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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 Belgium

Karel De Grote Hogeschool Katholieke Hogeschool Antwerpen, Belgium

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

Palliative care is largely described in the literature but the definition of a palliative patient is hardly ever described, even in the studies that included this patient population.

Three international organizations define the term “palliative care”: the World Health Organisation (WHO), the European Association of Palliative Care (EAPC) and the International Association for Hospice and Palliative Care Organization (IAHP).

The 2002 WHO definition states that “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Davies, 2004; World Health Organisation 2002; 2007).

The IAHP organization has a definition that is very similar to the WHO definition: “Palliative care is the care of patients with active, progressive, far-advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life” (International Association for Hospice & Palliative Care, 2008). The main focus is therefore the improvement of quality of life, no matter what the type and the stage of the disease.

The EAPC defines palliative care as “interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death” (European Association for Palliative Care, 2008).

A “standard operational procedure” is a technique, method or therapy performed 'by the book,' using a standard protocol meeting internally or externally defined criteria. It is a formal, written procedure that describes how specific techniques or interventions are to be performed. Together, these written procedures form a procedures manual. Purpose of “Standard operational procedures” is to achieve standard care (MeSH-term introduced in 2011). Standard care [MeSH] is the minimum acceptable patient care, based on statutes, court decisions, policies, or professional guidelines.

Provision of statistical data, at national level

Population milions	Surface km^2	Density inhab/ km^2	GDP	Nr doctors/ 1000 inhabitants	Nr of nurses/ 1000 inhabitants
11,323,973 (July 2015)	30,528	369.72 people per sq.km (2013)	$481.5 billion (2014 est.)	4,9 (2013)	16,8 (2013)

Is the palliative medicine/care supported by legislation?

In Belgium, the first specialist palliative care services developed autonomously, and the absence of a planning policy isolated them from the rest of the health system. The Belgian health authorities decided to put an end to this situation by legislation: the laws introduced determine the number, mission and modus operandi of the various palliative care services, as well as the links to be established between them (interaction of the home care support team and the mobile function in hospitals or institutions for the elderly and association for cooperation) (Desmedt, 1999).

Furthermore, since 2002 three important laws were introduced in Belgium:

- **Law about rights of the patient** gives explicitly the rights to the patient for: guarantee of good quality medical services; free choice of a caregiver; Understandable information; right to refuse information; use of an confidence person; informed consent for medical “interventions”.
- **Law about the palliative patient** regulates: the right for good quality palliative care at the end of live; the right for information about his situation and about the possibility of having Palliative Care.
- **Law about euthanasia**: basic principles; general conditions; conditions of execution of demand for euthanasia; way of reporting the euthanasia to a federal commission.

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Identification of National Strategies in palliative care

In Belgium, the palliative care offer is equitably distributed in the different regions of the country, regardless of the care location of the patient (home, hospital, specialized retirement home, etc.). A coherent plan equipped with a comprehensive legislative framework was developed in 1997, thanks to the consultation and combined efforts of the experts in palliative care united in federations, and the Authorities.

The first palliative care service and palliative home care team were created more than 25 years ago (first initiative dates 1985). From 1991 onwards the Ministry of Social Affairs financed experiments for palliative care at home, in hospitals and in nursing homes.

Palliative networks were created in 1997 (Royal Decree of June 19, 1997) (KB 1997a). Today there are 25 networks (1 network/300.000 inhabitants). These networks cover the entire Belgian territory (15 networks in Flanders, 1 bilingual network in Brussels, 8 networks in Wallonia and 1 network in the German-speaking community). The networks develop the following activities:

- to heighten public awareness;
- to organize palliative care trainings for health caregivers and for volunteer persons;
- to coordinate different local actions like defining cooperation protocols to guarantee an optimal complementarity between organisations and services;
- to give advice and logistic support in order to enhance the efficiency of the actions and the support to patients;
- to evaluate the palliative services and to estimate the gap between needs and services.

Identification of specialized services in palliative care

Support for the palliative patient at home in Belgium

The palliative home care team has the following missions:

- To discuss the problems with the caregivers and to advise them about all aspects of palliative care (e.g. pain and symptom control, psychological and spiritual support).
- To inform the patient and his/her family about diagnosis, treatment and prognosis. These two first missions justify that somebody would be on duty for phone calls 24h/24.
- To coordinate palliative care by making arrangements with general practitioners, other health care givers and volunteers.
- To ensure that the necessary care material is available at the patient’s home.
- To provide psychological and spiritual support to the caregivers of the first line of care. In specific situations, only after consultation and with their permission the palliative home care team can perform specific care tasks.

