

National research about the procedures on palliative medicine in Belgium

The aim of this activity is to research & 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 first years students enrolled in EU medical universities or used by the professionals & volunteers active in the medical world of work.

Objectives:

- Identification of the operational procedures reported to be used by the students during the hospital internship in pre-clinical years; identify the needs of the target groups in connection to the use of specific procedures
- Research of specialised recent literature in connection to these procedures
- Identify the ways to introduce new & 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 & found to be effective to meet the needs of those who use/will use procedures on palliative medicine

1. Definition of main concepts

The first part of this report comprises our search for definitions of essential concepts in this project, and by enlargement the palliative care practice in healthcare.

1.1 Methodology

Definitions of “*palliative care*” and “*palliative patient*” were searched on associations’ websites, as well as in scientific indexed medical literature and grey literature. Some references were added by hand searching. The definition of “*Medical operational procedure*”

1.1.1 Search on the internet

The search for these definitions started with the most widely used definitions that are currently used by:

- International institutions: the World Health Organisation (WHO), the European Association of Palliative Care (EAPC);
- National associations in Western countries known for their advance in palliative care and whose website was in English, French, Dutch or German: Belgium, UK, The Netherlands, Germany, France, Sweden, Switzerland, Australia, Canada, USA.

Definitions were found on scientific societies' websites as well as on websites from governmental health departments.

1.1.2 Search in databases

The search for definitions was completed by articles selected in the medical literature indexed in Medline (PubMed), Embase, Psycinfo and CINAHL. We used the following terms as free text or as MeSH-terms: "Palliative care", "terminally ill", "terminal care", "critical illness", "palliative patients", "definition", "hospice care", "incurable", "attitude to death", "terminal cancer".

Papers published from 2002 on, in French, Dutch or English, concerning humans, whatever gender and whatever age were included. Letters and editorials were excluded. Articles were selected on title and abstract.

1.2 Results

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.

1.2.1 Definitions of "palliative care"

Table 1 : Number of definitions per country

Country	Number of relevant organisations identified	Number of		
		Definitions	Referrals to another* definition	Own definition
International	3	3	Not applicable	3
Belgium	5	5	1	4
UK	15	7	5	2
The Netherlands	5	3	3**	0
France	5	5	2	3***
Germany	7	3	3	0
Sweden	3	2	2	0
Australia	7	3	3**	0

Canada	3	2	0	2
USA	7	4	1	3
Switzerland	2	2	1	1

Definitions from WHO, EACP or NICE - ** additional information sometimes added –

*** one definition of “palliative patient”

International definitions (WHO, IAHP and EAPC)

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 lifethreatening 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).

In other words, palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement;
- Includes counselling, if indicated;
- Enhances the quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications” (Davies, 2004).

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 “the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is 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).

Both definitions (IAHP & EAPC) are similar but also mention specific aspects:

- The target: both definitions mention the patient and his/her family; EAPC furthermore encompass the community.
- The type of care: the WHO definition clearly encompasses the concomitant use of therapies; the EAPC definition does not mention it.
- Holistic approach (spiritual, psychological and physical needs).
- Importance of life: both definitions mention quality of life as an objective and consider dying as a normal process.
- The start and end of palliative care: the EAPC definition does not precise when palliative care could start while WHO consider that it might begin early in the course of illness. The WHO definition includes furthermore bereavement in the palliative care while EAPC does not mention it.
- The caregivers: the WHO definition insists on the need for a team in palliative care.

Definitions from other associations

At least one association in every country in our search (except Canada) mentioned the 2002 WHO definition of palliative care. Next to the international definitions (WHO and EAPC) UK organizations also refer to the definition of NICE.

Some associations created their own theoretical definition of palliative care or started from the WHO definition and completed it with the EAPC definition or with other specific features. For instance, the WHO definition does not specify where the palliative care should be provided. Some associations clearly mention the setting. In most cases, all settings are considered, including community care and (specialized) hospital settings. Nevertheless, the absence of mention does not mean that any setting is excluded. For this item, the comparability between countries also implies the fact that the health care systems should offer similar palliative care settings or services (e.g. hospices, nursing homes).

