Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
KCE

Organisation of palliative care in Belgium

KCE reports 115C

Federaal Kenniscentrum voor de Gezondheidszorg
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FOREWORD

Notre société et son système de soins de santé accordent une importance particulière à la naissance et aux soins qui l'entourent, comme en témoignent plusieurs rapports du KCE. Le présent rapport se penche cette fois sur l'autre extrémité de la vie, sujet qui revêt une importance tout aussi primordiale.

Il est coutume d'associer le terme « soins palliatifs » aux derniers moments de l'existence. De nombreuses voix s'élèvent cependant pour attirer l'attention sur les périodes parfois beaucoup plus longues durant lesquelles les personnes en fin de vie nécessitent des soins spécifiques, soins dont l'intensité va crescendo jusqu'en phase terminale. D'où l'importance de la question : « comment définir un patient palliatif ? »

Une fois cette définition esquissée, qui sont ces patients en Belgique ? Combien d'entre eux nécessitent des soins spécifiques soit chez eux, soit en institution ? Quels seraient les soins les mieux adaptés à leur situation particulière ? Comment y répondre en termes d'organisation des soins et quelles sont les répercussions sur notre système de santé ?

Ce rapport dévoile une par une les réponses à ces questions complexes et ce, grâce à une combinaison de méthodologies originales. Cette multiplicité d'approches a bénéficié d'une collaboration avec les fédérations de soins palliatifs et plusieurs équipes universitaires (KULeuven, UA, UCL, UGent). Leur travail de pionniers apporte une pierre d'angle solide pour bâtir l'organisation des soins palliatifs en Belgique avec le patient et ses proches au coeur des préoccupations.

Jean-Pierre Closon

Director General a.i.

Executive summary

BACKGROUND AND OBJECTIVE OF THE STUDY

The 2002 WHO definition states that "palliative care (PC) 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".

Belgium has developed many structures and services for palliative patients. Palliative networks were created in 1997 e.g., to develop PC culture, to organize trainings for caregivers, to coordinate actions between organisations and services, to evaluate the palliative services.

In home settings, palliative home care teams support caregivers and additional measures facilitate the care for the palliative patient who wishes to stay at home. First a "palliative lump sum" ("forfait/forfeit") covers during two months the additional costs linked to PC. Furthermore, the palliative patient at home does not have to pay any personal contribution when treated by nurses, physiotherapists and general practitioners. Finally, palliative day centres give the families some respite.

Two types of palliative care structures were set up in the hospitals. First, approximately 400 SP-palliative beds are clustered in small Palliative Care Units (PCU). Secondly, the palliative function has been developed in all hospitals to provide specific care support for palliative patients not staying in a PCU. A similar palliative function has been created in nursing homes (NH).

Little scientific research has been conducted in Belgium on PC. The National Institute for Health and Disability Institute (NIHDI) has published statistics on the evolution of the budgets for the different PC structures. Sickness Funds and the "End-Of-Life Research Group" also published studies on end-of-life patients e.g. their health care pathway. This report completes those data by including in the research all palliative patients, independently of the care they receive. Moreover, the pilot study on costs analyses all of them, reimbursed or not by the health care system.

OBJECTIVE OF THE STUDY

The objective of this study is to define the palliative patient and his/her needs, to analyse the PC models described in the literature, to figure out the perception and experience of the general practitioners (GPs) in PC, to assess the prevalence and the care pathway of patients who need PC in Belgium. A pilot study on costs completes this analysis.

METHODOLOGY

The literature review was based on indexed literature (Medline, Embase, Cochrane) and on grey literature for the part on definitions (websites of international, scientific, professional and governmental institutions).

A first web based transversal survey has been conducted in order to collect data on the perception and experience of 909 GPs in relation with PC.

Three other prospective epidemiological surveys were conducted: the first one analyzed in 14 hospitals the care pathway of 249 patients selected out of a population of 2639 hospitalized patients. In 50 nursing homes selected at random, a sample of 168 residents (out of 3849) was considered as answering to the definition of "a palliative patient". Thirdly the researchers analyzed the care pathway of 239 patients who stayed at home.

Finally, a pilot study analyzed the costs of the last 30 days of life of patients who died in 19 nursing homes (NH) (181 residents) and in 6 hospitals (146 patients). This retrospective analysis was based on accountancy and invoice data. Moreover, a small scale prospective study analyzed the expenses (based on receipts) of 17 palliative patients who stayed at home.

LITERATURE REVIEW

DEFINITION OF THE PALLIATIVE PATIENT AND PALLIATIVE CARE

The literature review on definitions has three parts i.e., the theoretical definitions of PC, the operational definition of a palliative patient for research purposes and definitions used by other health care systems.

Most theoretical definitions of PC rely on the comprehensive definitions of the WHO and of the European Association of PC. The European School of Oncology group further makes a relevant distinction between "basic PC" (standard care provided by any health professional) and "specialized PC" (involving a multidisciplinary team with specific expertise and group dynamics).

No unequivocal operational definition used for research purpose could be identified in the surveys in order to define who is a palliative patient. Most studies only include end-of-life patients or patients who receive PC. A definition that could be possibly used for research purposes is the one of the "Société Française d' Accompagnement et de Soins Palliatifs" i.e. asking to health professionals if the patient is "in an advanced or terminal stage of severe, progressive and life-threatening disease".

Definitions linked to benefits in other health care systems (e.g., medical, financial, social support) mostly rely on the clinical judgment of a clinician or specialized team. The Global Standards Framework tool proposed by the NHS in the United Kingdom is an example of instrument that guides the clinician to assess the patient's needs. A notion of limited period for benefits is mostly present, as in Belgium for the "forfait/forfeit". However, the literature emphasizes the serious limitations of life prognosis, mostly impossible to predict and unreliable reflect of the care needs of the palliative patients.

NEEDS OF PALLIATIVE PATIENTS

The exhaustive literature search about needs of palliative patients identified multiple needs clustered in five groups (physical needs - mainly the control of symptoms, psychological needs, social needs, health care needs and spiritual needs). Two types of (frequently unmet) needs require further attention: the need for stepwise delivered information and the support for activities of daily living.

Two groups of palliative patients have a longer life expectancy and needs that are frequently overlooked. Firstly, patients with advanced chronic illnesses like heart failure or pulmonary disease are seldom identified as palliative patients and have often unmet needs, mostly social needs. Secondly, patients with dementia suffer from lack of symptom management, lack of forward care planning and have limited access to specialist PC. They further need specific communication means while their family also needs communication about the evolution of the disease.

PALLIATIVE CARE MODELS

Most models found in the systematic literature review were either home care settings or transmural care models. The PC models analysed were heterogeneous in terms of objectives, caregivers, target populations and interventions. The main group of interventions included interventions in relation to case management, interventions in relation with outreach services, systems to answer to unexpected events, information and psychological support for the patient and his/her family.

No evidence could be found to demonstrate the superiority of any model in terms of better outcomes. Some models had an effect on control of symptoms, patient comfort and psycho-social outcomes (e.g., quality of life, communication, anxiety, spiritual well-being). Effects on other outcomes were more inconsistent between studies and some authors did not identify any effect of the PC model on the outcomes under study. One common finding is the importance of the multidisciplinary teamwork and of the training of the health professionals who compose the team.

EPIDEMIOLOGICAL SURVEYS

RESULTS COMMON TO ALL SURVEYS

This study gives point prevalence estimates of the population of palliative patients in different settings in Belgium using the following definition "*a patient suffering from an incurable, progressive, life-threatening disease, with no possibility to obtain remission or stabilization or restraining of this illness*". Based on the results of the three cross-sectional surveys, GPs in Belgium care for 8.000 to 13.000 palliative patients, approximately 5.500 palliative residents live in NH and 3.000 palliative patients stay in hospitals. Frequent transfers between settings make it difficult to sum up those estimates to make a global estimate. Nevertheless, between 10.000 and 20.000 patients need today PC in Belgium according to their health care professionals: this estimate highlights the need for qualified PC in all settings.

Many physicians found it difficult to discuss PC and advanced care planning with patients and families. The surveys show indeed that the hospital physicians and the GPs do not know the patients' wishes concerning the treatment options in about one quarter of cases. A similar observation was made about the place of care and/or the place to die. However, when the preferred place of care and death had been discussed, (nursing) home was preferred by most patients in all settings. Communication between settings is therefore of utmost importance as a proportion of patients (one third from home, 10% in NH) will experience a hospitalisation during their last weeks of life.

The curative treatment of the main pathology had been stopped for half of the patients at home and in hospital and for most patients in NH. The comfort of the patient was a main care objective in most cases, in particular in NH. Further invasive treatments were usually excluded, in particular in the home care setting and for nearly all patients in NH. When further treatments were considered, antibiotics, par-enteral and enteral perfusions were the most frequent treatments mentioned.

Many in- and outpatient services exist in Belgium but health professionals do not call them as frequently as it would be expected. Results show that most GPs know about the existence of PC teams but less than 10% of the GPs called a PC team during the preceding year. (Potential) Referrals to PC team in hospitals concern in reality less than half of all the potential patients. No data were available for specialized referral in NH. Not all patients require a specialised PC intervention but there is an assumption that some people could miss out these services and others would be referred too late as described in the literature.

The surveys show that patients' wishes (perceived by their health professionals) were usually fulfilled when the physicians were aware of them. Most patients want to die at home, whilst family members do agree to some extent. Three quarters of the patients who were in home settings and expressed this wish, indeed died at home. Nearly all residents who passed away died in their NH. In hospital, 70% of the "return to home" demands were fulfilled at the end of the follow-up (76% for returns to NH).

