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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 Italy

Azienda Sanitaria Locale TO3, Italy

Contents

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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

In the daily activities, the terms “palliative care” and “palliative medicine” are interchangeable. The term “palliative medicine” is considered as related to a medicine specialization, while the term “palliative care” is related to a multiprofessional and multidimensional dimension of the taking care of the person and of his/her family during the last period of life. When the patient lives an unfavorable prognosis, a „total suffering and pain” situation is evident: beyond the physical problems, the psychological and spiritual aspects are evident, together with social and interpersonal relationships problems and economics complications. Taking care of the patient with unfavorable prognosis means to face all questions related to pain and suffering of the patient, so applying the philosophy of palliative care.
There are four main ways in which definitions of palliative care may differ:

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- Palliative care is sometimes defined as solely being care that alleviates pain and other symptoms. With these definitions palliative care does not include any other support for either the patient or their family.
- In the 1960s hospices provided palliative care for people who were dying of cancer. As a result palliative care was defined as being care that was provided for people who were not receiving any treatment to actively treat their disease. It has since been realised that many aspects of palliative care are applicable earlier in the course of a disease and that palliative care can, and often should, be provided alongside disease modifying treatment. Some definitions of palliative care such as the one given above, either implicitly or explicitly allow for this.
- Palliative care is still sometimes defined as solely being for people with cancer, but palliative care is more often now defined as being for people facing a life-threatening illness. Palliative care is not usually defined as being for people with chronic conditions such as diabetes.
- When palliative care first began to be provided for people with AIDS in the 1980s, it was realised that the provision of palliative care for a “family” could exclude the person who mattered most to a person with AIDS. Some definitions of palliative care now try to ensure that the word “family” is interpreted as including everyone who matters most whether a “blood” relative or not.

Provision of statistical data, at national level

The Italian national healthcare service (SSN) was created in 1978 to replace a previous system based on a multitude of insurance schemes. The SSN was inspired by the British National Health Service and has two underlying principles. Firstly, every Italian citizen and foreign resident has the right to healthcare and, secondly, the system covers all necessary treatments.

Although the Ministry of health is ultimately responsible for the administration of the Health Service, much of the control has been passed to the Regions and onto the local health authorities known as ASL (Azienda di Sanità Locale). ASLs are responsible for the management of all health services in their area and private providers can also operate within the SSN.

There have been a number of reforms to the SSN since the early 90s. Competition has been increased by allowing citizens to choose their healthcare provider. Payments have been regularized using a Diagnostic Related Group (DRG) system and a small amount of co-payment has been introduced. Later reforms were aimed at increasing planning at the regional level and increasing efficiency of all managers within the SSN. Managers were placed on fixed contracts with regular performance reviews.

Population milions	Surface km^2	Density inhab/ km^2	GDP	Nr doctors/ 1000 inhabitants	Nr of nurses/ 1000 inhabitants	Nr of patients in palliative care services	Nr doctors in palliative care
60.78	301,338	201.7	$2.066 trillion	4.2	7.7	9.6834	11.988

Is the palliative medicine/care supported by legislation?

- National Law n.38/2010 about the palliative care and therapy for the management of pain (Piemonte Region)
- Regional Law n. 30-866/25.10.2010. "Regional network for palliative care and Pain Centers". This network promotes an integrated and interoperable approach among acute care hospitals, general practitioners, home care, units of pain management and palliative care, hospice for palliative care;
- Regional Law n. 31-1482/11.02.2011. Individuation of members and functioning procedures of Regional Committee about the Coordination of Palliative Care and Pain Centers

Identification of National Strategies in palliative care

The continuing development of palliative care must be accompanied by an extraordinary attention on some strategic points, to make them available to all patients who need them, and to ensure that they best express the level of social and health care evolution, so that we can say they are developing not only in number, but in quality too.

The first aspect is the **appropriateness** of our care: we have to get better systems to recognize the need of care, the timing of care, and to develop quality assessment and performance improvement.
The second aspect is the attention to **human** factor, (someone called the Palliative Care the Science of Compassion - The National Institute of Nursing Research Summit, USA, 2011): we have to bring with us to patient’s home technology but also good skills in helping relationship, and this means to improve strategies and programs to provide health professionals with specific personal training and team training, education and support.