Comments on common features and divergences in the definitions

All but one definition propose palliative care for any life-threatening illness, not only for cancer patients. Nearly all definitions encompass the patient and his/her family. Community is less often mentioned but is never explicitly excluded. The WHO definition goes in the same way.

Three main characteristics emerge from most definitions:

1. Almost all associations consider that palliative care is a holistic approach of the patient. This global approach encompasses e.g. pain relief, care of symptoms, care of the emotional, psychological, social and spiritual needs of the patient. A consequence of the global approach is that every definition mentions the control of symptoms as well as the control of other problems. Most associations include the bereavement period in their support to the family. However some associations consider that palliative care ends with the death of the patient.
2. Nearly all associations mention the need for interdisciplinary work: “team approach”, “interdisciplinary”, “multi-professional teams” are terms that describe this feature. The possible conjunction with another therapy is cited in most definitions in relation with the original definition of the WHO.
3. The third pillar of the definitions is the goal of palliative care i.e., the quality of life of the patient. As an illustration, the UK National Health Service says that “if the patient is comfortable, has company and is not experiencing suffering or pain, they are less likely to consider the route of euthanasia”. Offering quality of life is often coupled with the fact that palliative care does not hasten or postpone death. Dying is a normal process. This distinction puts the stress on the specificity of palliative care, independently of any further end-of-life decision.

Divergences exist in the reference to the start of palliative care treatment. In line with the WHO approach and evolution, many associations consider that palliative care should begin during the course of a life-threatening illness, and even, as early as possible, while others only mention the terminal phase.

Two questions rose from this approach. First, what is a “life-threatening disease”? The literature cites specific pathologies e.g. cancer, HIV/AIDS, multiple sclerosis, chronic circulatory (Farquhar, 2002). However, the definitions do not give any explanation on this term, sometimes used in conjunction with ‘incurable disease’ and/or ‘with limited prognosis’.

These aspects of an illness allow identifying more precisely the pathologies but the limit with palliative status depends on the subjective appreciation of the medical staff or it can be assessed by prognostic tools. As a consequence, no consensus emerges from the definitions on the diseases that could benefit of a palliative approach. Secondly, the moment to start palliative care is also unclear i.e., “in the course of the illness”? On the other hand, when definitions state that palliative care is the care during the terminal phase of the disease, the duration of this ‘stage’ may also vary from several hours to several months.

1.2.2 Definitions of “palliative patient”

This part summarizes the definitions used in the following Western countries: France, the Netherlands, UK, Switzerland, Denmark and Canada. The objective was to find the definition of a palliative patients in those countries i.e., criteria that allow them to benefit of specific care, support or financial help. The Belgian definition (INAMI/RIZIV) as well as the criteria were presented in point 6 of this report.

France

(Programme national de développement des soins palliatifs 2002-2005; L'assurance maladie: Service Communication c 2007)

A French law defines the palliative patient. It stipulates that ‘every ill person who needs it has the right to access to palliative care and to benefit from a support’. Next to the access to palliative care, patient is entitled to receive a financial help, i.e. an intervention from the health insurance for 85% to 90% of his/her out-of-pocket expenses in function of his/her revenues (with a threshold). The eligibility is based on a medical record made by a specialized recognized team (network, team of home hospitalization or mobiles hospital team). The help also encompasses domestic help at home and ‘life auxiliaries’.

The relative(s) can receive a special leave that allows them to stop working during maximum 3 months. There is no explicit prognosis or duration linked to the decision to identify a patient as palliative. Nevertheless, the special leave is limited to a 3 month period.

The Netherlands

(Agora landelijk ondersteuningspunt palliatieve zorg c 2008)

There are no explicit criteria to decide if a patient is eligible for palliative care. It is left to the assessment of the GP. The financial consequence is the payment of an additional amount to the GP by the health insurer. Health Insurance could control it afterwards.

The carers can also negotiate with their employer to get a leave to take care of the palliative patient.

United-Kingdom

(Priez, 2004; NHS, 2008).

In the UK, the palliative care services act from the diagnosis (supportive care) through the cure phase and rehabilitation to the potential death (palliative care). They also give a psychological support to the family (bereavement). To be eligible for home care services, the death should be expected in the next six months.

