives of the national research

- Identification of the operational procedures reported to be used by the students during the hospital internship in pre-clinical years; and of the needs of the target groups in connection to the use of specific procedures.
- Research of specialised recent literature in connection to 20 procedures proposed.
- Identify the ways to introduce new and consensually agreed procedures on palliative medicine to the academic medical field (university) and the medical world of work (hospitals, hospices).
- Collect information on specific sectorial impact, country differences, cultural specific aspects, etc.
- Identify innovative solutions that have been implemented and found to be effective to meet the needs of those who use/will use procedures on palliative medicine.
- Evaluate the input of trainees, practitioners, patients and families to better understand the relevance of the procedures for the academic world and direct care of patients.

## 2. Theoretical research

### Definitions of essential concepts in palliative care

Palliative care refer to medical assistance that target preservation of quality of life of those suffering from life-threatening advanced diseases in which standard medical interventions had become of no efficiency. This care address the patient and also his family members and it deals with physical symptoms as well as with psychosocial and spiritual problems. Nurses, physicians, medicine and social workers, priests are part of the team required in palliative care. In Romania palliative care services did grow in the last decade, but still the number of services is not meeting the demands of patients in need for palliative care. General practitioners recognize the need for palliative care in Romania. Despite recommendations from the World Health Organisation and the Council of Europe expertise on palliative care, adequate services and information on palliative care are in shortage. The need for palliative care is still enormous from the patient's perspective, from the professional's perspective and from the human rights perspective. The right to have access to appropriate care is not realised yet in Romania for patients with life threatening diseases like cancer and dementia. Palliative care at home should be one of the priorities since most people want to die at home and family ties are still strong in Romania.

### Provision of statistical data, at national level

Population millions	Surface km <sup>2</sup>	Density inhab/ km <sup>2</sup>	GDP	Nr doctors/ 1000 inhabitants	Nr of nurses/ 1000 inhabitants	Nr of patients in palliative care services	Nr doctors in palliative care	Nr nurses in palliative care
19.96	238.391	84.4	669,5 billion RON	2,5	5,8	150 000/ yearly	396	6500

### Is the palliative medicine/care supported by legislation?

In Romania there was strong advocacy to change restrictive policies

- O.M. nr.916/23.12.1999, OM nr 480/2005 on getting specialization / competence / certified / in palliative care
- OMECT nr. 2713 / 29.11.2007 on the approval of training standards, the curriculum and syllabus for qualification for general nurse who provides pre-university education post
- Law nr.339/2005 on the legal regime of plants, substances and preparations with narcotic and psychotropic
- OUG nr.115/2004 on wages and other rights of contractual staff of public health facilities in the health sector, HG 76/2008 on the organization and functioning of the National System of Judicial Genetic Data
- Law nr.95/2006 on health reform

### Identification of National Strategies in palliative care

In Romania the National Strategy for palliative care follows to create coordinated and accelerated development of palliative care services at national level aiming the improvement of quality of life for patients with chronic and progressive or incurable diseases and their families. The National Programme was officially presented, with the occasion of the 13th Conference of the National Association of Palliative Care (<http://www.anip.ro/>) in Iasi, in the period 6-8 September, 2012.

According to complexity of needs different levels of competencies will be enhanced:

Level 1: Support for self-care: offered to patients and their families by community medical assistance team with basic palliative care education, but also by specialized palliative care teams. This level assures that the patient and his family gain knowledge, abilities and self-confidence for self-care and for proper care in between medical staff interventions.

- a. Non-pharmacological methods for control different symptom
- b. Communication
- c. Food and feeding
- d. Bodily care
- e. Mobilization techniques
- f. Negotiation goals of care with professionals etc.

Level 2: Palliative approach represents direct care offered to patients and their families/carers by clinical staff with basic instruction in palliative care, having a certificate that confirms participation to different programs accredited by competent institutions.

Level 3: Specialized palliative care assures direct care offered to patients and their families/carers, but also includes consultancy for level 1 and 2 of competence. It is provided by professional interdisciplinary teams with specialized studies in palliative care field: doctors with palliative care competence, nurses, social workers, psychologists, therapists, clerics and other staff with palliative care competence, according to national standards of palliative care.

### Identification of specialized services in palliative care

Types of patients cared for: children with life limiting diseases, adults mainly with cancer but also with non-cancer diseases like dementia and different organ failure

Mechanisms of funding for the services in different settings: state funds, private funds, donations, campaigns.