Palliative care in Belgian hospitals

Two palliative care structures were set up in Belgian hospitals. First, 379 SP-palliative beds were created, evenly spread over the country. These SP-beds are clustered in Palliative Care Units (PCU) with (minimum) 6 to (maximum) 12 beds. The beds are spread over several hospital units, or united in an independent unit. The number of palliative care units per hospital is restricted to one. In most hospitals such unit counts 6 to 12 beds (rooms). Staffing is 1.5 nurses per bed (in general hospital units this is: 0.67) + 1 head nurse; a dedicated psychologist, social worker, spiritual workers. Traditionally these units can count on the support from volunteers.

Support for the palliative patient in Belgian residential and nursing homes

The responsibility of the physician and head nurse is to introduce a culture of palliative care in the institution, to make the staff sensitive to it, to formulate advices concerning palliative care and to organize training in palliative care (KB 1997c). Another measure provides money for training via part C of the health insurance allowance (MB 2001; 2003).

Career break for the family

The Belgian law on career break offers every employee the possibility to take a palliative care leave – fulltime, halftime or 20% - to give medical, social, administrative and psychological care and assistance to their next of kin. The time period is limited to a maximum of two months for the same patient.

Identification of support specialized literature or organizations

Specialized recent literature in palliative care: In Medline (PubMed) we could identify 78 publications on palliative care from Belgian authors published in the last 5 years.

Is the palliative care visible/debated at national level?

The Belgian government is providing information about all the available health care services including end-of-life services. This is a national platform (e-Health), and is free accessible: http://www.belgium.be/nl/gezondheid/gezondheidszorg/levenseinde/palliatieve_zorgen/

In Belgium we have another nationwide electronic platform (www.portal4care.be) offering free access to practice guidelines, sites and journals on a broad range of health care topics, including palliative care.

This platform is funded by the government and was launched in 2014. The content of the platform is managed by nurses with back-up of an expert panel. Intended users of this platform are professional health care workers, however, this platform is accessible for lay people.

Other free accessible national links are:

- Palliative care (Palliatieve zorg): http://www.palliatief.be
- Early planning of your care (vroegtijdige planning van je zorg): www.delaatstereis.be
- Children and teenagers confronted with palliative care (kinderen en jongeren geconfronteerd met palliatieve zorg): www.palliatieve-zorg-en-kinderen.be
- Guidelines palliative care (richtlijnen palliatieve zorg): www.pallialine.be
- Brussels Federation of Palliative care (Fédération Bruxelloise de Soins Palliatifs et Continus): www.fbsp-bfpz.org/

Scientific journals on palliative care:

- Tijdschrift voor Palliatieve Zorg
- Nederland-Vlaams Tijdschrift Palliatieve Zorg

Best practices/ projects on innovative solutions in palliative care

Starting with early identification of palliative care patients by general practitioners (GPs), the Care Pathway for Primary Palliative Care (CPPPC) is believed to help primary health care workers to deliver patient- and family-centered care in the last year of life. The care pathway has been pilot-tested, and will now be implemented in 5 Belgian regions: 2 Dutch-speaking regions, 2 French-speaking regions and the bilingual capital region of Brussels. The overall aim of the CPPPC is to provide better quality of primary palliative care, and in the end to reduce the hospital death rate (Leysen B, 2015).

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3. Practical research

Decision makers - Interpretation of the questionnaire results

The decision makers category has been represented by 2 members: the Principal nursing training of the Karel de Grote University College and by the Coordinator Skills Team of University of Antwerp.

Regarding the question related to what are the ways to continuously improve the curricula in your university, the 2 members mentioned as follows:

- Continuous consultation at different levels within the University College; A program to stimulate teachers to participate in national and international meetings, courses and symposia; Regular structured resonance meetings with managers and decision makers from healthcare organizations; Regular visitations and quality controls by the government.
- Comparison and evaluation of the curriculum with national and international medical courses; Internal and external quality

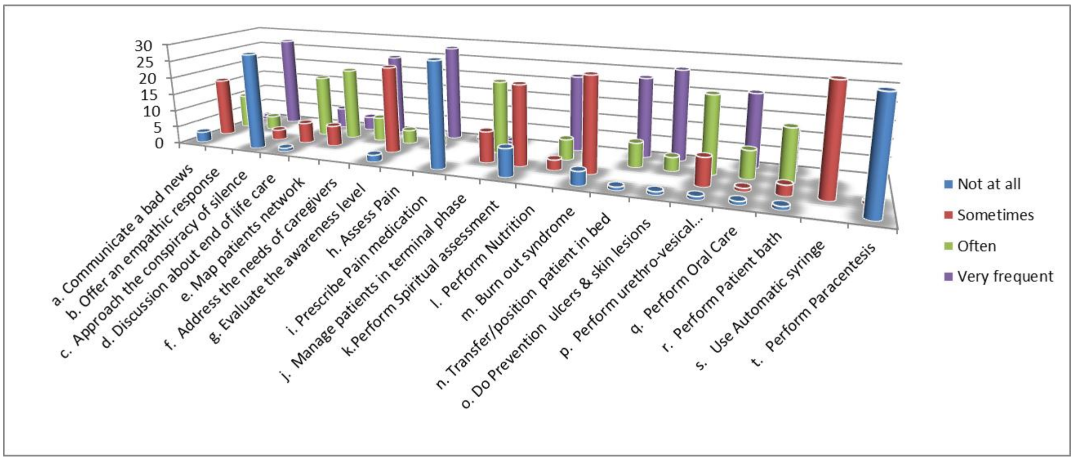
Both of the respondents mentioned that there is a need of a period of 1 academic year to include a new topic in the curriculum in the university from the moment of a concrete proposal.

