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 Spain

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Contents

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

End of life is a complex circumstance to afford, requiring a special approach. For that reasons health professionals should manage several different situations, included those related to the dying process emotional impact. The role of quality in this special setting is extremely important in order to give all the guarantee to patients and family and pro mote the best quality of life.

Palliative health care present several obstacles for patients and families, clinical setting involves a plurality of different professionals, treatments and clinical circumstances where quality is not always allowed in the best way. The application of standardized procedures consents to improve physical and psychological care, coordination among professionals and improve the quality of care.

A procedure is a specific action strategy, as consequence we can define operational procedure a pathway describing specific steps of clinical intervention with the aim to promote health care. In Palliative care medicine the application of standardized procedure is commonly a consequence to the need to solve a clinical problem in a defined time.

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Provision of statistical data, at national level

Health Care System in Spain has a decentralized management spread between Central Government and Autonomous Regions, each one with a specific and independent health care policy and strategy. For that reasons statistical data related to palliative care in Spain are not centralized in a national database reporting the exact characters of users' target group, as well as are the specific resources allocated at national level.

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	Nr nurses in palliative care
46.81	505.990	92	$1.407 trilion	4.6	5.2	215.388	567	1016

Is the palliative medicine/care supported by legislation?

In Spain the Autonomous Regions have the power to legislate about health care system. Central Government can develop health law but Autonomous Regions have the last word in order to how enact the legislation.

In the Constitution of 1978 there aren't specific references to palliative care, even though in the art. 43.1 there is a more general reference to the "health right respect and public health protection" as duties of public institutions. For that reason at national level there's not a specific legislation about palliative care and a common definition of palliative care services.

Just three Autonomous Regions such as Andalucía, Aragón and Navarra have legislated a specific law about the end of life process where the concept of palliative care is defined in a more or less common way.

The legal foundation of information, informed consent, advanced directives and confidentiality are established at national level in the law 41/2027. Each Autonomous Region has defined the conditions related to the informed consent and advanced directives.

Identification of National Strategies in palliative care

Spanish Society for Palliative Care (SECPAL) was created in 1992. It is the body that brings together more than 1800 professionals working in the field. Since 1994, SECPAL publishes the "Palliative Medicine" magazine (Medicina Paliativa. Scored with 0,162 in Journal Citation Reports-2013. Indexed journal in: Science Citation Index, Scopus, ScienceDirect) which is the only Spanish publication specialized in hospice-palliative care so that shows the work carried out in Spain and Latin America. This multidisciplinary journal aims to share knowledge and experiences in order to respond to the multidimensional patient care and his/her immediate environment. Training programs, congresses and meetings organized by this body have increasingly greater impact on Spanish society. In 2001 Núñez Olarte published an article about the key ethical issues in clinical practice in palliative and end-of-life care in Spain and how these issues are influenced by Spanish culture. Although there is a general consensus that a new philosophy of care is needed, the interpretation and application of this general philosophy are different in diverse sociocultural contexts. The Spanish palliative care movement has shifted its focus from starting new programs to consolidating and expanding the training of the professionals already working in the existing programs. Still, as said above, half of the terminally ill does not receive the required assistance. Universities have not

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incorporated palliative medicine at the undergraduate levels and the current lack of specialists in this field is still not alleviated. Despite that mass media coverage has greatly increased in the last years (see below), Spain needs a law to ensure a dignified death for all patients. The current law requires that doctors offer palliative care but the formulation of this obligation is extremely ambiguous. Andalusia is the first region that regulated dignified death with the approval of the Bill of Rights and Guarantees of the Dignity of Persons in the Process of Death. This law prohibits aggressive therapy and allows patients to refuse treatment that artificially prolong their life permitting palliative sedation to alleviate the suffering of the sick. Navarra and Aragon in 2011 passed similar laws. The foremost national newspapers and public access information sources have extensively faced the topic in the last five years. Accordingly, in the library of the best-selling newspaper in Spain (El País), for the period 2010-2015 there is more than 800 news and opinion articles related to palliative care and end-of-life issues. Since January 2015, the Spanish public television has addressed the issue of palliative care with two documentaries, an interview with a specialist and a movie. All were broadcasted around February 4, World Cancer Day.