Number/Types of services: inpatient units: 38; homecare: 19; day centres: 4; outpatient: 5.

### Identification of support specialized literature or organizations

- Specialized recent literature in palliative care: [literature in PC](#)
- 2 National associations in palliative care: [National Association of Palliative Care](#) and Asociatia Nationala de Tanatologie si Paliatologie - both collective members in European Association of Palliative Care (EAPC); Romania since mai 2015 has a representative in the EAPC board <https://eapcnet.wordpress.com/2015/05/13/new-beginnings-all-change-at-the-eapc/> Research centers in palliative care: main centre Hospice Casa Sperantei- Education and National Development Department

### Is the palliative care visible/debated at national level?

National conferences/events on palliative care:

- National Conference of Palliative Care ([National Association of Palliative Care](#)) organized every year since 1998; in 2015 the national conference will be held in Tg Mures, Romania 8-10 October when we also celebrate World Hospice Day

For educational events please see education calendar

- <http://www.studiipaliative.ro/calendar/>
- Governmental Commission for Palliative Care, regularly meetings with NACP members
- Scientific journals on palliative care: apart of articles published in journals like the Lancet and Journal of pain and symptom management ([Developing a costing framework for palliative care services](#); [Reform of drug control policy for palliative care in Romania](#)); there is also a national PC journal Paliatia.ro <http://www.paliatia.eu/new/> and since May 2014 a palliative care column in the national medical magazine Viata medicala with a palliative care article published every second week
- <https://www.facebook.com/media/set/?set=a.635455646535881.1073741830.198247400256710&type=3>

### Best practices/ projects on innovative solutions in palliative care

- [IZERZO](#): “Integration of medical oncology and palliative care procedures in various institutional and economical settings: Development of tailored interventions based on patient needs and testing of its preliminary efficacy on patient reported outcomes, tumour control and costs” financed by Romanian-Swiss Research Programme – IZERZO 142226
- [Swiss-Romanian Cooperation Programme: Overcoming disparities on access to quality basic palliative care in the community](#)

### 3. Practical research

#### Decision makers - Interpretation of the questionnaire results

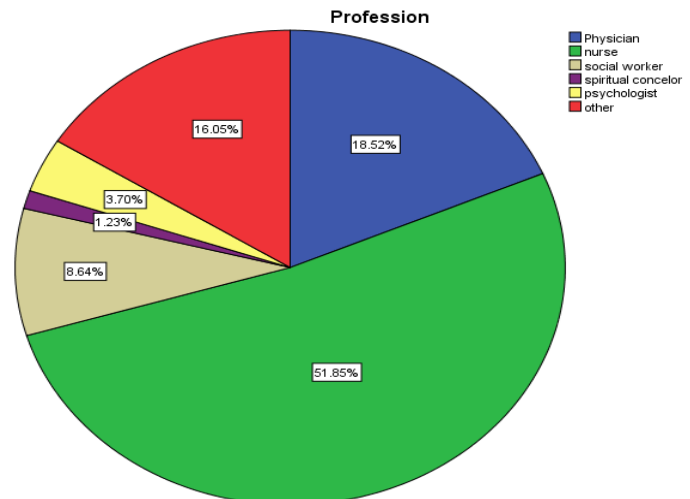
The appliance of questionnaires has targeted vice deans, dean and vice rectors. It was a general opinion that the implementation of a new direction of study must follow the steps that are indicated in the operational procedure (code PO-12) that is in use starting with September 2015 and approved by the Rector of the Gr.T.Popa University of Medicine and Pharmacy Iasi, Romania.

The start point in of the decision makers response to the research questionnaire was the fact that the study of the palliative care is already introduced in the University curriculum and that they are extremely interested and open to include the new standardized procedures that the project will develop. As the palliative care study is already introduced in the curriculum the use of the new proposed products and educational resources will happen from the moment of the concrete proposal, also due to the fact that the trainers of the University are the ones involved in the development of the project products.

#### Providers - Interpretation of the questionnaire results

In Romania, 2 centers have been involved – Iasi and Brasov and a total of 85 respondents have been involved in the research. In the following charts can be visualized the professions of the respondents and the percentage reached (there are 4 missing answers).