Providers - Interpretation of the questionnaire results

In this research, a total number of 33 providers (1 physician and 32 nurses) have been involved. The age of the respondents is between 28 and 57 years old and both categories of men and women have been included (3 men and 30 women) and all are from urban area.

In what concerns the length of the professional experience, the respondents mentioned between 1 and 30 years. And the length of the clinical practice is between 0.5 to 12 years of experience.

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:



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Most of the respondents agreed the fact that the mentioned procedures have been trained during the high school/ college studies.

Among the most mentioned operational procedures, remarked as being extremely important to be standardized for palliative care practice are: with between 30 and 25 options: Prevention/management of pressure ulcers & skin lesions; Prescribing Pain medication; Assessing Pain; Managing patients in terminal phase; Addressing the needs of caregivers.
With 24 to 20 options: Active listening and offering of empathic response; Nutrition /Feeding patient in bed; Male/Female patient – urethro- vesical catheterization; Oral Care; Transfering/positioning patient in bed. The less important procedure considered as important to be standardized is the approach of conspiracy of silence (family knows the diagnosis and request you not to tell to the patient).

Students - Interpretation of the questionnaire results

In this research, a total number of 107 students have been involved, all of them in the 3rd academic year of Nursing. The age of the respondents is between 21 and 33 years old and both categories of men and women have been included (12 men and 95 women) and 6 are from rural area and 101 from urban area. Only 8 respondents mentioned that they have clinical exposure to palliative care, most of them had a clinical placement as part of their training.

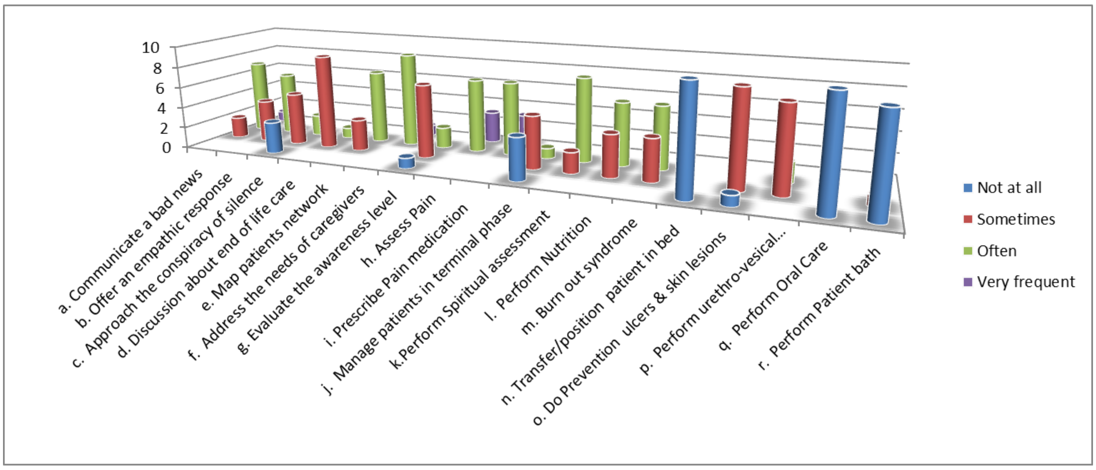
All the respondents mentioned the fact that they received the training of the presented procedures during the college study.