Identification of specialized services in palliative care

Palliative care in Spain are considered a patients' right to protect the end of life and are organized principally in three different service areas:

- Primary or basic services: conventional care
- Secondary or specialized services
- Tertiary, for those hospitalized patients requiring complex care

Spread in this three different area there are specific typology of services:

- **Conventional services**: they improve the quality of services among the task group of patients with serious or terminal illnesses. This kind of services are available:

1) Primary o basic medicine as home services, where patients are assisted by palliative care professional at home.
2) Hospitalized services, they can be available only at hospital or in day-hospital, generally are provided through the units of oncology, geriatrics and internal medicine.
3) Hospices.

- **Specific services:** multidisciplinary team with specific training in palliative care available for terminal patients. This kind of service provides an integral care, where a multidisciplinary team work with a specific palliative care technology devices with formal procedures and intervention protocol. Specific palliative care services they are located in university hospital with clinically complex target group of patients, where research and medical teaching are practiced.

Among palliative care services available for patients in Spain there are:

- **Patients and family and support**: patients and carers share with a multi-disciplinary palliative care team decision making processes related to the end of life, clinical evaluation and monitoring, medical teaching and research, social network and quality of life assessment;
- **Psychological support:** the principal function of palliative care team in Spain is psychological support to the patients and carers in order to manage emotional distress and at the same time avoid palliative care professionals burn out. Psychologists have also a coordination role in the team in order to control patients' pain and support family through the development of an action plane and specific common therapeutic aims. Finally psychologists are involved moreover with oncological patients to control anxiety and adaptation difficulties process.
- **Home care services:** in Spain palliative care home services are required in a rate of 400 clinical cases /100.000 inhabitants. Target group of patients requiring this kind of service have more than six months life expectation. Home palliative care services

benefits are efficacy in control pain, and other symptoms, reduce hospitalization and emergency care services more than 30%, promotion of scheduled admissions toward emergency admissions and probability rate to die at home up 50%-70% with a final result to reduce cost up the 50%.

- **Pain control:** control pain is an essential requirement in palliative care, treatment aims are oriented to improve patient’s comfort and protect hits dignity in the end of life process.

Identification of support specialized literature or organizations

After the application of World Health Organization Program about palliative care in Catalonia in 1989 several guideline have been developed about the most important aspects of palliative care, such as the National Program about Palliative Care (Plan Nacional de Cuidados palliativos) and National Strategy about Palliative Care (Plan Nacional de Cuidados Palliaitivos) promoted by the National Health System.

The main organization to promote and improve the application of palliative care in Spain are:

- Organización Mundial de la Salud, www.who.int
- Programa de las Naciones Unidas para el SIDA, www.UNAIDS.org
- Fundaciones Princesa de Gales Memorial Fund, www.theworkcontinues.org
- Robert Woods Johnson Foundation, www.rwjf.org
- International Association for Hospice and Palliative care, www.hospicecare.com

Handbook generally used by medical students and health care professional to train in palliative care among the most important in Spain:

- Doyle D, Woodruff R. Manual for palliative care, www.hospicecare.com/manual/IAHPCmanual.htm
- Sociedad Española de Cuidados Paliativos. Guía de Cuidados Paliativos, www.Secpal.com
- Sociedad Vasca de Cuidados Paliativos: varios libros en PDF, www.sovpal.org

Training program available in Spain for medical and biomedical students and health professionals about palliative care:

- Universidad Autónoma de Madrid: máster en Cuidados Paliativos y Tratamiento de Soporte del Enfermo con Cáncer http://www.uam.es/ss/Satellite/es/1242654675830/1242656616884/estudiopropio/estudioPropio/Master_en_Cuidados_Paliativos_y_Tratamiento_de_Soporte_del_Enfermo_con_Cancer.htm
- Universidad de Valladolid: máster en cuidados paliativos http://www.enclaveformacion.com/master-paliativos/
- Máster universitario en enfermería en cuidados paliativos (Univ. de Navarra): http://www.universia.es/estudios/unav/unav-master-universitario-enfermeria-cuidados-paliativos/st/193269#
- Enfermería en los Cuidados Paliativos. Hospitalización Domiciliaria (Escuela de Ciencias de la Salud. Centro adscrito a la UCM). http://www.emagister.com/enfermeria-cuidados-paliativos-hospitalizacion-domiciliaria-cursos-2576225.htm

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Is the palliative care visible/debated at national level?