The NHS proposes to use the Gold Standards Framework (GSF Central Team - NHS;2008), a framework of strategies, tasks and enabling tools to help primary care teams to deliver the best possible care for people nearing the end of their lives. The three main processes of GSF involve the identification of patients in need of palliative/supportive care towards the end of life, the assessment of their needs and a planning of their care based on their needs and preferences. Seven key tasks are summarized by 7 C's i.e., Communication, Coordination, Control of symptoms, Continuity of care, Continued learning, Carer support, Care in the dying phase.

Switzerland

(Sous-commission de la Commission Centrale d'Ethique de l'ASSM Soins palliatifs, 2004).

There are no explicit criteria to identify palliative patients. The physician asks for specific support according to the progressively deteriorating health status of the patient.

Denmark

(Aabom, 2005)

The "terminal declaration" is a document that gives right to economic benefits and more intensive care for the patient whose life expectancy prognosis is less than 6 months. This declaration gives the entitlement to increased reimbursement of medicines and to a paid leave of an informal carer either full time or part-time.

Canada

(Carrefour virtuel canadien des soins palliatifs, 2008)

Some provinces set up special programs that cover the cost of medications for terminally ill people registered on palliative care programs. The criteria for eligibility vary from province to province. However, in each province the application form must be completed by a physician. The paragraphs below illustrate examples from some provinces.

Québec

(Raymond, 2007)

In Quebec, a 'compassion benefit' allows one or more family members of the patient to support him/her during the last months of his/her life based on the revenues (with a maximum). To be eligible, the family member has to produce a medical certificate proving that the patient has a serious disease that could lead him/her to die in the next 26 weeks.

Alberta

(Alberta Health and Wellness, 2001)

In Alberta, the benefit is available once the assessment of the patient concludes that he/she will die within three months.

Saskatchewan

(Government of Saskatchewan, 2008)

The Palliative Care Drug Program of Saskatchewan provides drug plan benefits for patients who are in the late stages of a terminal illness: i.e. where life expectancy is measured in months, and for whom treatment aimed at cure or prolonging life is no longer deemed appropriate. The care they receive is aimed at improving or maintaining the quality of remaining life (e.g. management of symptoms such as pain, nausea and stress). This status is assessed by the patient's physician.

Manitoba

(Manitoba, 2008)

The Manitoba is an example where criteria are especially vague: the patient and his/her physician must agree on palliative care, dealing with an advanced phase of a terminal illness.

1.2.3 Definition of "Medical operational procedures"

The term "*procedure*" is not a known term in the MeSH-database (Medline-PubMed). In this thesaurus the term "*method*" is used. This term was introduced in 1967 and was updated in 1991. It is advisable to use the MeSH-term "*methods*" as a subheading. Since 1975 this subheading was introduced and defined as: "*Used with techniques, procedures, and programs for methods*".

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.

The need for learning standards in palliative care certification programs

Palliative medicine, still in the development phase, is a new, growing specialty aimed at caring for both oncology and non-oncology patients. There is still confusion about the training offered in the various European palliative medicine certification programs. Processes leading to certification are generally long and require substantial clinical training. The programs on specialization in palliative medicine education are heterogeneous. There is a need for common learning standards, leading to additional European-based recognition of expertise in palliative care (Centeno, 2015).

This lack of standard palliative medicine education has been identified as a barrier to the development of the discipline and to the implementation of standard palliative care in practice. Today, palliative medicine is taught in a substantial number of undergraduate medical programs at European universities, and a qualified teaching structure is emerging; however, there is a wide variation in the level of palliative medicine educational development between individual countries (Carrasco, 2015).

2. Is the palliative 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:

1. 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”

- Refusal of an “intervention”
- Copy of the medical record
- Medical secret
- installation of an ombudsperson in every hospital, ...