Profession			
	Frequency	Valid Percent	Cumulative Percent
physician	15	18.5	18.5
nurse	42	51.9	70.4
social worker	7	8.6	79.0
spiritual counselor	1	1.2	80.2
psychologist	3	3.7	84.0
other	13	16.0	100.0
Total	81	100.0	



Related to the question of how often in their current practice confronted with the need to perform palliative care maneuvers, respondents offered the following answers (mode levels: 1 - Not at all; 2 – Sometimes; 3 – Often; 4 - Very frequent).

**Statistics**

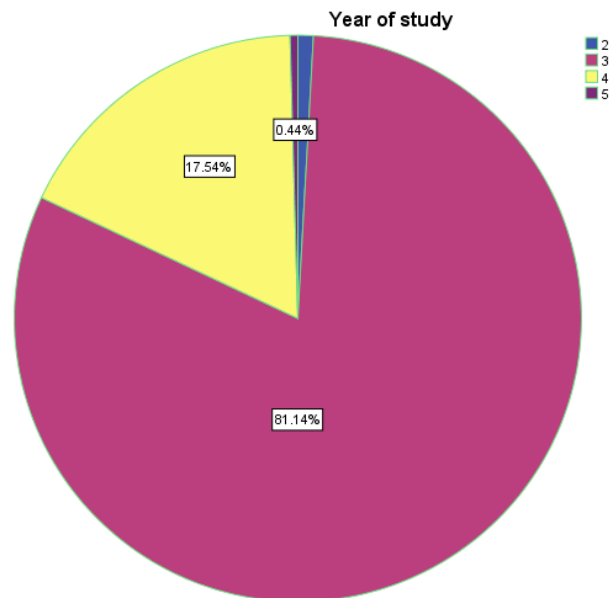
	N		Mean	Median	Mode
	Valid	Missing			
1.Communicating "bad news"	85	0	2.45	2.00	3
At what level	75	10	2.81	3.00	3
2.Listen to your patients and offer an empathic response	85	0	3.52	4.00	4
At what level	82	3	2.55	3.00	3
3.Approach the conspiracy of silence	85	0	2.59	3.00	2
At what level	71	14	2.82	3.00	3
4.Discuss about end of life care	83	2	2.42	2.00	3
At what level	72	13	2.82	3.00	3
5.Map patients network	80	5	2.83	3.00	3
At what level	72	13	2.76	3.00	3
6.Address the needs of caregivers	84	1	3.23	3.00	4
At what level	78	7	2.63	3.00	3
7.Evaluate the awareness level of patient disease and illness	85	0	2.89	3.00	3
At what level	76	9	2.72	3.00	3
8.Assess Pain	83	2	2.96	3.00	4
At what level	72	13	2.63	3.00	3
9.Prescribe Pain medication	82	3	1.99	1.00	1
At what level	57	28	2.44	3.00	3
10.Manage patients in terminal phase	83	2	3.07	3.00	4
At what level	76	9	2.72	3.00	3
11.Perform Spiritual assessment	82	3	2.85	3.00	3
At what level	73	12	2.68	3.00	3
12.Perform Nutrition /Feeding patient in bed	83	2	2.92	3.00	4
At what level	73	12	2.51	3.00	3
13.Measures to apply in order to prevent Burn out syndrome	85	0	2.78	3.00	2
At what level	74	11	2.76	3.00	3
14.Transfer/position patient in bed	83	2	2.93	3.00	4
At what level	71	14	2.56	3.00	3
15.Do Prevention/management of pressure ulcers & skin lesions	83	2	2.95	3.00	4
At what level	72	13	2.53	3.00	3
16.Urethro-vesical catheterization	84	1	2.11	2.00	1
At what level	68	17	2.34	3.00	3

### Students - Interpretation of the questionnaire results

In Romania, 2 centers have been involved – Iasi and Brasov and a total of 228 respondents have been involved in the research. In the following charts can be visualized the study year.

**Year of study**

	Frequency	Valid Percent	Cumulative Percent
2	2	0.9	0.9
3	185	81.1	82.0
4	40	17.5	99.6
5	1	0.4	100.0
Total	228	100.0	



Respondents have been invited to check palliative care maneuvers and answer at what stage in their previous education training they received information on how to perform the maneuvers (levels: 1 – before university; 2 – university; 5 – other).