Scientific journals on palliative care:

- Cancer Pain Release, www.WHOcancerpain.wisc.edu
- Hospice Information, www.hospiceinformation.info
- IAHPC, www.hospicecare.com
- World Hospice Palliative Care Online, avril@hospiceinformation.info
- Palliatif (en francés), irzpalli@vtx.ch
- Medicina Paliativa, www.secpal.com/medicina_paliativa/index.php

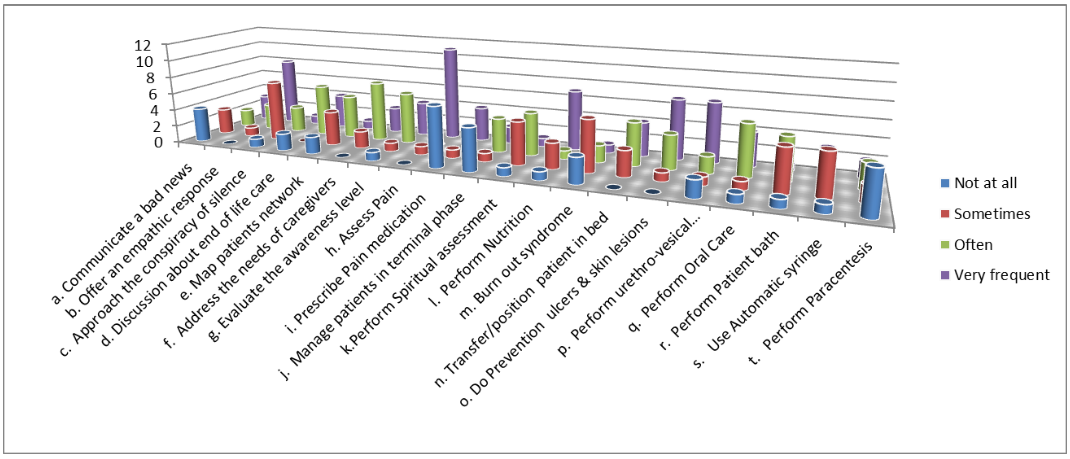
3. Practical research

Decision makers - Interpretation of the questionnaire results

The decision makers category has been represented by the Head of clinical department of the Universidad Europea de Madrid. Regarding the question related to what are the ways to continuously improve the curricula in your university, the head of clinical department mentioned innovation and education projects/ actions. And that there is a need of a period of 6 months to include a new topic in the curriculum in the university from the moment of a concrete proposal. The head of the clinical department showed as being interested to include training concerning the mentioned palliative care procedures in the curriculum of the represented university.

Providers - Interpretation of the questionnaire results

In this research, a total number of 12 providers (5 physicians and 7 nurses) have been involved. The average age of the respondents is 39 years old and both categories of men and women have been included (4 men and 8 women) and 2 are from rural area and 10 from urban area.



Most of the respondents agreed the fact that the mentioned procedures have been trained during the university studies.