2. 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

3. Law about euthanasia

- Definition of euthanasia (in the law):
 - making an end to one’s life by a “third” person on voluntary demand of this person
- Basic principles:
 - the third person can only be a physician
 - this physician is not prosecuted if all regulations are fore filled
(is different of saying that euthanasia is legally allowed!)
- General conditions:
 - patient : > 18 j, mentally competent
 - written demand for euthanasia (or with two witnesses)
 - demand : deliberately and repeated
 - hopeless situation of persistent unbearable disease (physical or psychological)
 - patient must be informed about his/her medical situation
 - patient must be informed about other possibilities
 - medical situation must be verified by a second independent physician (and a third if psychological based); advice noted in medical record
 - advice of treating nurses, psychologist ...
- Extra conditions:
 - at least one month between demand and execution
 - demand is revocable
- Stipulates also:
 - conditions of execution of demand for euthanasia in case of coma or an situation of incompetency
- Describes way of reporting the euthanasia to a federal commission
- Describes this commission and way of reporting to the parliament
- Stipulates also:

- No physician is obliged to execute an euthanasia
- No other person is obliged to cooperate
- If refused : patient has the right to consult other physician, medical record must be passed
- Euthanasia = natural death (insurance !)
- This law came into force since 28/08/2002

3. 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, specialised 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.

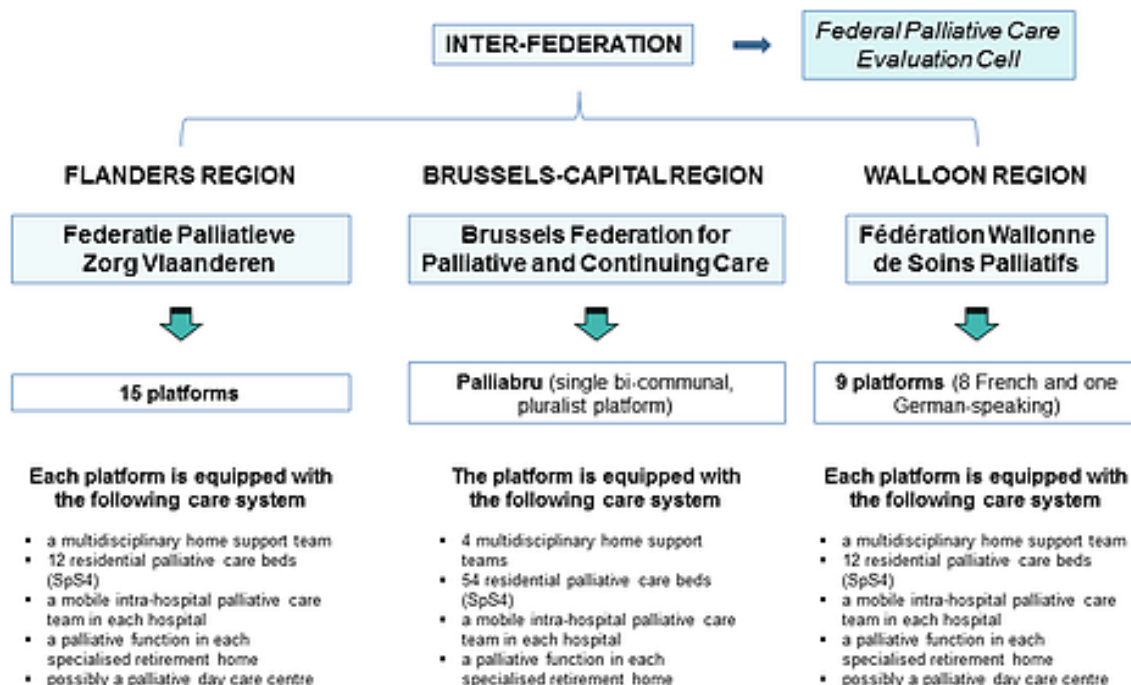


Figure 1: distribution of palliative care offer in Belgium

3.1 Support for the palliative patient at home in Belgium

The palliative home care teams are the extra-mural component of the Belgian PC system. They were created to support caregivers in the first line of care. The Royal Decree of Oct 13, 1998 (KB 1998) defined minimal criteria for the agreements between these teams and the ‘Comité van de Verzekering voor Geneeskundige Verzorging’ of the National Institute for Health and Disability Insurance (INAMI–RIZIV). Today, 28 teams signed such an agreement (at least 1 per regional network), 1 per 200,000 inhabitants. Typical constitution of a palliative home care team is 2.6 fte per team; for 100 patients per year, as follows:

- 1 physician (part-time)
- 1 coordinator
- 3-4 nurses,
- 1 psychologist,
- 1 adm. co-worker

As defined in the conventions with INAMI-RIZIV, 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.