### Statistics

	N		Mean	Median	Mode
	Valid	Missing			
1.Communicating "bad news"	278	0	4.31	5.00	5
At what level	278	0	2.33	2.00	2
2.Listen to your patients and offer an empathic response	278	0	4.42	5.00	5
At what level	278	0	2.30	2.00	2
3.Approach the conspiracy of silence	278	0	4.18	5.00	5
At what level	278	0	2.49	2.00	2
4.Discuss about end of life care	278	0	4.32	5.00	5
At what level	278	0	2.53	2.00	2
5.Map patients network	278	0	4.03	5.00	5
At what level	278	0	2.88	2.50	2
6.Address the needs of caregivers	278	0	4.08	5.00	5
At what level	278	0	2.84	2.00	2
7.Evaluate the awareness level of patient disease/illness	278	0	4.30	5.00	5
At what level	278	0	2.62	2.00	2
8.Assess Pain	278	0	4.47	5.00	5
At what level	278	0	2.48	2.00	2
9.Prescribe Pain medication	278	0	4.49	5.00	5
At what level	278	0	2.60	2.00	2
10.Manage patients in terminal phase	278	0	4.36	5.00	5
At what level	278	0	2.58	2.00	2
11.Perform Spiritual assessment	278	0	3.99	5.00	5
At what level	278	0	2.83	2.00	2



12.Perform Nutrition /Feeding patient in bed	278	0	3.75	5.00	5
At what level	278	0	2.74	2.00	2
13.Measures to apply in order to prevent Burn out syndrome	278	0	4.19	5.00	5
At what level	278	0	2.96	3.00	2
14.Transfer/position patient in bed	278	0	4.06	5.00	5
At what level	278	0	2.62	2.00	2
15.Do Prevention/management of pressure ulcers & skin lesions	278	0	4.10	5.00	5
At what level	278	0	2.74	2.00	2
16.Urethro-vesical catheterization	278	0	4.22	5.00	5
At what level	278	0	2.57	2.00	2
17.Perform Oral Care	278	0	4.00	5.00	5
At what level	278	0	2.71	2.00	2
18.Perform Patient bath	278	0	3.62	5.00	5
At what level	278	0	2.87	2.00	2
19.Use Automatic syringe for subcutaneous perfusion	278	0	4.03	5.00	5
At what level	278	0	2.95	2.50	2
20.Paracentesis	278	0	4.29	5.00	5
At what level	278	0	2.61	2.00	2

### Patients - Interpretation of the questionnaire results

In Romania, 2 centers have been involved – Iasi and Brasov and a total of 56 respondents have been involved in the research. In the following chart can be visualized the duration of illness, the patients that were able to tell the diagnosis of their illness in your own words and the status performance (1 - You are able to care for yourself (feeding, bath.); 2 - You spend more than 50% of your day time in bed or chair; 3 - You are able to do house work, sedentary work?; 4 - You are able to perform the same activities as previous before being ill?).

#### Statistics

	Duration of actual illness	Patient own words expressing the diagnosis	Performance status
Valid	47	55	54
Missing	9	1	2
Mean	5.00	1.24	1.41
Median	4.00	1.00	1.00
Mode	2	1	1

Invited to express their opinion related to the fact to whom do the patients prefer to discuss the issues related to palliative care, respondents offered the following answers (mode codes: 1 – Physician; 2 – Nurse; 3 - Social worker; 4 – Psychologist; 5 - Spiritual counselor).

#### Statistics

	N		Mean	Median	Mode
	Valid	Missing			
1.Communicating "bad news"	55	1	2.82	3.00	2
Comfortable to address the issue 1	53	3	1.70	1.00	1
2.Listen to your patients and offer an empathic response	56	0	2.89	3.00	2