The results of the surveys have to take account of the methodological limitations such as a selection bias in the web survey, biases linked to the selection of the patients by the caregivers, the small sample sizes, and the answers given by proxy's (health professionals).

WEB BASED SURVEY AMONG GENERAL PRACTITIONERS

About half of the GPs who participated to this survey had at least one palliative patient at the time of the survey. Some important conclusions come from the results of this web survey. First, the GPs who answered to this web survey consider PC as an essential task and like to coordinate PC, in collaboration with other health care professionals. Second, the training in PC influences the way GPs perceive and fulfil their task for palliative patients. Third, many GPs experience barriers to communicate with palliative patients and with their family. Finally, further research would be needed to understand why some of these services were hardly used during the preceding year.

EPIDEMIOLOGICAL SURVEYS IN HOME SETTINGS, NURSING HOMES AND HOSPITALS

The survey in home settings included 342 GPs who enrolled 239 patients. Most palliative patients identified by GPs were older than 70 years and suffered from an oncology problem. Half of them had a life expectancy exceeding 3 months at the beginning of the study. The follow-up survey confirmed the data from the literature: GPs have difficulties to estimate the patients' survival time. GPs stated that in about 25 % of the cases, the disease, the care planning and wishes about place to be cared and to die were not discussed with the patient.

The survey in NH included 168 palliative residents from 50 institutions (randomly selected) i.e. only 4% of the NH population under study. NH that had a formal view on PC identified a higher proportion of patients to be included in the study. Mean age was 84 years and two out of five palliative residents suffered from dementia as main diagnosis. Most patients (80%) had a life expectancy exceeding 3 months. Treatment options were discussed (and often written) for most patients, usually with the family, due to the cognitive impairment of the resident. When clarified, treatment options were usually followed as well as the wish to die in the NH.

The survey in hospitals randomly selected 14 institutions (4646 beds) in lists that took into account three criteria i.e. type, size, geographical location. Nurses and physicians agreed on the selection of most (83%) palliative patients: 249 of them were included in the study i.e., nearly 10% of the total inpatient population. Mean age was 72 years but cancer patients were younger. This diagnosis was the most frequent one but nearly half of the patients had a non-malignant disease. Half of the inpatients had a life expectancy exceeding 6 months. Patient's and family's preferences were unknown by the interviewed caregivers in one third of the cases. The advanced care planning was discussed for most patients in geriatric wards. The intervention of the PC team happened or was considered for 44% of the patients, in particular when they were younger, suffered from cancer and had a shorter survival prognosis.

COSTS OF PALLIATIVE CARE

LITERATURE FINDINGS

Few studies calculated PC costs across different health care settings. Hospital palliative care is cheaper than usual care or care delivered in hospital units other than PC units. There is some evidence pointing to cost advantages of PC at home as compared to alternative care models, although this finding needs to be confirmed by further research. The population of patients receiving palliative care is heterogeneous from a cost perspective. Also, different care models appear to target different patient groups and offer varied packages of services. This implies that different approaches to delivering palliative care are not substitutes for each other.

COSTS IN DIFFERENT SETTINGS

The retrospective pilot study on costs in hospital calculated the costs during the 30 last days of life of patients deceased in geriatry, oncology and cardiology wards. Results suggest that the mean daily cost was lower if the medical record mentioned that the patient had received PC: fixed costs (paid by the NIHDI) were in particular lower, an observation that might witness a switch in the therapeutic choices i.e. less medical interventions when health professionals identify the patient as a "palliative patient". The highest costs have been recorded in PC units that benefit from more human resources.

There was little variation in costs between NH. AS in the hospital, the mean daily cost was higher for patients who received usual care versus the patients with PC. This difference was mainly explained by more frequent hospitalizations when the patients did not benefit from specific PC.

LIMITATIONS

These epidemiological studies give an approximation of the prevalence of palliative patients in Belgium but their interpretation has to take account of some limitations.

The first one refers to the sample sizes, given the complex methodology that has been used to identify the palliative patients independently of the care they receive. Moreover, the recruitment in hospitals considered the characteristics of the institutions but the final sample could not be representative of the whole population of patients. The prevalence study is based on the patients' selection by the health professionals: this procedure might bias the estimate. Finally, the answers are also those of the health professionals, given the impossibility to interview this patient group.

The data on costs is a pilot study. It gives an insight into the cost differences between patients who have a similar profile but do receive (or not) PC.

RECOMMENDATIONS

Based on this report, KCE formulates the following recommendations for the definition of palliative patients, the organization of palliative care, the training of health professionals, the registration, budget and research.

Patients who should benefit from a "palliative status":

- patients should be recognized as "palliative patients" when they are in an advanced or terminal stage of severe, progressive and life-threatening disease whatever their life expectancy;
- this "palliative status" is different from the "terminal stage" of a disease and includes the needs assessment of the patient. This assessment should be initially performed and followed at regular intervals by the main physician in collaboration with a palliative care team;
- the meaning of "needs" should consider all dimensions, including the need for information and for social support in order to allow patients to stay at home when feasible and preferred by the patient;
- this definition of a patient who needs palliative care should be different from the definition that gives access to financial or social support, a definition that is specific for each health care system and that requires a consensus at the level of the Belgian health care system.

Importance to identify all palliative patients, including non-oncological patients:

- patients with advanced chronic conditions (e.g., heart failure, pulmonary disease) need to be identified during the course of their disease as "palliative patients" as their palliative needs are often unrecognized;
- patients with dementia represent a large and growing proportion of palliative patients in home (replacement) settings: their specific, frequently unmet needs require an early assessment and an adapted answer from specialized health care professionals.

Importance of training health care professionals:

- courses in palliative care ("basic training") should be included in the curriculum of all health professionals and should also be offered as continuing education by scientific societies;
- the content of this basic training should encompass common major subjects across all curricula e.g., the control of symptoms, communication skills, social problems, spiritual needs;

Importance of a strong palliative care organization:

- the care model should be multidisciplinary and tailored to the individual patient (patient preferences, family wishes, health status, social support);
- relatives are a target group to be included in the care models in home settings in order to prevent their exhaustion and to allow the patients to stay at home when they expressed this preference;
- Belgium has a large offer of palliative care structures: however, the high proportion of patients who wish to stay and to die at home calls for a reinforcement of links between settings to offer a continuity of care to the patient;
- standardized records are required in all settings to register and to follow advance care planning and preferred place of death.

Importance of registration:

- the registration of palliative activities is required for all settings that benefit from a specific financing for caring for palliative patients, including the nursing homes;
- this data collection should be standardized and include data on the number of patients, their profile, the process of care and when available, quality indicators.

Costs of palliative care:

- one has to encourage explicitly the intervention of palliative care mobile teams in hospitals in the light of the lower costs incurred by this type of intervention (in comparison with classical care) and the better balance between this care model and the patient's needs. For that purpose it is important to screen systematically patients in hospitals to identify those ones who would benefit from a palliative care treatment.

Need for further research:

- to identify the most appropriate instrument to standardize the assessment of the needs of the palliative patients;
- to explain the limited and selective referral to specialized palliative care structures and the underutilization of the "financial forfeit/forfait" for terminal patients;
- to measure the quality of palliative care using the few available quality indicators (e.g. forthcoming results from NIVEL in the Netherlands).

Scientific summary

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Part one: Introduction and objectives

1 INTRODUCTION

Palliative care has grown from the desire to improve the quality of life of patients with life-limiting conditions by emphasizing relief from pain and symptoms, by involving their family and friends, and by adopting a holistic, non-curative focus. However, health care systems have limitations to meet adequately the needs of terminal ill patients whilst keeping an optimal balance between costs and quality of care at the end of life[1].

1.1 BACKGROUND AND AIM OF THE STUDY

Belgium also faces a rising prevalence of progressive and chronic illnesses and at some point, those patients will need palliative care, sometimes over a long time period. The paragraph below describes e.g. the report of the Federal Evaluation Cell for Palliative Care that concludes to the diversity of efficacious palliative structures in Belgium with a lack of funding to answer to the rising palliative care demand. Statistics from sickness Funds suggested that palliative advantages at the end of life could be underused by the patients who need them. A patient at home is considered as "palliative" according to his/her life prognosis and this criterion seems often inadequate as he/she lives longer or shorter than expected by his/her physician. A further issue is to know if the care patients receive exactly answers to their palliative needs. Some illustrations are curative treatments that go on for patients with a terminal illness or patients who never get the palliative support that they would need despite of the existing structures.

The balance between costs and quality of palliative care also raises questions: the multiple solutions currently on the market imply various investments for the society. Financial considerations might also influence the patient's and family choice: little information is available on the charges that the patients/family have to pay according to the setting they choose for the palliative care.

The aim of this study is to analyse the current situation of palliative care in Belgium and to propose optimal solutions to ensure that palliative patients receive the care most appropriate to their needs. First a systematic literature review analyses the definitions and needs of palliative patients and the palliative care models. An epidemiological study examines the prevalence of palliative patients in different settings and the care that they receive. Finally, the costs of care in the different settings are also examined. Based on these results proposals are made in order to optimize palliative care in Belgium.

1.2 HISTORY AND STRUCTURE OF PALLIATIVE CARE IN BELGIUM

The first palliative care service and palliative home care team were created more than 20 years ago. 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)[2]. 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 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.