Besides the creation of the home care teams, a number of additional measures guarantee a good quality of care for the palliative patient who wishes to die at home.

The Royal Decree of December 2, 1999 (KB 1999) introduced a 'palliative lump sum' ("forfait") for palliative patients staying at home to cover the costs of medicines, aids and medical care materials. This Royal Decree defines the palliative home patient as a person who suffers from one or more irreversible diseases that are evolving unfavourably; his/her physical/psychological situation is seriously and generally deteriorating; therapeutic interventions and revalidation do not longer affect this unfavourable evolution; the prognosis is bad and death is due in short time (life expectancy between 24 hours and 3 months); there are serious physical, psychological, social and spiritual needs that require time-consuming and continuous assistance; if necessary, caregivers with specific competences are called upon and appropriate technical means are used; the patient is staying at home or has the intention to die at home and he/she meets the conditions defined in the form annexed to the Royal Decree.

Furthermore, a sum is provided for nursing (KB 2001a) and the palliative patient at home does not have to pay any personal contribution when treated by nurses, physiotherapists and general practitioners (KB 2001b; 2002; 2006).

Finally, the creation of palliative day centres aimed to give the family some respite.

These centres were first financed as pilot projects by the National Health Insurance Institute (INAMI-RIZIV). In 2006, these pilot projects were transferred to the Communities and integrated in the legislation on geriatric day centres.

3.2 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.

Secondly, the palliative function in hospital has been developed for palliative patients not staying in a PCU (KB 1997a; 1997b). This palliative function (called palliative support team), is obligatory in every hospital, and comprises all activities for the treatment, care and support of terminal patients i.e.:

- introduction of a palliative culture in order to make the caregivers aware of its necessity;
- advice to the hospital staff (physicians, nurses and paramedics) with regard to palliative care and to the management with regard to palliative care policy;
- organization of palliative care training;
- continuity of care when a terminal patient goes back home;
- record and evaluation of the palliative mission within the hospital.

This palliative function is carried out by a multidisciplinary team whose members belong to the medical, nursing and paramedical services. The team is completed by a psychologist, a social worker or a social nurse. (0.5 MD, 0.5 nurse, 0.5 psy if hospital < 500 beds). This multidisciplinary team is assisted by a mobile palliative support team composed of at least three halftime members: a physician-specialist, a nurse and a psychologist.

3.3 Support for the palliative patient in Belgian residential and nursing homes

A similar palliative function has been created in 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). From the first of July 2008, an additional budget is available for a part-time palliative reference person.

3.4 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.

4. Provision of statistical data, at national level, on the following aspects:

Population: 11,323,973 (July 2015)

Age structure (estimation 2015):