Comfortable to address the issue 2	56	0	2.27	2.00	1
3.Approach the conspiracy of silence	55	1	2.47	2.00	2
Comfortable to address the issue 3	54	2	1.93	2.00	1
4.Discuss about end of life care	56	0	2.46	2.00	2
Comfortable to address the issue 4	54	2	1.65	1.00	1
5.Map patients network	54	2	2.56	2.00	2
Comfortable to address the issue 5	52	4	2.54	3.00	3
6.Address the needs of caregivers	52	4	2.29	2.00	2
Comfortable to address the issue 6	54	2	2.24	2.00	2
7.Evaluate the awareness level of patient disease and illness	55	1	2.91	3.00	2
Comfortable to address the issue 7	55	1	1.89	1.00	1
8.Assess Pain	56	0	3.07	3.00	3
Comfortable to address the issue 8	55	1	1.47	1.00	1
9.Prescribe Pain medication	56	0	2.86	3.00	3
Comfortable to address the issue 9	56	0	1.45	1.00	1
10.Manage patients in terminal phase	0	56			
Comfortable to address the issue 10	0	56			
11.Perform Spiritual assessment	56	0	2.89	3.00	3
Comfortable to address the issue 11	52	4	4.19	5.00	5
12.Perform Nutrition /Feeding patient in bed	50	6	2.70	3.00	4
Comfortable to address the issue 12	53	3	1.83	2.00	2
13.Measures to apply in order to prevent Burn out syndrome	0	56			
Comfortable to address the issue 13	0	56			
14.Transfer/position patient in bed	50	6	2.02	2.00	2
Comfortable to address the issue 14	46	10	1.98	2.00	2
15.Do Prevention/management of pressure ulcers & skin lesions	49	7	2.20	2.00	2
Comfortable to address the issue 15	50	6	1.92	2.00	2
16.Urethro-vesical catheterization	50	6	1.78	2.00	1
Comfortable to address the issue 16	44	12	1.73	2.00	2
17.Perform Oral Care	52	4	2.62	2.00	4
Comfortable to address the issue 17	48	8	1.98	2.00	2
18.Perform Patient bath	51	5	1.82	2.00	1
Comfortable to address the issue 18	42	14	1.81	2.00	2
19.Use Automatic syringe for subcutaneous perfusion	52	4	1.94	2.00	2
Comfortable to address the issue 19	45	11	1.71	2.00	1
20.Paracentesis	51	5	1.57	1.00	1
Comfortable to address the issue 20	44	12	1.27	1.00	1

## Families - Interpretation of the questionnaire results

In Romania, 2 centers have been included – Iasi and Brasov and a total of 48 respondents have been involved in the research. In the table below can be visualized the results of the age of the family members indicator of the questionnaire.

### Statistics

Age

N	Valid	48
	Missing	0
Mean		49.31
Median		47.00
Mode		47

Respondents have been invited to answer at what level they as a family member of a patient with chronic progressive disease did experience the need for the health care teams to address the followings concerning their sick relative. (Mode code: 1 - Not at all; 2 – Sometimes; 3 – Often; 4 - Very frequent).

### Statistics

	N		Mean	Median	Mode
	Valid	Missing			
1.Communicating "bad news"	47	1	2.45	2.00	2
At what level	46	2	1.13	1.00	1
2.Listen to your patients and offer an empathic response	48	0	2.44	2.00	2
At what level	45	3	1.87	1.00	1
3.Approach the conspiracy of silence	48	0	2.54	3.00	3
At what level	47	1	2.19	2.00	1
4.Discuss about end of life care	48	0	2.63	3.00	3
At what level	47	1	1.62	1.00	1
5.Map patients network	48	0	2.73	3.00	3
At what level	47	1	2.66	3.00	3
6.Address the needs of caregivers	47	1	2.62	3.00	3
At what level	45	3	2.93	3.00	3
7.Evaluate the awareness level of patient disease and illness	46	2	2.76	3.00	3
At what level	44	4	2.09	2.00	1
8.Assess Pain	48	0	3.19	3.00	3
At what level	48	0	1.77	1.00	1
9.Prescribe Pain medication	48	0	3.00	3.00	3
At what level	47	1	1.62	1.00	1
10.Manage patients in terminal phase	0	48			
At what level	0	48			
11.Perform Spiritual assessment	47	1	2.79	3.00	3

At what level	46	2	3.96	5.00	5
12.Perform Nutrition /Feeding patient in bed	47	1	2.51	3.00	3
At what level	46	2	2.09	2.00	2
13.Measures to apply in order to prevent Burn out syndrome	0	48			
At what level	0	48			
14.Transfer/position patient in bed	47	1	2.47	2.00	2
At what level	47	1	2.17	2.00	2
15.Do Prevention/management of pressure ulcers & skin lesions	0	48			
At what level	0	48			
16.Urethro-vesical catheterization	48	0	2.19	2.00	2
At what level	45	3	1.82	2.00	2
17.Perform Oral Care	48	0	2.52	2.00	2
At what level	45	3	2.09	2.00	2
18.Perform Patient bath	48	0	2.35	2.00	2
At what level	45	3	2.00	2.00	2
19.Use Automatic syringe for subcutaneous perfusion	47	1	2.34	2.00	2
At what level	47	1	1.74	2.00	2
20.Paracentesis	47	1	2.00	2.00	2
At what level	45	3	1.38	1.00	1