1.2.1 Support for the palliative patient at home

The palliative home care teams were created to support caregivers in the first line of care. The Royal Decree of Oct 13, 1998[3] 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)[a]. In 2008, 28 teams signed such an agreement. 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 advice 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[4] 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[5] and the palliative patient at home does not have to pay any personal contribution when treated by nurses, physiotherapists and general practitioners[6-8].

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. An evaluation after 3 years functioning should help decision makers to decide about the future of those centres.

1.2.2 Palliative care in hospital

Two palliative care structures were set up in the 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. Secondly, the palliative function in hospital has been developed for palliative patients not staying in a PCU[2, 9]. This palliative function, obligatory in every hospital, comprises all activities for the treatment, care and support of terminal patients i.e.:

---

[a] INAMI: Institut National d'Assurance Maladie Invalidité; RIZIV: Rijksinstituut voor ziekte- en invaliditeitsverzekering

- 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. 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.

1.2.3 Support for the palliative patient in 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[10]. Another measure provides money for training via part C of the health insurance allowance[11, 12]. From the first of July 2008, an additional budget is available for a part-time palliative reference person ("personnel de reactivation – personeel voor reactivering").

1.2.4 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.

1.3 STUDIES ABOUT END-OF-LIFE CARE

1.3.1 International literature

Over the past decades, empirical research in the domain of end-of-life care and palliative care has grown substantially. The number of peer reviewed publications increased exponentially[13]. Some large-scale studies have been performed on end-of-life care delivery. In the United States, the 'Support study'[14, 15] and more recently the 'mortality follow-back study' with bereaved family members[16] have pinpointed important problem areas in the quality of US health care for patients at the end of life. In the United Kingdom, the 'Regional Study for Care of the Dying' has made contributions in highlighting the importance of palliative care for non-cancer patients[17, 18]. Many countries started to explore existing databases e.g. mortality statistics based on official death certification, for a better understanding of the epidemiology of end-of-life period[19, 20].

1.3.2 Studies in Belgium

In Belgium little research had been done on palliative care till recently. In 1981, a study was conducted on death of elderly in hospital[21]. Some qualitative studies were also carried out concerning the circumstances in which hospitalized elderly people are dying[22], experiences of nurses with palliative care[23]. 'Dying at home with care' is a literature review written as a guideline for general practitioners[24].

The Federal Evaluation Cell for Palliative Care has to present a report to the Chambers of Parliament every other year to evaluate the quality and the structures of palliative care and to propose improvements[25]. This evaluation is only based on the experience and expertise of palliative caregivers and organisations. That explains the need for completing this evaluation by this current scientific project coordinated by the Belgian Health Care Knowledge Centre.

Some research projects are now in progress, conducted by The End-of-Life Care Research Group. This research group has two aims:

- to evaluate end-of-life care and end-of-life decisions in medical practice in Flanders;
- to develop quality indicators of end-of-life care and end-of-life decisions, and investigate possible monitoring systems.

Many publications and further information are available from the group's website[26]. The project has two main axes.

The first axe aims at developing representative databases and analysis tools, with six parts:

- study of end-of-life decisions via the death certificate method[19];
- a permanent three year end-of-life care registration, via Belgian Sentinel Health Network of General Practitioners (SENTI-MELC study)[27, 28];
- registration of end-of-life care via the Dutch sentinel networks of general practitioners;
- problems and needs in consultations with physicians specialized for euthanasia questions;
- study of the existence and implementation of institutional guidelines and policy with respect to end of life in Flemish care institutions;
- study of the notification procedure for euthanasia and reported euthanasia cases.

The second axe encompasses policy-oriented analyses i.e., analyses of the legislation and regulation concerning palliative care and euthanasia. The different parts are: analysis of laws and regulations on palliative care and euthanasia, analysis of (non-competent) minors, trend analysis of end-of-life decisions 1998-2001-2006, social inequalities in end of life care (palliative care and end-of-life decisions), systematic comparative analysis between Flanders and The Netherlands and analysis of quality indicators of end-of-life care and monitoring systems.

Details and publications on the different parts are available on the research group's website[26].

2 OBJECTIVE OF THE STUDY AND STRUCTURE OF THE REPORT

This study completes those previous works by adding scientific elements on the palliative patient, his/her needs, the palliative care settings and to what extent these structures answer to the needs.

The objective of this study is to propose an optimal organisation of palliative care in Belgium based on a literature review, on a survey among general practitioners and in palliative care settings and on an exploratory analysis of the costs in the different settings.

2.1 SYSTEMATIC LITERATURE REVIEW

After the introduction (part one), the second part of the report is a systematic literature review on three topics.

First section analyses the definition of a palliative patient from three angles i.e., in theory, for research purposes and the use of this term within the health care organisation. This distinction has been defined after a first screening of the literature sources that indicated that the definitions vary according to their purpose.

The second section of the literature review analyses the needs of the palliative patient (including children). Clarity about the needs will allow to link palliative care to the needs of the patients.

Finally, a systematic review of the reviews analyses the care models in palliative care to give an insight into their conditions for implementation and their outcomes.

2.2 EPIDEMIOLOGICAL SURVEYS

The third part of the report describes four epidemiological surveys.

First, a web based survey among a large sample of general practitioners explores their experience with palliative care. GPs have been chosen as target population as all palliative patients are first cared in primary care and many of them will stay at home during the palliative period.

Three other epidemiological surveys estimate the prevalence and health care pathways of palliative patients i.e., "*a patient suffering from an incurable (1), progressive (2), life-threatening disease (3), with no possibility to obtain remission or stabilization or restraining of this illness (4)*"

The surveys have been conducted in three different settings:

- A study on the prevalence, profile and pathway of palliative patients in home settings (data collection by the GP at baseline and 3 months later);
- A cross-sectional study in residential and nursing homes to assess the prevalence and health profile of palliative residents. A second data collection 12 weeks later analyses their pathway during the follow-up and place of death if applicable;
- A similar survey in hospitals with baseline data and 14 or 42 days later.

Those surveys evaluate moreover the adequacy between the advanced care planning and the subsequent treatments. They rely on the perception of the caregivers as the direct contact with patients and families could not be considered for this topic.

The choice of epidemiological surveys was the optimal solution to have an insight into the prevalence in a large population of patients, despite of two shortcomings. First, some findings would need further in depth analysis to explain the results: one illustration is the importance of qualitative studies to explain the low referral rate to specialized teams. Secondly, palliative care is often organized for the same patient in different settings: this point prevalence survey did not give any insight into the content of transmural care received by the patients. This would need a follow-up survey of a sample of patients across settings.

2.3 COSTS OF PALLIATIVE CARE

The fourth part of the report is a pilot study that estimates the costs of palliative care for terminal patients. The research has been conducted in hospital units with and without palliative team support (oncology, geriatrics and cardiology), in palliative care units, in nursing homes and at home.

The design of the studies differed between settings for reasons linked to the feasibility of the research. In hospitals and institutions for the elderly the data on costs could only be collected retrospectively as they are available a few months after the discharge. On the opposite, the bills paid by the patients at home had to be collected prospectively, in order to be as exhaustive and accurate as possible.

The designs of the surveys on costs have as a consequence that the populations of those studies differ from the populations included in the epidemiological surveys. In hospitals and nursing homes, data on costs were collected retrospectively for terminal patients who died within a given period. In the home setting, patients were recruited by palliative home care networks: those patients answer to conditions of prognosis and all of them benefit from specialized care.

2.4 ROUND UP

The last part of the study is a round-up based on the conclusions drawn in the former parts of the study. Conclusions formulated in this last part help to formulate potential avenues for the future optimization of palliative care offer in Belgium. The initial protocol planned to couple these proposals with an estimate of the budgetary consequences. However, the sample size of the economic part only allows suggesting an estimate of costs in each setting.

PART TWO: Literature review

The literature review has three parts:

- Definition of the concepts "palliative care" and "palliative patient";
- Definition of the "needs of a palliative patient",
- Literature on health care models in palliative care.

3 DEFINITIONS OF PALLIATIVE CARE AND PALLIATIVE PATIENT

3.1 INTRODUCTION

The aims of this first part are:

1. To define theoretically what is "palliative care";
2. To define operationally a palliative patient in order to:
   a. include subjects in the surveys of this project;
   b. propose a practical definition of patients who are eligible for a financial covering of the compulsory health insurance.

3.2 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.

3.2.1 Search on the Internet

The search started with the most widely used definitions that were currently used (at the start of the project i.e. 2007) 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.

3.2.2 Search in medical databases

Detailed search strategies are presented in the appendices.

3.2.2.1 Databases

The search was completed by articles selected in the medical literature indexed in Medline, Embase, Psychinfo and CINHAL.

3.2.2.2 Keywords

We used the following terms as free text or as terms of the thesaurus when possible: "Palliative care", "terminally ill", "terminal care", "critical illness", "palliative patients", "definition", "hospice care", "incurable", "attitude to death", "terminal cancer".