The third aspect is the attention to **multidisciplinary approach** in palliative care: we know we rely on cooperation among physicians, nurses, psychologists and other health professionals, and no less important are social workers, chaplains and every other allied people who can contribute to diminish patient’s suffering. This means promoting and implementing a specific and firm network which needs maintenance and updating to be appropriate to the needs of the patient and of the care team.

Finally, the fourth aspect is the indispensability of involving all the patient’s family in our care; we know that palliative care is a **family centered approach** that embraces all the family members, (and the family is defined by the patient), during the patient’s illness and after his death, in the bereavement process.

So there is a specific affordable and flexible need for guidelines of care, because in these cases the bereavement processes last longer, and have multiple and maybe unexpected effects. That’s why we also need to better identify guidelines for Palliative Care in Primary Care Settings and Specialty Level Palliative Care.

Identification of specialized services in palliative care

Hospital services - You or your primary doctor can request palliative care services at any time while you are for treatment. Specialists initially meet with you and your family to begin building a care plan that meets your physical, emotional and spiritual needs. Research indicates that early use of palliative care services can extend life and provide you with a better quality of life.

Outpatient services - Palliative care services are not always available locally or through your own health care clinic. Outpatient services help you and your local doctor evaluate your needs and develop a care plan that is right for you. Outpatient service can supplement your care even if you are not being treated by a doctor.

Pediatric services - In addition to all the disciplines and specialists represented in an adult palliative care team, pediatric palliative care programs often include child life specialists who offer developmentally appropriate education and therapeutic play activities related to the health care experience.

Identification of support specialized literature or organizations

- ACCD – Association for pain treatment in Cremona
- ACP - Bergamo – Association Palliative Cares in Bergamo
- ANLAIDS – National association against AIDS
- Associazione Antea
- Associazione Volontari Presenza Amica
- Federazione Cure Palliative (FCP) Onlus – Federation grouping 70 Italian NGO's
- Fondazione Floriani
- Fondazione italiana di leniterapia – Italian Foundation for Lenitherapy
- Fondazione Maruzza Lefebvre D'Ovidio Onlus
- Fondazione Lu.V.I.
- Fondazione Maria Teresa Chiantore Seràgnoli
- Lega italiana per la lotta contro i tumori – National Association against cancers
- S.A.M.O.T. Onlus – Italian Society for assisting terminally ills from cancer

Specialized recent literature in palliative care

- www.fremedicaljournals.com ;
- www.academicjournals.org ;
- www.biomedcentral.com ;
- www.bmj.com.bvs.cilea.it;
- www.ncbi.nlm.nih.gov ;
- www.sciencedirect.com

Is the palliative care visible/debated at national level?

National conferences/events on palliative care:

- Ciclo di incontri "STARE vicino a chi vive il dolore di una perdita", Firenze, 16 gennaio - 15 maggio 2015

- Approccio palliativo nelle malattie avanzate inguaribili e nelle gravi fragilità psico-fisico-sociali che vivono nella Comunità, Milano, 17 gennaio - 10 luglio 2015
- CORSO "GIORNATE MONOTEMATICHE IN CURE PALLIATIVE", Milano, 19 gennaio - 15 giugno 2015
- PROGETTO "IN RETE – NODO TERRITORIALE", Piacenza, 21 gennaio - 13 maggio 2015
- Audit clinico in Cure Palliative, Bologna, 28 gennaio - 31 marzo 2015

Scientific journals on palliative care:

- Annals of Internal Medicine - Journal of American College of Physicians
- Annals of Oncology - Journal of European Society for Medical Oncology ESMO
- BMC Palliative Care - Journal of BMC of Palliative Care
- BMJ Supportive and Palliative Care - Journal of BMJ for palliative care
- End of Life Journal - Journal of nurses who work in palliative care

Best practices/ projects on innovative solutions in palliative care

- www.cure-domiciliari.it/files/Testimonianza.pdf
- www.aniarti.it
- cplps2.altervista.org/…ambrosini%20nutrizione%20...