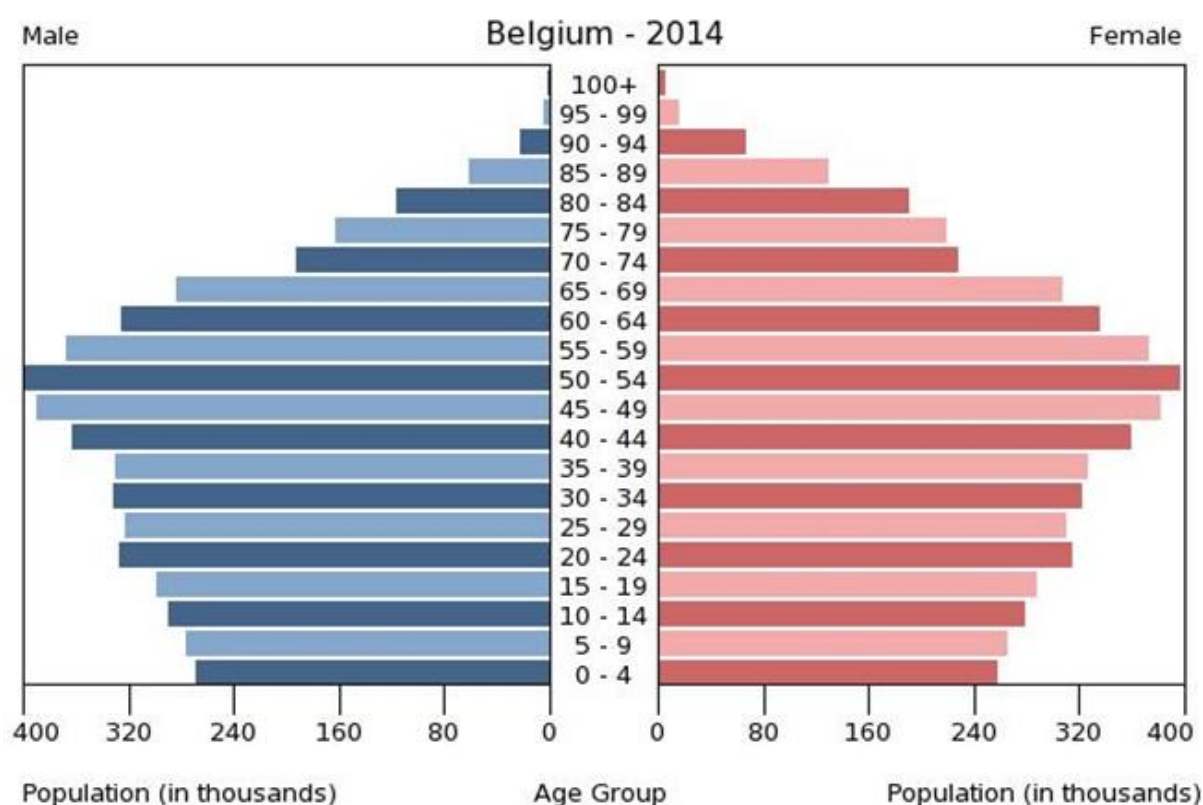
0-14 years: 17.08% (male 990,272/female 943,363)

15-24 years: 11.59% (male 669,540/female 642,486)

25-54 years: 40.45% (male 2,308,285/female 2,272,085)

55-64 years: 12.65% (male 709,347/female 723,696)

65 years and over: 18.23% (male 893,096/female 1,171,803)



Surface: 30,528 sq km

Density: 369.72 people per sq.km (2013)

The gross domestic product (GDP):

\$481.5 billion (2014 est.)

\$476.5 billion (2013 est.)

\$475.2 billion (2012 est.)

note: data are in 2014 US dollars

GDP growth rate:

1% (2014 est.)

0.3% (2013 est.)

0.1% (2012 est.)

Health expenditure: 11.2% of GDP (2013)

Estimation of costs of palliative care in Belgium (estimations 2013):

- Known costs:
 - Palliative Care Units: 3,500,000 €
 - Palliative Support Teams: 6,000,000 €
 - Home teams: 2,000,000 €
 - Hospices: 7,000,000 €
 - Networks: 5,000,000 €
 - Total= 23,500,000 €
- Unknown costs:
 - Package for patients
 - Package for relatives
- Total cost estimated: 35,000,000 € per year

Number of doctors/1000 inhabitants: 4,9 (2013)

Number of nurses/1000 inhabitants: 16,8 (2013)

Table 2: Belgian Palliative Workforce Capacity

Palliative Workforce Capacity			
	Full-time	Part-time	Total
MD	14	879	893
Nurses	466	2.772	3,238
Social workers	NK	NK	86
Psychologists	NK	NK	86
Physiotherapists	NK	NK	29
Occupational Therapists	NK	NK	29
Spiritual/Faith leaders	NK	NK	115
Volunteers	NK	NK	1000

Today, one in two non-sudden deaths in Flanders (Dutch speaking part of Belgium) occurs with the support of specialist palliative care professionals (Palliative Care Federation of Flanders, 2012), whether within mobile home care teams, hospital support teams or through 'reference persons for palliative care' in homes for the elderly.