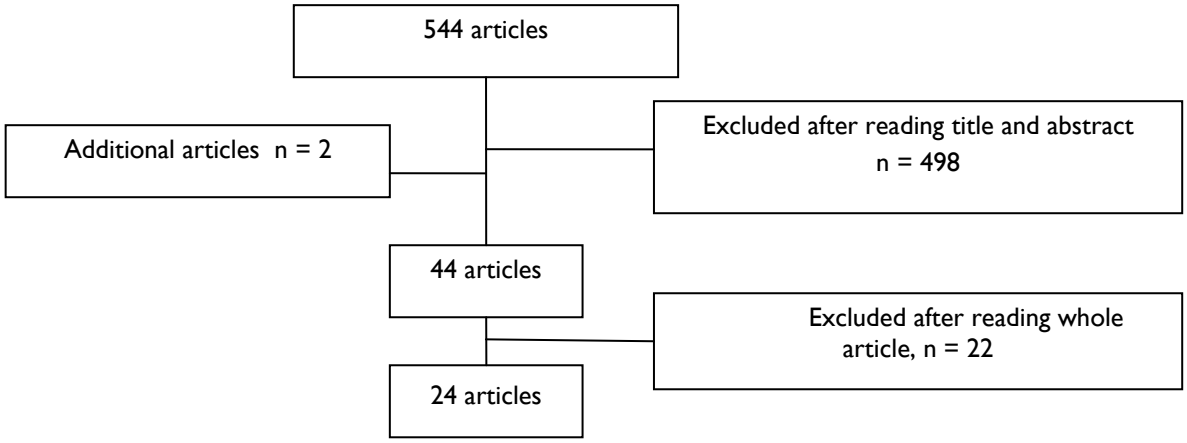
3.2.2.3 Inclusion / exclusion criteria:

Papers published from 2002 to 2008, 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 separately by two reviewers. In case of disagreement, reviewers tried to find out a consensus.

3.2.2.4 *Flow chart with the selection of the papers*



3.3 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.

3.3.1 Theoretical definitions of palliative care

3.3.1.1 *Definitions according to the (national) organisations*

The table below gives an overview of the number of definitions that were found per country.

Table 1 : Number of definitions per country

Country	Number of relevant organisations identified	Number of		
		Definitions	referrals to another definition *	own definitions
"international"	3	3	Not applicable	3
Belgium[b]	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"

Tables presented in appendix to this chapter summarize the content of the definitions of "palliative care" according to the official websites from palliative care associations. Details are provided in appendix. The crosses (X) indicate if the definition clearly mentions the item under study. The categories reported in 'type of care', 'place of care', 'target populations' and 'means of palliative care' sometimes did not explicitly mention an aspect of the category in the definition: that does not mean that this aspect was excluded of their palliative approach.

[b] We search only for definitions from official institutions, not isolated networks.

International definitions (WHO and EAPC): many common features

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"[29-31].

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"[29].

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"[32]. The main focus in 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"[33].

Both definitions 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: common international inspiration

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

SETTING OF PALLIATIVE CARE

Some associations created their own theoretical definition of palliative care or started from the WHO one 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).

COMMON FEATURES 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.

First, 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.

Secondly, 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.

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 precises 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 BETWEEN DEFINITIONS FROM ORGANISATIONS

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[34]. 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.

3.3.1.2 Theoretical definitions according to the indexed literature

As stated above, all theoretical definitions from the associations go in the same direction with here and there some specifications. The literature search in the indexed literature identified five additional articles for completing these theoretical definitions[35-39]: two papers specifically refer to palliative care in oncology[38, 39]. Those papers are presented in appendix.

General definitions of palliative care

Mathew et al.[35] reviewed 53 policy documents to identify a national view of policy intentions for palliative care. They concluded to an increasing recognition of the need to extend palliative care beyond the traditional focus on cancer services and terminal illness. They suggested applying a palliative approach regardless of the fact that the death is expected.

Harantty and al.[36] conducted focus groups with doctors to clarify their perception of "palliative care" for patients with heart failure. They found that palliative care was perceived as an ideal and holistic approach (patient, family), largely nursing-based. Palliative care should include psychosocial issues and spiritual aspects as well as communication. The doctors considered palliative care as a permission to fail. Palliative care was the "management of dying" i.e., the coordination and facilitating of services. Medical care, social context and environment were included in the palliative care.

Zwerdeling et al.[37] emphasized on the preventive aspects of palliative care. They proposed a holistic patient-centred approach where the cultural dimension and identification of potential barriers are important. The aim is to prevent complicated or ineffective grief and bereavement by anticipation or identification of people at high-risk. This prevention relies on the unique relationship developed between the patient, his/her family and the health care givers during the palliative phase. They moreover suggested more prevention though the identification of high-risk members of the family (e.g., hereditary genetic predisposition to cancer). The palliative care team could advice family members for specific disease screening and refer family members to the appropriate providers. Finally, education on the transmission modes for nonhereditary environmentally acquired disorder could also be proposed when necessary.

Palliative care in oncology

IMPORTANCE OF PALLIATIVE CARE IN ONCOLOGY

The oncology sector is particularly involved in the discussion on the definition of palliative care. Some factors explain this specificity. First, cancer patients were historically the first ones who benefited from palliative care. Moreover, according to Ahmedzai et al.[38] cancer receives more public attention because of potential greater pain and suffering, in comparison with others diseases associated with terminal outcome. Moreover, these authors report that in many countries, cancer patients have an easier access to palliative care than the other palliative patients. Another reason should be that the decision to withdraw is associated with a discharge from the hospital and a good communication is therefore necessary. Ahmedzai et al.[38] also underline that cancer patients are sometimes young: this implies more difficulties for the family (partner at work and/or dependent children) and confronts the caregivers with their

own mortality. Finally, the cancer prognosis is always uncertain, generating anxieties. The authors conclude that these reasons explain why cancer patients more frequently need continuing surveillance and psychosocial support.

WHO DEFINITION IN THE CONTEXT OF PALLIATIVE ONCOLOGY

Van Kleffens et al.[39] reviewed the WHO definition of palliative care with interviews of oncology patients and physicians. GPs state that palliative care answers to the WHO definition but is often associated to dying patients: they associate palliative care and treatment for terminally patients. Oncologists do not restrain palliative care to the terminal stage of a disease. They add to the WHO approach palliative treatments (chemotherapy, radiotherapy, surgery) that do not aim to cure. They think that the treatment should not only target symptoms but also the tumour. In consequence, the palliative treatment could aim to prolong life, what fundamentally differs from most approaches in palliative care. Finally, the patients themselves fear a worsening of symptoms and state that the goal of a palliative treatment is to preserve or even improve the quality of life.

POSITION PAPER OF THE EUROPEAN SCHOOL OF ONCOLOGY (ESO)

The ESO group defined palliative care as "the person-centred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimise the quality of life of patients and their families or close friends"[38]. They further distinguished basic palliative care and specialized palliative care.

- Basic palliative care is the standard care that should be provided by all health care professionals within their normal duties to patients with life-limiting disease. This team includes at least the GP and a community-based nurse who have good access to one of the members of the oncology team.
- Specialized palliative care is a higher standard of care provided at an expert level by a trained multi-professional team when difficult symptoms cannot be controlled by the usual healthcare team. The specialized team should ideally include at least one doctor and one nurse trained to higher level in palliative medicine, as well as input from named, permanent and higher trained professional from many disciplines e.g., social work, psychology/psychiatry, nutritional support. A 'multi-professional teamwork' implies a network of trained professionals in different branches of healthcare and social care who meet regularly and/or discuss about individual patients.

This distinction between basic and specialized palliative care should contribute to reflect the increasing multi professional specialization and to recognize different models for delivering this type of care.

The ESO group further discusses the following points:

- Definition of palliative care: that relies on the WHO definition with an emphasis on the need to include cancer patients at an early stage of the illness;
- Recommendations on how palliative care should be delivered e.g., patient-centred care, holistic approach, patient's preferred setting, bereavement support;
- The minimum requirements for palliative care: principles, clinical issues, educational and research needs.

Key messages: Theoretical definitions of palliative care

- **Theoretical definitions of palliative care vary according health organisations but mostly rely on the WHO and EAPC definitions.**
- **The WHO definition is the most comprehensive one, including any life-threatening illness and its physical, psychological and spiritual aspects.**
- **The ESO group makes a difference between "basic palliative care" and "specialized palliative care" based on the competences and multidisciplinarity of the team and its group dynamics.**

3.3.2 Definitions used in research projects

The variety and imprecision in the theoretical definitions preclude from using them for identifying the patients who require palliative care. Nevertheless epidemiological studies need precise inclusion criteria as for example for this project. Unfortunately, most studies that aim to determine the prevalence of patients that need palliative care include patients according to criteria linked to the care they currently benefit from. Few studies could therefore be used as inspiration to define inclusion criteria that are independent on the care received by the patient.

3.3.2.1 Inclusion criteria for research with palliative patients

General inclusion criteria for sampling palliative patients

This literature search identified several papers that used inclusion or exclusion criteria for sampling palliative patients:

- Several studies are exclusively conducted in palliative settings whilst many palliative patients are also hospitalized or stay in other home (replacement) settings;
- Palliative patients are usually defined by the fact that they receive palliative care[40];
- Some surveys include dead patients using a retrospective design[40].

These types of design are restrictive and underestimate the effective prevalence of patients who need(ed) palliative care in a region or a country.