3. Practical research

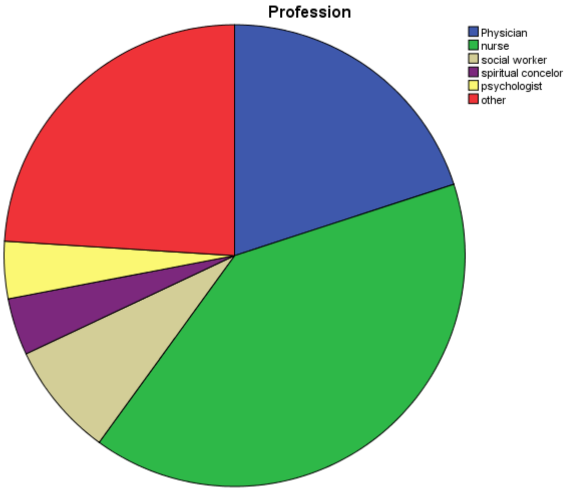
Decision makers - Interpretation of the questionnaire results

A coordinator from the University of Turin (Faculty of Nursery) was interviewed. Curricula are periodically checked and assessed by a group of teachers involved for each subject. A new topic can be inserted in the curricular programs every 4-5 years.

Providers - Interpretation of the questionnaire results

25 health workers were interviewed.
They were classified as follows:

- 5 doctors
- 10 nurses
- 2 social workers
- 2 psychologists
- 1 spiritual counselor
- 5 socio-medical operators



They were all professionals in palliative cares from the District of Pinerolo - ASLTo3. Average age: 48 years. Average professional experience: 30. Gender distribution: 19 women and 6 men.

With reference to the first questions “in your daily activities, how often do you have to carry out one the following procedures?”, healthy workers classified the following procedures as the commonest:

- patient listening and empathic response (19 health workers out of 25);
- management of terminally ills patients (16 health workers out of 25);
- mapping pf patients’ needs (15 health workers out of 25);
- pain assessment (14 health workers out of 25);
- level of awareness’ assessment (12 health workers out of 25);
- conspiracy of silence (12 health workers out of 25);
- prescription of drugs (11 health workers out of 25);
- nutrition and feeding (11 health workers out of 25);
- diagnosis of serious diseases (10 health workers out of 25);
- mapping of patients in terms of social support (10 health workers out of 25);
- patient mobilization (10 health workers out of 25);
- prevention and management of decubitus’ ulcer (10 health workers out of 25);
- paracentesis (10 health workers out of 25).

This data has to be related to the professional profiles of the operators involved: only Physicians (5 involved in the interview) may prescribe drugs.

Students - Interpretation of the questionnaire results

103 students were interviewed (100 Italians and 2 Romanians). Average age: 24 years. Gender distribution: 36 male and 67 female.

64 students have declared that they have never had experience in palliative cares, while 39 students have already had experience in this field. Amongst them, at the moment of the interview, 12 students had a relative in palliative care, one was a volunteer in a center providing palliative care, and 24 have carried out an internship in a palliative care center.

89 students out of 103 stated that the University provided them with a basic knowledge about palliative cares procedures. About 38 students declared they have had training outside the University system, largely due to attending voluntary organizations. About 37 students declared they had skills in palliative cares, even before their University career, thanks to being part of voluntary associations.

Statistics

	N		Mean	Median	Mode
	Valid	Missing			
1Communicating "bad news"	83	0	5.00	5.00	5
At what level of training 1	83	0	2.27	2.00	2
2Listen to your patients and offer an empathic response	83	0	5.00	5.00	5
At what level of training 2	83	0	2.01	2.00	2
3Approach the conspiracy of silence (family knows the diagnosis and request you not to tell to the patient)	83	0	5.00	5.00	5