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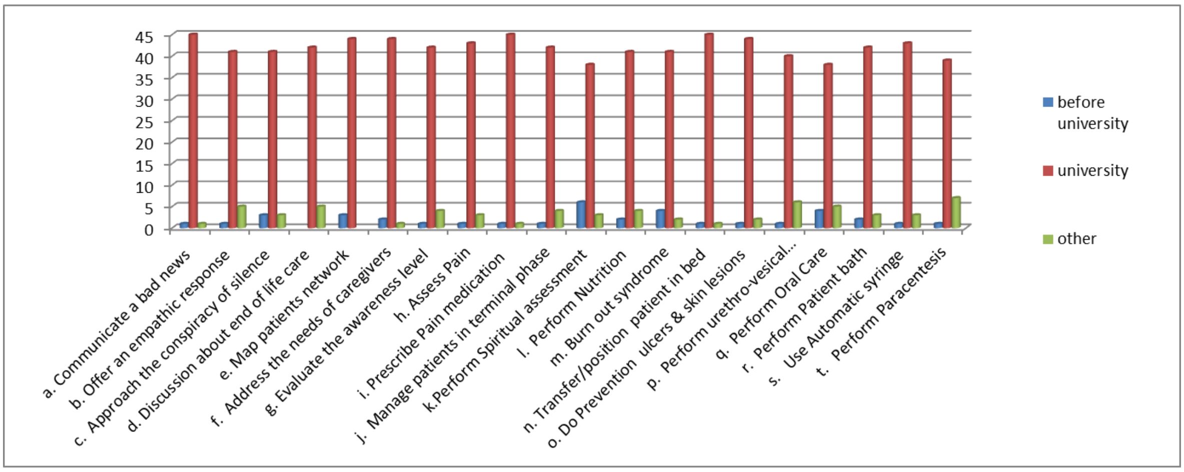
Among the most mentioned operational procedures, remarked as being extremely important to be standardized for palliative care practice are: with between 11 and 10 options: Evaluation of patient understanding about his/her disease and illness; Assessing Pain (cognitive impairment also); Managing patients in terminal phase (last days/hours of life). With 9 to 7 options: Active listening and offering of empathic response; Discussion about end of life care; Nutrition /Feeding patient in bed; Prevention/management of pressure ulcers & skin lesions; Paracentesis.

Students - Interpretation of the questionnaire results

In this research, a total number of 47 students have been involved (43 have clinical exposure to palliative care and only 9 not). The average age of the respondents is 22 years old and both categories of men and women have been included (13 men and 34 women) and 1 is from rural area and 46 from urban area.



Most of the respondents agreed the fact that the mentioned procedures have been trained during the university studies.

Patients - Interpretation of the questionnaire results

In this research, a total number of 10 patients have been involved (7 retired people and 3 housewife). The age of the respondents is between 56 and 98 years old and both categories of men and women have been included (3 men and 7 women) and 4 are from rural area and 6 from urban area. Level of education of the respondents is 3 followed the primary school, 2 secondary school and 5 university studies.

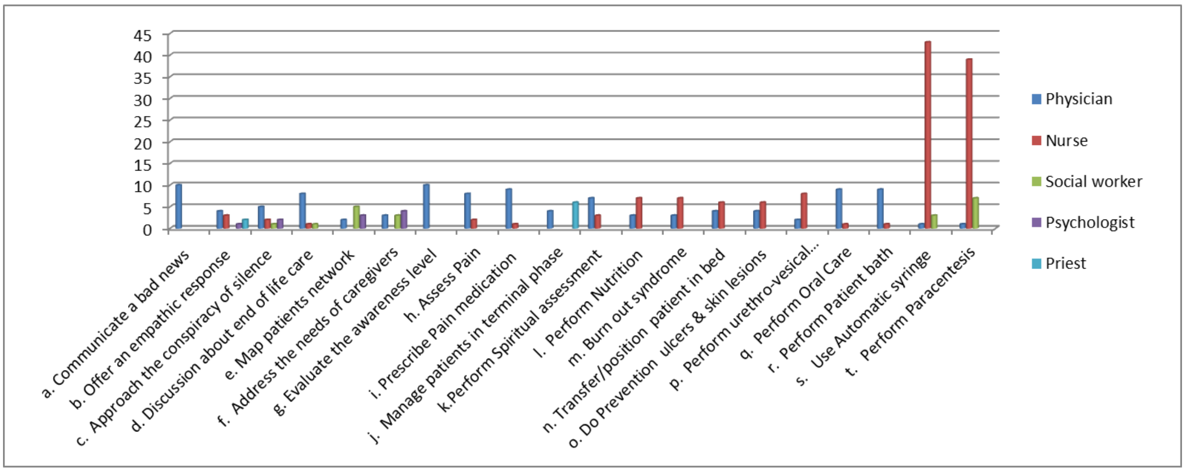
To the question "as a patient having a chronic progressive disease, for which of the following did you experience the need for health care teams?" patients replied as it follows:

- 4 out of 10 patients needed to communicate about diagnosis and evolution of the disease or prescribe pain medication
- 3 out of 10 patients needed to discuss the impact the disease has on you as person

At the opposite, patients mentioned that the most not requested procedures are:

- 9 out of 10 patients needed to do prevention measure for skin lesions or apply a urinary catheter or take care of mouth or offer a general bath in an therapeutic environment
- 8 out of 10 patients needed to do automatic syringe for subcutaneous perfusion or perform Paracentesis

To the question "With whom would you feel more comfortable to address your needs?" patients replied as follow:



Most of the respondents prefer to address their needs to physician rather than nurses, social workers, psychologist or priest. Based on the organization of home palliative care, patients usually spend more time with nurses than with any other professional.

Families - Interpretation of the questionnaire results

In this research, a total number of 8 family members have been involved (Wife 2/Brother 2/Son 4). The age of the respondents is between 21 and 72 years old and both categories of men and women have been included (3 men and 5 women) and 3 are from rural area and 5 from urban area. Level of education of the respondents is secondary school and 6 university studies.

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:

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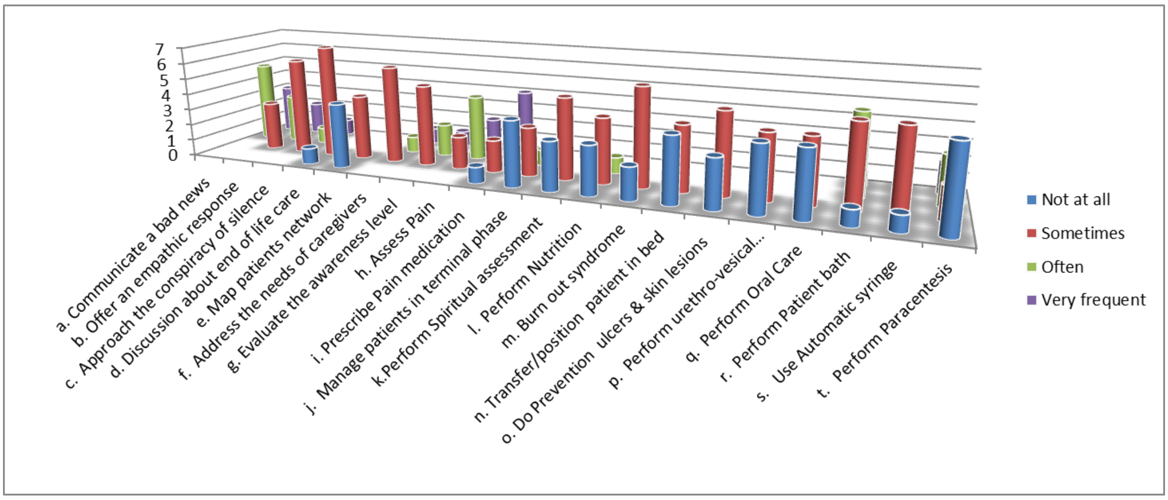

To the question "With whom would you feel more comfortable to address the needs of the patients?" family members replied that in most of the medical procedures they prefer to request the support of the physicians. The need of the nurse is most requested for procedures like: nutrition /feeding of the patient; applying a urinary catheter to the patient; mouth care for the patient. The social worker is the most requested for procedures like: the social support network around the patient or evaluation of your awareness level about the disease. The psychologist is the most requested for procedures like: mediate communication between all family members in order to insure there is no information withholds or address the needs of family caregivers. The priest is the most requested for procedures like: prescription of pain medication for your relative.

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