Inclusion criteria for sampling patients in need of palliative care

Studies that aim at identifying which patients are in need of palliative care, whatever they already receive it or not, are based on several types of inclusion criteria:

- Type of disease e.g., serious evolving life-threatening illness[41-45]; non acute pathology[41];
- Type of care received e.g., maximal medical therapy[46];
- Type of symptoms e.g. symptoms from a disease severely limiting the activity and/or needing help with personal care[46];
- Stage of the illness or evolution of the patient status e.g., evidence of recent clinical deterioration[46], being in a advanced stage (evolution radically unfavourable) of a disease[47], advanced or terminal stage[41-45];
- Prognosis e.g. less than 3 months[41, 47, 48], less than 6 months[49], terminally ill but with a prognosis of more than 6 months[49], less than 1 year[50, 51]; several days, weeks or months but death in a not too distant future[52];
- Patients whose status corresponds to official criteria: One illustration is the "terminal declaration", a document that gives right in Denmark to economic benefits and improved care when his/her expected life expectancy does not exceed 6 months. This declaration has been as a proxy to identify formal terminal diagnosis in a retrospective study[53];
- Clinical assessment of the nursing and medical staff (in a population already hospitalized)[48].

Finally a study whose aim was to identify patients susceptible to be admitted in a Palliative Care unit added as inclusion criteria the impossibility to stay at home for various reasons e.g., need of an hospital treatment, familial difficulties, exhaustion of the family, lack of psychosocial support[47].

The study of Morize et al.[42] allowed validating the use of SFAP definition of palliative care to identify the patients who require the support of Terminal care Support Teams (Société Française d'Accompagnement et de soins Palliatifs). They asked to the nurse and physician independently if the patient was "in an advanced or terminal stage of severe, progressive and life-treatening disease". Coefficient of agreement was high and consensus could be further reached when initial opinions diverged. However the paper makes an unclear distinction between "terminal" and "palliative" patients.

3.3.2.2 Criteria for research with terminally ill patients

This review (see also table in appendix) highlights that most studies on palliative patients have included 'terminally ill', or 'end-of-life' patients.

Lorenz et al. have in 2004 reviewed the literature to elucidate how a patient could be defined as a 'end-of-life' patient[54]. They proposed different approaches to define the 'end-of-life' status:

- By the patient 'readiness' i.e. the patient is ready to address end-of-life issues when he/she is aware of his/her prognosis;
- By the severity of illness: 'Is this patient sick enough that it would not be a surprise if he or she would die within 6 months (or 3 or 12 months)?';
- By prognosis expressed by the physician as the risk of dying at a time in the future.

Ahmedzai et al. defined the end-of life care by adding the content of care given: when curative or life-prolonging treatments are decided not to be pursued[38].

An Australian study analysed the interpretation of the term "terminal stage" in a sample of haematologists. One fifth of them (20%) considered it as a criterion to refer the patient to palliative care whereas the 80% suggest it for symptoms control[55].

3.3.2.3 Accuracy of criteria to define palliative patients

Criterion "patient readiness"

The patient readiness is not only tied to the prognosis: it depends also on the way the patient and his/her entourage perceive this state. This readiness is also influenced by other factors e.g., the diagnosis, socio-cultural factors, weariness with life[54].

Criterion "severity of illness"

No research have evaluated the performance characteristics of the question (see above) aiming at assess the severity of commonly fatal illnesses[54].

Criterion "prognosis"

The most problematic issue concerns the prognosis. As many clinicians, Billings et al. base the prognosis on clinical judgement and common sense[49]. However, multiple factors e.g. the underlying pathology, influence its accuracy. As an example a prognosis seems to be particularly difficult in non solid tumours patients[55].

For cancer patients, Christakis et al. report that prognoses are frequently too optimistic in hospices. Moreover, the prognosis is less correct in non oncological medical sub-specialties[56].

The prognosis was also not accurate compared to actual survival in the cohort study analysed by Higginson in UK: only 42% of range estimations of prognosis of patients referred for palliative care were accurate, 36% were overoptimistic and 22% were too pessimistic[57].

The literature offers scarce information on the validity of criteria to estimate the prognosis. Baka et al. used the Manchester Prognostic Score to identify patients with small cell lung cancer in needs of palliative care[50]. In a comment to Christakis[56], Parkes also cited other indexes or scores i.e. Morita's palliative prognosis index[58, 59] and Maltoni palliative score[60]). However they were not identified by the search strategy of this literature review.

In the US, guidelines from the National Hospice Organization propose criteria to define a prognosis[61]. Fox et al. studied 5 general and 2 disease specific criteria that are recommended in those NHO guidelines in a sample of hospitalized patients with 1 of 3 commonly fatal diseases. The authors concluded that these criteria were not effective in identifying patients with a survival prognosis of 6 months[61].

In conclusion, in accordance with the conclusion of Lorenz et al.[54], multivariable models as well as clinical judgment are not accurate to define accurately the survival prognosis of palliative patients.

3.3.2.4 Who is the most appropriate person to identify a palliative patient?

The paragraph above concluded that prognosis based on clinical judgment is far from being accurate. However, still most definitions rely on it and several papers analysed the influence of the clinical evaluator on the accuracy of the assessment.

The task to identify eligible patients for palliative care or palliative research could be given either to someone who is in charge of the patient or to an external evaluator.

The competence of these persons could be doctor, nurse, both, researcher or the palliative team.

In the longitudinal study of Farquhar in the UK[34], GPs show greater reluctance than hospital doctors to define a patient with lung or colorectal cancer as palliative. The authors suppose that they probably do not have access to the same information about the patient and about palliative care.

The concordance between the judgments of the nursing and the medical staff is also weak in the study of Gott et al[48], regarding the identification of patients in needs of palliative care (kappa=0.42) or candidate for referral to a specialized bed (kappa=0.35). Nevertheless, the concordance increased with the proximity of the death.

Finally, the study of Morize et al. showed that the 'terminal care support team' reach more easily a consensus than when the assessment is performed by a nurse, a physician or both together[42].

Key messages for definitions in research projects

- **No unequivocal definition of a palliative patient could be identified in the literature on surveys in palliative care. Most definitions only consider end-of-life patients or rely on the care they receive.**
- **Multivariable models as well as clinical judgment are not accurate to define accurately the survival prognosis of palliative patients. However, studies showed that the assessment of a patient would be more accurate if performed by a specialized team or physician.**
- **The prognosis is not enough accurate to allow a clear identification of palliative or terminally ill patients. This review did not identify any other valid tool to define a palliative patient.**
- **The definition from the "Société Française d'Accompagnement et de Soins Palliatifs" might be useful for research, although the distinction between "terminal" and "palliative" remains unclear.**

3.3.3 Definitions used by the national health care systems

This chapter summarizes the definitions used in other Western countries (see the methodology section). The objective was to find the definition of a palliative patient in those countries i.e., criteria that allow him to benefit of specific care, support or financial help. The Belgian definition (INAMI/RIZIV) as well as the criteria were presented in the introduction of this report.

3.3.3.1 France[62, 63]

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.

3.3.3.2 The Netherlands[64]

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.

3.3.3.3 United-Kingdom[65, 66]

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 propose to use the Gold Standards Framework[67], 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, Co-ordination, Control of symptoms, Continuity of care, Continued learning, Carer support, Care in the dying phase.

3.3.3.4 Switzerland[68]

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.

3.3.3.5 Denmark[53]

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.

This declaration could be used as a proxy for formal terminal diagnosis.

3.3.3.6 *Canada*[69]

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.

British Columbia[70] *(BC)*

The BC Palliative Care Benefits Program is accessible for patients who whish to receive palliative care at home. Their medical eligibility for the program has to be assessed and submitted by their physician. The program includes:

- a drug program (100% coverage of costs of prescription drugs and selected over-the-counter drugs);
- a medical supplies and equipment program (delivery of needles and syringes, intravenous therapy, wound care supplies).

Québec[71]

In Quebec, a 'compassion benefit'[c] 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[72]

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

Saskatchewan[73]

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[74]

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.

Key messages

- **No unequivocal definition of a palliative patient could be identified in this review of national health care systems in order to precise who should benefit from specific palliative support (e.g. special care, specific social status, financial support).**
- **Most systems rely on a declaration of "palliative patient" based on a declaration from a physician, linked to advantages that have a limited duration.**
- **The GSF tool proposed by the NHS is interesting for an operational definition of palliative care.**

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[c] prestation de compassion

3.4 DISCUSSION AND CONCLUSIONS

The initial objective of this literature review was to identify definitions of the palliative patient that should be used in the surveys of this project and/or that could be proposed for identifying patients who should benefit from palliative care in the Belgian health care system. A first overview rapidly came to the conclusion that the definition of a palliative patient greatly varies according to the purpose of that definition. The literature review was therefore split up in three parts i.e., the theoretical definitions, operational definition for research purposes and operational definitions for benefiting from social and health care advantages.

3.4.1 Theoretical definitions

The national and international associations give broad definitions that encompass e.g. the diagnosis, the start and duration of disease, the goals, the setting, the needs and the environment of the patient. These broad definitions are interesting by the different aspects covered by the definition. However they describe an existing palliative status but they do not help identifying (future) patients who (will) need palliative care.

The definition of the term "palliative care" evolved since last decades. The literature review show that the WHO definition (and to a lesser extent the EAPC one) inspires most theoretical definitions. This definition is exhaustive and reflects the general international approach to palliative care.

However, the literature review points out that palliative care is often associated with the terminal stage of a disease. Some definitions about palliative treatment "at any stage of the disease" also remain unclear about the moment to start palliative care. One way to answer to this puzzle is to rely on the patient's needs as described in the following chapter i.e., physical, psychological, social, health care and spiritual needs. This approach should care that not all needs call for a professional intervention.