Patients - Interpretation of the questionnaire results

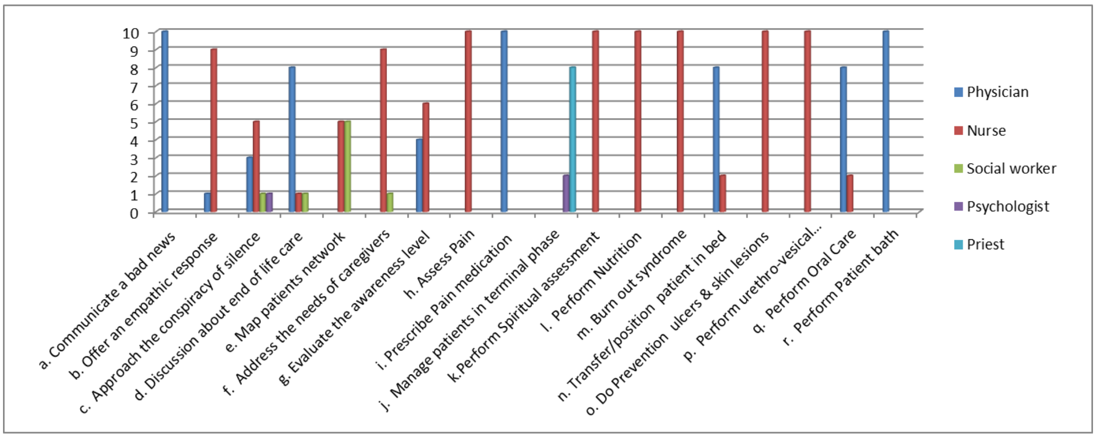
In this research, a total number of 10 patients have been involved (9 retired people and 1 housewife). The age of the respondents is between 58 and 88 years old and both categories of men and women have been included (4 men and 6 women) and all of them are from urban area. Level of education of the respondents is 8 followed the secondary school and 2 university studies.

All the patients were able to specify the diagnosis of their illness: Cervix cancer; History of breast cancer; heart-failure; COPD and diabetes; colorectal cancer; Lung-cancer; Multiple sclerosis; swallowing problems; lung infections. Most of the respondents mentioned that they spend more than 50% of the day time in bed or chair.

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:



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

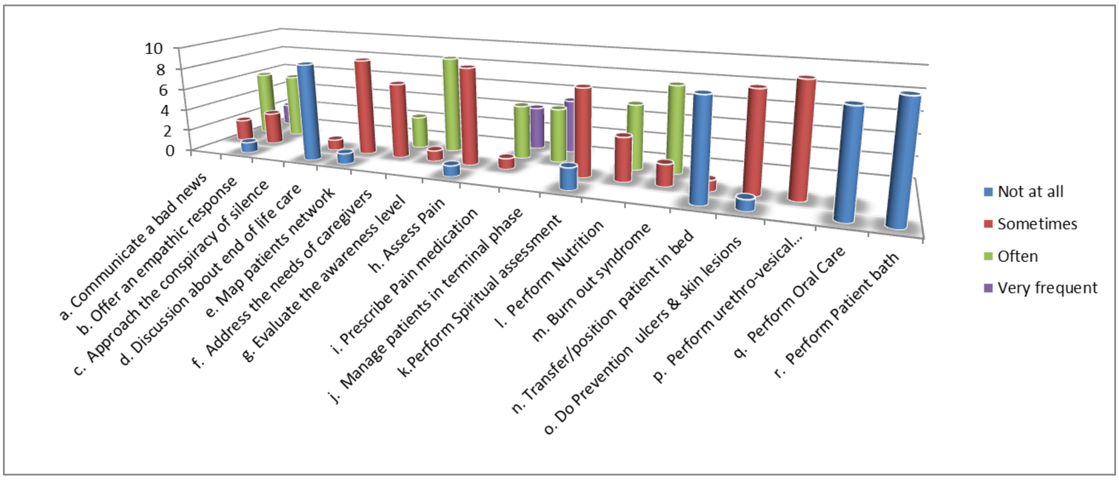


Most of the respondents prefer to address their needs to nurses rather than physician, social workers, psychologist or priest. Based on the organization of home palliative care, patients usually spend more time with nurses than with any other professional.

Families - Interpretation of the questionnaire results

In this research, a total number of 10 family members have been involved (daughter/in low; brother; sister; son). The age of the respondents is between 46 and 73 years old and both categories of men and women have been included (3 men and 7 women) and all are from urban area. Level of education of the respondents is 7 secondary school and 3 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:



The most mention category was sometimes, by 68 options, followed by often with 48 and not at all with 43 options. Only 11 responses are in the very frequent section.

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 nurses – 98 responses. The most mentioned procedures are: Discuss the impact the disease or Nutrition /Feeding of the patient or Transfer/position the patient in bed or Mouth care for the patient or General bath for the patient in an therapeutic environment.

The need of the physician is most requested for procedures like: Prescription of Pain medication for your relative or Draining fluid from the abdomen (paracentesis) or Discussion about place of care, aggressive treatment.

The social worker is the most requested for procedures like: the social support network around the patient or address the needs of family caregivers

The psychologist is the most requested for procedures like: assessment of the spiritual needs of your relative or 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: assessment of the spiritual needs of your relative.

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