At what level of training 3	83	0	2.24	2.00	2
4Discuss about end of life care	83	0	5.00	5.00	5
At what level of training 4	83	0	2.08	2.00	2
5Map patients network	83	0	5.00	5.00	5
At what level of training 5	83	0	2.49	2.00	2
6Address the needs of caregivers	83	0	5.00	5.00	5
At what level of training 6	83	0	2.41	2.00	2
7Evaluate the awareness level of patient disease and illness	83	0	5.00	5.00	5
At what level of training 7	83	0	2.27	2.00	2
8Assess Pain	83	0	5.00	5.00	5
At what level of training 8	83	0	2.20	2.00	2
9Prescribe Pain medication	83	0	5.00	5.00	5
At what level of training 9	83	0	2.35	2.00	2
10Manage patients in terminal phase	83	0	5.00	5.00	5
At what level of training 10	83	0	2.25	2.00	2
11Perform Spiritual assessment	83	0	5.00	5.00	5
At what level of training 11	83	0	2.63	2.00	2
12Perform Nutrition /Feeding patient in bed	83	0	5.00	5.00	5
At what level of training 12	83	0	2.05	2.00	2
13Measures to apply in order to prevent Burn out syndrome	83	0	5.00	5.00	5
At what level of training 13	83	0	2.33	2.00	2
14Transfer/position patient in bed	83	0	5.00	5.00	5
At what level of training 14	83	0	2.06	2.00	2
15Do Prevention/management of pressure ulcers & skin lesions	83	0	5.00	5.00	5
At what level of training 15	83	0	2.06	2.00	2
16Urethro-vesical catheterization	83	0	5.00	5.00	5
At what level of training 16	83	0	2.06	2.00	2
17Perform Oral Care	83	0	5.00	5.00	5
At what level of training 17	83	0	1.99	2.00	2
18Perform Patient bath	83	0	5.00	5.00	5
At what level of training 18	83	0	2.04	2.00	2
19Use Automatic syringe for subcutaneous perfusion	83	0	5.00	5.00	5
At what level of training 19	83	0	2.23	2.00	2
20Paracentesis	83	0	5.00	5.00	5
At what level of training 20	83	0	2.07	2.00	2

Patients - Interpretation of the questionnaire results

11 patients were interviewed by operators in palliative cares. They were all Italians. Average age: 62 years. Gender distribution: 5 men and 6 women. Average length time of their disease: 27 months.

5 patients had a secondary school diploma, 4 had a high school diploma, and 2 had a University degree. At the moment of the interview, 9 out of 11 patients spent more than 50% of the day in bed or chair, was only 1 patient was able to autonomously heal himself.

To the question “as a patient having a chronic progressive disease, for which of the following did you experience the need for health care teams?” patients replied as it follows:

- 8 out of 11 patients needed to be assessed for pain;
- 7 out of 11 patients needed the support of social services;
- 6 out of 11 patients needed an answer to the practical needs of those family members supporting them.

To the question "With whom would you feel more comfortable to address your needs?" patients replied as follow: 6 out of 11 patients prefer to address their needs to nurses rather than to doctors (3 patients out of 11). Based on the organization of home palliative care, patients usually spend more time with nurses than with any other professional. During home visits by nurses, there are different activities to be integrated into the procedures listed in the questionnaire.

Statistics

	N		Mean	Median	Mode
	Valid	Missing			
1Communicating "bad news"	11	0	3.00	3.00	3
Comfortable to address the issue 1	11	0	1.73	1.00	1
2Listen to your patients and offer an empathic response	11	0	2.82	3.00	3
Comfortable to address the issue 2	10	1	1.90	2.00	2
3Approach the conspiracy of silence	11	0	2.45	2.00	2
At what level of training 3	7	4	1.71	2.00	2
4Discuss about end of life care	11	0	3.00	3.00	3
At what level of training 4	10	1	1.70	2.00	2
5Map patients network	11	0	3.64	4.00	4
At what level of training 5	7	4	1.86	2.00	2
6Address the needs of caregivers	11	0	3.45	4.00	4
At what level of training 6	10	1	1.70	2.00	2
7Evaluate the awareness level of patient disease and illness	10	1	3.10	3.00	3
At what level of training 7	11	0	2.00	2.00	2
8Assess Pain	11	0	3.55	4.00	4
At what level of training 8	11	0	1.55	2.00	2
9Prescribe Pain medication	11	0	3.36	4.00	4
At what level of training 9	11	0	1.00	1.00	1
10Manage patients in terminal phase	0	11			
At what level of training 10	0	11			
11Perform Spiritual assessment	8	3	2.38	2.00	2
At what level of training 11	7	4	3.71	5.00	5
12Perform Nutrition /Feeding patient in bed	9	2	3.22	3.00	3
At what level of training 12	10	1	1.90	2.00	2
13Measures to apply in order to prevent Burn out syndrome	0	11			
At what level of training 13	0	11			
14Transfer/position patient in bed	10	1	3.00	3.00	3[a]
At what level of training 14	10	1	1.90	2.00	2
15Do Prevention/management of pressure ulcers & skin lesions	10	1	2.90	3.00	4
At what level of training 15	9	2	2.00	2.00	2
16Urethro-vesical catheterization	7	4	1.00	1.00	1
At what level of training 16	4	7	1.75	2.00	2
17Perform Oral Care	9	2	2.56	3.00	1
At what level of training 17	7	4	2.00	2.00	2
18Perform Patient bath	8	3	2.88	3.00	4
At what level of training 18	8	3	2.13	2.00	2
19Use Automatic syringe for subcutaneous perfusion	9	2	2.11	2.00	1
At what level of training 19	7	4	1.71	2.00	2
20Paracentesis	6	5	1.00	1.00	1
At what level of training 20	3	8	1.67	2.00	2