The ESO group proposed a difference between "basic palliative care", under the responsibility of all caregivers and "specialized palliative care" provided by a multidisciplinary team of caregivers specialized in palliative care. This distinction already exists in the Belgian health care setting described above. "Specialized care" is available e.g. thanks to home care palliative teams, palliative care units, palliative functions in hospitals and nursing homes. "Basic palliative care" also exists for patients at home: palliative patients (defined by their estimated survival time) do not have any financial barrier to receive first line of care. The only potential barrier to this free access to "basic care" is the need for a declaration by the general practitioner. "Basic palliative care" does not refer to a unique situation in Belgium as the GPs have various levels of specialization. The epidemiological survey among GPs will further highlight the importance of this palliative training on the GP experience with palliative care.

3.4.2 Definitions used in research papers

In the research papers, the definitions depend on the objective and context of the study. They are useful for targeting a sample of palliative patients but do not help defining a palliative patient in general or a patient whose situation would require a specific support.

The definitions found in research papers on palliative patients could therefore not be used for the epidemiological and economics surveys of this project. The inclusion criteria were not validated, relied on heterogeneous factors, depended on the clinical judgment, or varied according to the context of the study (hospital setting, country). The most widely used definition in the French papers analysed is the one of the Société Française d'Accompagnement et de soins Palliatifs (SFAP): "a patient in advanced or terminal stage of a severe progressive and life-threatening disease without cut off of prognosis". The distinction is unclear between "palliative and "terminal" but this definition inspired the one used in the epidemiological survey of this project i.e. "a patient suffering from an incurable, progressive, life-threatening disease with no possibility to obtain remission or stabilization or restraining of this illness".

3.4.3 Definitions for defining who should benefit from a "palliative patient" status in the health care system

A specific search of information aimed to identify in other countries that has access to palliative care or to benefits associated with a palliative patient status. It is important to identify early the increased needs (medical and non medical) linked to the palliative stage of the disease.

Definitions from other countries show that the criteria for being identified as a "palliative patient" (and benefit from extra social/medical advantages) vary between countries and even within countries. A notion of disease duration (prognosis) is mostly present, as in Belgium (from 3 months to 'prognosis measured in months'). However, the literature on the value of a prognosis in palliative care emphasized the serious limitations of this criterion in palliative care, even if the prognosis becomes more accurate in the latest stages of the illness. Several countries offer specific support to palliative patients without any link with prognosis, at least for the benefits directly linked with medical care or professional support.

Yet, some health care systems have no definition of palliative patient: the patients benefit from increasing advantages when his/her status deteriorates. There is a continuity of care from curative to palliative care until death.

A common criterion used in most healthcare systems is the clinical judgment of the physician. Except in UK, the criteria that support this physician's assessment are unknown. The UK recommendation to use the GSF is useful to determine who need palliative support but this framework goes further, assessing the needs and the preferences of the patients. This approach is the most in concordance with the holistic approach of the patient recommended among others by the WHO.

If the palliative status is defined by the clinical judgment, the most appropriate 'person' to decide if a patient is palliative should be the palliative team according to the literature. However, the evaluation varies depending on the pathology and on the specialization of the physician.

4 NEEDS OF PALLIATIVE PATIENTS

> *"There can be few concepts so frequently invoked and yet so little analysed as that of human needs"* K. Soper

4.1 OBJECTIVE

The aim of this second part of the literature review is to make a broad inventory of palliative care needs of people of different age groups, suffering from different diseases, in different settings.

4.2 BACKGROUND: WHAT ARE HUMAN NEEDS?

Higginson et al.[75] conducted a systematic review on needs assessment in palliative care. Two types of definitions emerge i.e. that of Maslow from the field of psychology, and that of Bradshaw from the field of sociology.

4.2.1 Maslow's definition of needs

Maslow, a U.S. psychologist and philosopher, proposed that human motivation can be understood as resulting from a hierarchy of needs. These needs, starting with the most basic physiologic demands (food, water) progress upward through safety needs and culminate in self-actualization. Maslow[76] argued that the motivation to meet the higher level needs becomes active when lower-level needs are met.

The first level of needs, physiological needs, corresponds to the biological or physical aspects of the individual. The psychosocial aspects are encompassed in several categories of Maslow, including the need for safety, belongingness and love, and esteem. The spiritual aspect is evident in increasing levels, beginning with the safety needs and ending with self-actualization. Maslow stated that when a person is self-actualized, (s)he has become everything that (s)he is capable of becoming. When self-actualization is present, the needs of the individual have been met, including not only bio-psycho-social needs but also spiritual needs[77].

According to Higginson[75] Maslow's theory is useful in palliative care: symptom relief implies that basic needs like food would be already met. However, the model implies a simplistic linear ordering of needs, which may not apply. For example, it is not necessarily true that all higher needs, such as appreciation of relationships and art, cannot be important unless lower-level needs are already met.

4.2.2 Bradshaw's definition of needs

Bradshaw[78], a sociologist, considered need in the context of who defines it. He distinguished four types of needs: felt need, expressed need, normative need and comparative needs[d] :

- What the individual feels he/she needs (felt need);
- What the individual demands (expressed need, i.e. felt need turned into action; this is also called demand in some contexts);
- What a professional thinks that an individual wants (normative need);
- How we compare with others' areas or situations (comparative needs).

This taxonomy is valuable in the context of palliative care because it draws attention to the person who assesses or defines the need. For example, many patients with progressive illness are not able express their need for palliative care or symptom relief and will rely on normative need that depend on the knowledge of professionals,

Bradshaw's definition is helpful in identifying the different factors that might influence reported need, who determines it (professionals, politicians, or the general public), and what the cultural effects on need might be (e.g. social and media influences on knowledge of what is available, expectations, ability to express need).

Finally, Stevens and Raftery[79] defined the need in the context of health care, as *"the ability to benefit from health care*". Their definition implies that a need only exists if there is an effective solution in health care. In this definition, "need" is equated with "capacity to benefit". Benefit is not only restricted to clinical benefit, but can also include reassurance, supportive care, and relief of carers[80].

4.3 METHODOLOGY

This chapter describes the systematic literature search conducted on needs in palliative care in western civilisation as published since 1998.

4.3.1 Scope of the search of literature

We searched the literature following several criteria:

- literature relevant for Western countries since the conclusions have to be relevant for the Belgian healthcare system;
- literature published the last 10 years since health care context is changing rapidly;
- literature primarily from Medline, Embase, PsychInfo, CINAHL and British Nursing Index.

4.3.2 Stages of the literature review

The literature review had five steps:

1. definition of the research question;
2. definition of the search strategy and link with the different parts of the ECLIPS research question;
3. combination of search terms (Mesh, Emtree and Major Index terms) to identify all potentially relevant studies, selected by reviewing the title and abstract;
4. further selection by two independent reviewers for further analysis;
5. analysis and description of the relevant articles.

4.3.2.1 Step 1: Definition of the research question

"Which needs do people experience in end of life stages in Western civilisation, irrespective of the setting of the care and of the caregiver to have an impact on their health and non health outcomes (such as effective and efficient symptom relief, reassurance, supportive care and relief of carers)?"

4.3.2.2 Step 2: Definition of the research question according to the ECLIPS principle

This question was built up by the ECLIPS principle where ECLIPS stands for:

- Expectations (about improvement or innovation or information): Needs = "the ability to benefit from health care";
- Client group (at whom is the service aimed?) : Patient in end-of-life stage in Western civilisation;
- Location : at home, in homes for the aged, in hospice or in hospital;
- Impact :on health and non health outcomes:
  - Effective and efficient symptom relief,
  - Reassurance,
  - Supportive care,
  - Relief of carers.

- Professionals involved : Home care givers, GPs, specialists, multidisciplinary medical staff;
- Service: palliative or terminal care in bio-psycho-social-existential dimensions.

4.3.2.3 Step 3: Search strategy

Databases

The following databases were searched by OVID: Medline, PsycINFO, Embase, CINAHL, British Nursing Index.

Search terms and search strategies

The search terms used in the different databases and the detailed search strategies are in the appendix on needs (search strategy). The search was mainly oriented towards two major topics i.e.:

- expectations (needs) e.g. "needs assessment", "health services needs and demands";
- client groups (patients) e.g. « palliative care », « terminal care », « terminally ill patient ».

4.3.2.4 Step 4: selection of the articles: Methodology of the selection

The lists of papers coming from the consecutive searches were merged in one main database that finally included 1.051 publications. All potentially relevant studies were screened independently upon title and abstract by two reviewers.

The most important criterion for selection was a main focus on the patient's perspective of "palliative needs". Literature focusing on families' needs, (home) carers' needs, different health care services' needs or even pure medical topics or treatment options was rejected. Qualitative and quantitative studies were considered. Additional details on inclusion/exclusion criteria and kappa coefficients between reviewers are in appendix (Needs-search strategy – selection of articles).

After screening, 193 of the 1051 papers were included for data analysis. Twelve (n=12) could not be found and 49 were further excluded because palliative care needs were not explicitly described in the main text or because they concerned non western populations.

Finally 132 papers were included in this study.

4.3.2.5 Step 5: Analysis of the selected articles

This review first describes papers that analyse general points including:

- Needs assessment in palliative care;
- Information and communication in terminal illness;
- Link between palliative care and cancer care;
- Spiritual needs in palliative care.