5. Identification of specialized services in palliative care.

In a population-based survey (n 6188) regarding end-of-life care in Flanders (Dutch speaking part of Belgium) it was found that specialist palliative care is not initiated in almost half of the people for whom it could be beneficial, most frequently because physicians deem regular caregivers to be sufficiently skilled in addressing palliative care needs. This implies that the safeguarding of palliative care skills in this regular 'general' care is an essential health policy priority (Beernaert, 2015).

6. Identification of support specialized literature or organizations.

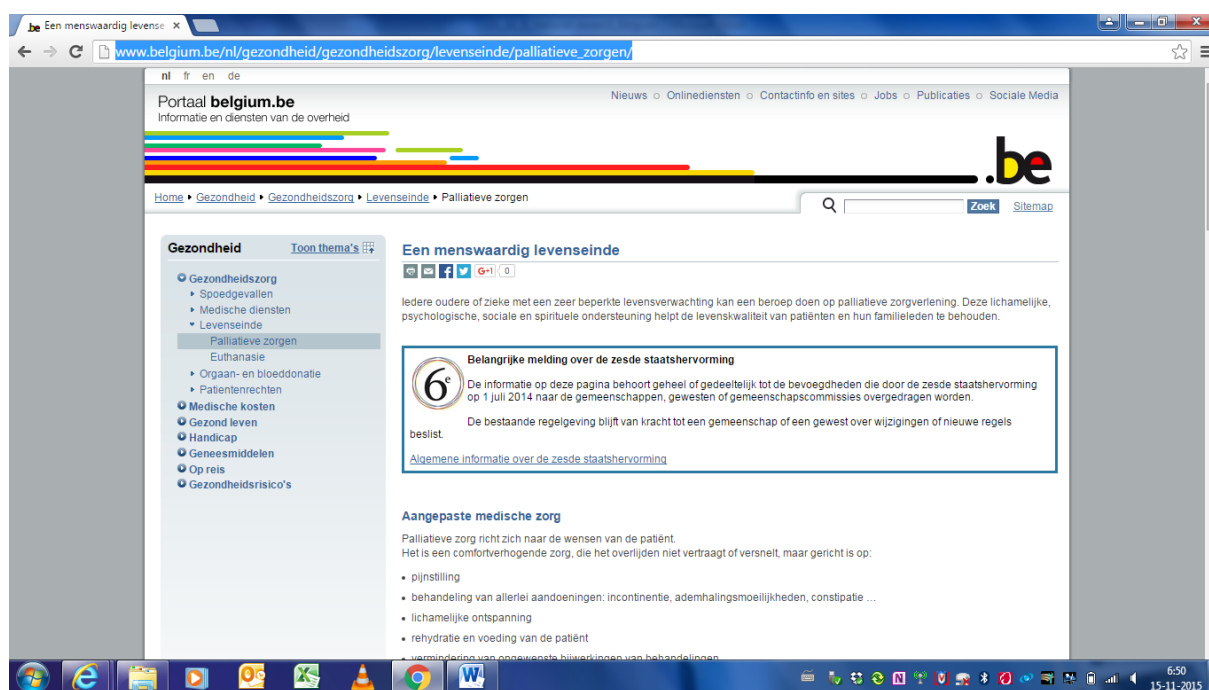
Specialized recent literature in palliative care: In Medline(PubMed) we could identify 78 publications on palliative care from Belgian authors published in the last 5 years.

7. Is the palliative care visible/debated at national level?

7.1 Visibility: Internet

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/
- Palliative care in the Walloon Region (Fédération Wallonne des Soins Palliatifs): www.soinspalliatifs.be
- Pluralistic association of palliative care in Brussels Capital Region (Pluralistische Vereniging voor Palliatieve Zorg van het Brussels Hoofdstedelijk Gewest): www.palliabru.be
- Life information forum LEIF (Levensinde Informatie Forum): www.leif.be

- Cancer center (Kankercentrum): www.e-cancer.be
- Cancer Foundation (Stichting tegen Kanker): www.kanker.be
- Flemish League against Cancer (Vlaamse Liga tegen Kanker): www.vlk.be

7.2 (Scientific) journals on palliative care

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

8. Provision of examples of best practices/ projects

An example:

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).

10. REFERENCES

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