Families - Interpretation of the questionnaire results

11 families' members were involved. They were all Italians. Average age: 52 years. Gender distribution: 5 men and 6 women. At the moment of the interview, 3 out of 11 had a secondary school diploma, 4 had a high school diploma and 4 had a University degree.

The relationship with the patient was the following: 3 out of 11 were the husbands of the patient; 4 were the wives of the patient; finally there were 2 sons and 2 daughters of the patient.

To the question "as a family member of a patient with chronic progressive disease, for which of the following did you experience the need of support from the health care teams?" family members replied as follows:

- assessing the level of awareness of the disease (8 families' members out of 11);
- assessment of pain (7 families' members out of 11);
- communication of the diagnosis and evolution of the disease (4 families' members out of 11);
- discussing the best location for medical assistance (4 families' members out of 11);
- procedure to be followed for oral cares(4 families' members out of 11);
- discussing the impact of the disease on their lives (6 families' members out of 11);
- assessment of spiritual needs (6 families' members out of 11).

Statistics

	N		Mean	Median	Mode
	Valid	Missing			
1Communicating "bad news"	11	0	3.18	3.00	3
Comfortable to address the issue 1	11	0	1.09	1.00	1
2Listen to your patients and offer an empathic response	11	0	3.09	3.00	3
Comfortable to address the issue 2	11	0	1.73	2.00	2
3Approach the conspiracy of silence	10	1	2.70	3.00	3
At what level of training 3	10	1	1.60	2.00	2
4Discuss about end of life care	11	0	2.91	3.00	3
At what level of training 4	11	0	1.73	2.00	2
5Map patients network	11	0	3.27	3.00	3[a]
At what level of training 5	10	1	1.80	2.00	2
6Address the needs of caregivers	11	0	2.73	3.00	3
At what level of training 6	8	3	1.75	2.00	2
7Evaluate the awareness level of patient disease	11	0	2.73	3.00	4
At what level of training 7	10	1	1.70	2.00	2
8Assess Pain	11	0	3.27	4.00	4
At what level of training 8	10	1	2.00	2.00	2
9Prescribe Pain medication	11	0	3.09	3.00	4
At what level of training 9	10	1	1.00	1.00	1
10Manage patients in terminal phase	0	11			
At what level of training 10	0	11			
11Perform Spiritual assessment	9	2	2.89	3.00	4
At what level of training 11	8	3	3.00	2.00	2
12Perform Nutrition /Feeding patient in bed	10	1	3.20	3.00	3
At what level of training 12	10	1	1.80	2.00	2
13Measures to apply in order to prevent Burn out syndrome	0	11			
At what level of training 13	0	11			
14Transfer/position patient in bed	10	1	2.80	3.00	3
At what level of training 14	8	3	2.00	2.00	2

15Do Prevention/management of pressure ulcers & skin lesions	0	11			
At what level of training 15	0	11			
16Urethro-vesical catheterization	10	1	1.30	1.00	1
At what level of training 16	5	6	1.80	2.00	2
17Perform Oral Care	11	0	2.64	3.00	3
At what level of training 17	8	3	1.88	2.00	2
18Perform Patient bath	11	0	2.73	3.00	3
At what level of training 18	9	2	2.00	2.00	2
19Use Automatic syringe for subcutaneous perfusion	10	1	2.10	1.50	1
At what level of training 19	7	4	1.86	2.00	2
20Paracentesis	9	2	1.33	1.00	1
At what level of training 20	3	8	1.00	1.00	1