The body of the review is based on papers that relate to three main chapters:

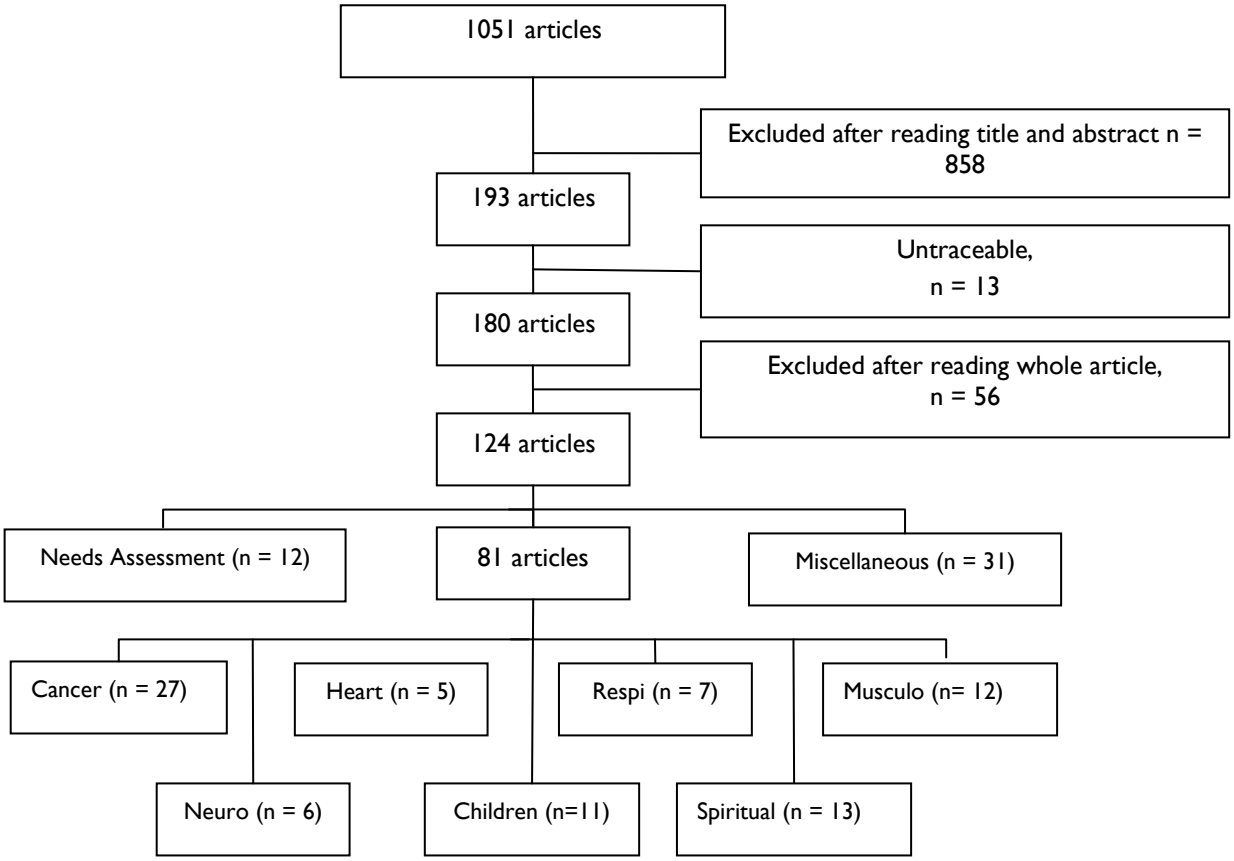
- Five specific pathology groups: cancer, heart failure, respiratory diseases, muscular- and neurodegenerative diseases, neurological diseases;
- Palliative needs in children and their carers;
- Palliative needs in miscellaneous settings.

The report listed all palliative care needs for different diseases and different settings. The researchers used a holistic model of palliative care (as supported by WHO) that added the cultural, spiritual and health care context related axes to the bio-psycho-social axes.

The classification of some needs was sometimes problematic and implied consensus between researchers. For example patients' needs for information were split up in disease specific information (within the biological needs group) while other aspects of communication relating to patient's illness perception were classified under psychological needs.

No quality appraisal was performed on the selected studies since most papers had a descriptive (qualitative or quantitative) design.

4.3.3 Flow chart with the selection of the papers



4.4 RESULTS: NEEDS IN PALLIATIVE CARE

4.4.1 General points

4.4.1.1 Needs assessment in palliative care

The literature shows that patients tend to disclose the full nature and extent of their problems in order to protect their relatives, carers and health professionals[81]. This hypothesis suggests that there might be serious gaps in palliative care, particularly in the identification of the needs for help. An objective inventory of specific palliative care needs is therefore necessary.

Prioritizing palliative care rely on rigorous needs assessment to propose the right services, appropriate in scale and type, to the needs within a community[75]. Different approaches exist to assess needs, however, with to date, little analysis or comparison[75].

Two ways for assessing palliative care needs

Franks[82] proposed two ways for assessing palliative care needs, either by using the epidemiological approach or through the evaluation of health service use. The first approach uses the cause-specific mortality in diseases likely to benefit from palliative care, and then relates this to the type and frequency of symptoms experienced by patients suffering from the terminal stages of these diseases. This method is useful in identifying all palliative care needs, since it is not dependent on the source of the care offered. However, evidence based simply on symptom prevalence (presence and severity) will fail to identify the type of care required and how effectively that care may be delivered, both in terms of cost effectiveness and user and professional satisfaction with care.

An alternative to this methodology is health service use: it may provide a useful starting point in evaluating needs. However, this method does not evaluate unmet needs. A complete picture implies the evaluation of unmet needs that also includes patients who do not receive the care but could benefit from the service on offer[82].

Questionnaires for the assessment of palliative care needs

In the literature, the most conspicuous method for needs assessment in palliative care is the use of questionnaires aiming to evaluate the needs of cancer patients' and their carers.

QUESTIONNAIRES FOR THE ASSESSMENT OF CANCER PATIENTS' NEEDS

A literature review by Osse et al. evaluated the questionnaires for the systematic assessment of needs experienced by individual cancer patients for help, care, or support, as well as the needs of their family members. Some of them are listed here[83]:

- CARES: Cancer Rehabilitation Evaluation System SAQ: Self-Assessment Questionnaire,
- CPNQ: Cancer Patients Needs Questionnaire,
- CPNS: Cancer Patient Need Survey,
- PNS: Patient Need Scale,
- PIS: Patient Information Survey,
- HCS-PF: Home Care Study – Patient Form,
- SAT scale: Satisfaction scale,
- OCPC: Oncology Clinic Patient Checklist,
- CNS; caregivers Need scale,
- Home Caregiver Need Survey,
- PC-QLI: Palliative Care Quality of Life Instrument[84],
- NA-ACP is an instrument to assess the specific needs of advanced cancer patients[85].

Finally, the "Problems and Needs in Palliative Care" questionnaire, separately addresses experienced problems and the needs for care because patients might have needs for which they do not need professional care[86-88]

QUESTIONNAIRES FOR THE ASSESSMENT OF PATIENTS' NEEDS IN GENERAL

Other assessment tools were compiled for use in more general conditions.

- INTERMED: to assess and document integrated information concerning patients' care needs[89];
- SIAM-PC: a patient-centred, model driven, database derived, evidence based, and technology assisted System for Interactive Assessment and Management in Palliative Care to reliably measure the multiple dimensions of patients' needs for palliative care, and then to provide information to

clinicians, patients, and the patients' families to achieve optimal patient care[90];

- POS: Palliative Care Outcome Scale[91];
- Finally, one specific instrument, the Spiritual Needs Inventory (SNI)[77] was developed for assessing spiritual needs of patients near the end of life.

Most instruments were constructed for research purposes. Their validity and reliability were satisfactory and well documented. However, data on feasibility of questionnaires in daily care were scarce. Issues frequently omitted in these questionnaires were spiritual issues, the personal needs of family members, and the continuity of care. Only one questionnaire for patients specifically addressed the need for help.[83].

Besides this quantitative assessment of palliative care needs in patients and their carers, many qualitative data are available after structured (in depth) interviews, focus group analyses, etc.

4.4.1.2 Information and communication in terminal illness

Communication is important in terminal illness, when the appropriate course of action may depend more on patient values than on medical dogma. Kutner et al.[92] described via a multi-method approach the communication issues important to terminally ill patients receiving palliative care.

Discrepancy between patient's expectations and information

Terminally ill patients look for information but they may not be easily satisfied with the information they receive because health care providers might not offer the specific types of information these patients seek. This discrepancy may reflect differences between 'disease' and 'illness' orientations. If caregivers only address disease oriented issues, such as diagnosis and prognosis, they miss a wide variety of illness related issues which are of paramount importance for the patient[92].

Need for tailored information

A relation between easily identifiable patient characteristics and expressed concerns or palliative care needs could not be demonstrated, suggesting that physicians need to individually assess patient needs[92]. Physicians and other health care workers should be aware of the diversity of needs and concerns of the terminally ill and should routinely identify, negotiate and address specific individual needs and expectations.

Common concerns of patients

In Kutner's paper[92] the most commonly mentioned primary concerns and effects of the illness were physical decline, changes in functional status and activity level changes, including loss of independence and fear of becoming a burden. Other common themes were concern about: the effect of illness on the family, whether the disease would improve or continue to worsen, financial or personal affairs and pain. The most commonly mentioned concerns about dying were: avoiding pain, suffering or a prolonged dying process; worrying about the effect of dying on the family; resolving unfinished business prior to death and questions about the actual event of death. Spirituality was important for most participants (87.5%) but a smaller percentage (39.3%) thought that doctors should discuss spiritual issues with their patients, implying that health care providers need to be attentive to, but not intrusive with, spiritual issues[92, 93].

Patients with unmet needs show higher psychological and symptom distress[94]. Physicians may be able to benefit from specific communication training to better meet patients' communication needs from the diagnosis until the terminal phase of disease[94].

Balance between optimism and truth

While in Kutner's study[92] 100% of respondents wanted doctors to be honest, 91% also wanted doctors to be optimistic. This presents a difficult conundrum for health care providers. How does one remain optimistic while being honest about a poor prognosis?

The acknowledgement of conflict, between wanting and not wanting more information, highlights, from the patient perspective, a difficulty that health care providers also struggle with in deciding what to address with an individual patient[92].

The lack of consensus regarding the importance of specific items further complicates the picture of what health care providers should discuss with terminally ill patients. There was little agreement on the importance of life expectancy, what to tell one's family, or resuscitation issues, issues which health care providers may feel should routinely be discussed with all terminal ill individuals[92].

4.4.1.3 Link between palliative care and cancer care

Advances in cancer care and treatment have created a new category of patients suffering from an incurable disease, with a considerable period of life expectancy, mostly without any need for clinical care[95]. There has been a rapid expansion in the provision of hospice and specialist palliative care services in response to the unmet physical, social, psychological and spiritual needs of terminally ill cancer patients and their families. Palliative terminal care aimed to relieve the patients' suffering in the last phase of their lives and to include the alleviation of physical symptoms, besides attention to emotional, spiritual and social aspects[96].

However, the scope of palliative care has been recently broadened and coupled with supportive care to incorporate the provision of care in the early stages of the disease trajectory[97], in the care of those with progressive non-malignant diseases, in different age groups (even in children) and settings (home care, hospice, hospital).

4.4.1.4 Spiritual needs in palliative care

What is spirituality?

Spirituality has been defined as "an inherent quality of all humans that drives the search for meaning and purpose in life [that]… involves relationships with oneself, others and a transcendent dimension"[98]. The basic concept of spirituality is the idea that human beings need to seek and find a meaning beyond their suffering, allowing them to make sense of that specific situation. Patients desire to transcendent hardship and suffering[99].

Spirituality is broader than religion: it has been described as a personal quest to find meaning and purpose in life and as a sense of relatedness to a transcendent dimension. It involves all aspects of the individual as lived in relationship with self, others, and a transcendent dimension and applies to everyone, regardless of religious beliefs[77, 100, 101]. Actually, the realization is growing that the spiritual needs, spiritual distress, and spiritual wellbeing can affect the quality of life, even so when dying[98].

Classification of spiritual needs

The classification of spiritual needs relies on the structure of Galek's instrument on spiritual needs assessment[102]. She included 7 main constructs: belonging, meaning, hope, the sacred, morality, beauty, and acceptance of dying.

In her qualitative analysis, Hermann[103] also identified major themes for spiritual needs in dying patients. Similarities with Galek's scheme are prominent: need for religion (relates to 'divinity'), need for companionship (relates to 'love / belonging / respect'), need for involvement and control (relates to 'meaning and purpose'), need to finish business (relates to 'resolution / death'), need to experience nature (relates to 'appreciation of beauty'), need for positive outlook (relates to 'positivity / gratitude / hope / peace').

Papers included

The description of papers excluded and included is in appendix. Twelve papers using different research methods lead to a broad spectrum of spiritual palliative care needs:

- two reviews: about methods of spiritual assessment, appraisal of the various beliefs regarding the concept of spirituality and spiritual needs of terminal ill patients[99, 104];

- one controlled intervention[105] : "life-Threatening Illness Supportive-Affective Group Experience" (LTI-SAGE) for reducing patient spiritual, emotional, and death-related distress in patients with life-threatening illness at the end of life;
- five quantitative surveys[98, 100, 101, 106, 107];
- three qualitative studies[103, 108, 109] and one case study[110].

Results

The papers that deal with needs for spirituality in palliative care converge towards common broad concepts:

LOVE / BELONGING / RESPECT

- "To be accepted as a person":
  - Talking with someone about spiritual issues: important and sometimes unmet need[98];
  - Expressing feelings and not to be judged: regarded as important by 2 patients out of 3[106];
  - Talking about the important relationships in my life: regarded as important by 64%[106];
  - Opportunity to talk about myself: regarded as important by 52%[106];
  - Expressing fears: regarded as important by 50%[106];
  - Input into own life[103];
  - Information about own care[103];
  - To stay as independent as possible[103];
  - To have steady things in life[103];
  - To be helped by others[103].
- To give / receive love:
  - Be with family[98, 100]: most patients perceived it as need. Two thirds of patients perceived it as met[100], 5% perceived the need as unmet[98, 103];
  - To be involved with family activities[103];
  - Be with friends[98, 100]: most patients perceived it as need, met for two patients out of three[98, 103];
  - To help care for others[103].
- To feel a sense of connection with the world:
  - Have information about family and friends[98, 100]: 88% of patients perceived it as need[100], seen as frequently or always needed between 46,9%[98] and 64%[100], 77% of patients perceived the need as met[100] and 1.1% perceived the need as unmet[98];
  - Being near children[98, 100]: 83% of patients perceived it as a need[100], seen as frequently or always needed between 25.0%[98] and 51%[100]. Seventy-two percent of patients perceived the need as met[100] and 3.3% perceived the need as unmet[98,103].
- For companionship:
  Being with people who share the same beliefs[98, 100]: 88% of patients perceived it as need[100], seen as frequently or always needed between 23.0%[98] and 67%[100]. Three out of four quarters (74%) of the patients perceived the need as met[100], none of them perceived the need as unmet[98];
- Two last needs were also mentioned in the literature i.e., the need for compassion and kindness and the need for respectful care of your bodily needs.

DIVINE

- To participate in religious or spiritual services:
  - Pray[98, 100]: most (95%) patients perceived it as need[100], seen as frequently or always needed between 50.0%[98] and 85%[100]. Furthermore, most patients estimated that this need as met[98, 100, 103];
  - Go to religious services[98, 100, 103]: 85% of patients perceived it as need[100], seen as frequently or always needed between 25.0%[98] and 67%[100]. One third of the patients perceived the need as met[100] and 21.1% perceived the need as unmet[98].
- To have someone pray with or for you[99];
- To seek religious reconciliation or redemption[99];
- To read spiritual or religious material:
  - Read a religious text[98, 100];
  - To read the Bible[103];
  - To use scripture[103];
  - To read and to use inspirational material[98, 100, 103]: 6 to 7 out of the patients perceived it as need[100];
  - Use phrases from religious texts[98, 100]: 65% of patients perceived it as need according to Hermann et al.
- Need for guidance from a higher power:
  - Loss of confidence in God or religion: discussed in 0.3% of palliative care consultation[101];
  - To find grace and strength from God[99].

POSITIVITY / GRATITUDE / HOPE / PEACE

- To feel hopeful, to have hope in my life is regarded as important by 87% of the patients[106].
- To feel a sense of peace and contentment:
  - to take one day at a time[103],
  - to affirm the positives in people's lives[99].
- To keep a positive outlook:
  - To see smiles of others[98,100]: almost all patients perceived it as need[100], seen as frequently or always needed between 70.9%[98], whilst many patients also perceived the need as met[98, 100,103];
  - To have happy thoughts[98, 100]: was similarly important for nearly all patients, mostly (75%) met[100] and rarely (1.1%) perceived as unmet[98,103].
- To have a quiet space to meditate or reflect;
- To be thankful or grateful;
- To experience laughter and a sense of humour[98, 100]: all patients perceived laugh as a need[100], or seen as frequently or always needed between 64.6%[98] and 68%[100]. Two thirds of the patients perceived this need as met[100], few patients (3.3%) perceived it as unmet[98, 103].

MEANING AND PURPOSE

The acceptance of the illness has been discussed in 5.6% of palliative care consultations[101]: to find meaning in suffering, meaning and purpose in life covers the following points:

- Talk about day-to-day issues[98, 100]: most (95%) patients perceived it as need[100], seen as frequently or always needed between 62.5%[98] and 64%[100]. Many patients (82%) perceived the need as met[100], none of them perceived it as unmet[98, 103];
- Talk with someone about spiritual issues[100]: most (79%) patients perceived it as need, seen as frequently or always needed in 43%[100]: this need was mainly (75%) met[100];
- To ask questions: important for 61% of the interviewees[106];
- To discover and to affirm meaning in my life: regarded as important by 48%[106];
- To be of value for others and to be usefully busy were points seldom discussed (1.1%) in palliative care consultation[101];
- To be able to have time to think is regarded as important by 92% of the patients[106].

APPRECIATION OF BEAUTY

- To experience or appreciate beauty was also a need mentioned by palliative patients;
- To experience or appreciate music[98, 100]: 80% of patients perceived it as need[100], seen as frequent or always needed between 23.0%[98] and 49%[100] Many patients (80%) perceived the need as met[100], infrequently (3.3%) unmet[98];
- To experience or appreciate nature included to look outside[103],to be outside[103], to have flowers in the room[103].

RESOLUTION / DEATH

- Reviewing life has been described by Hermann et al[103];
- To address unmet issues before death included to deal with unresolved issues (84% of the patients[106]), to prepare the death[106], to finish life tasks[103];
- The understanding of death and dying was sometimes perceived as a need: discussion on the meaning of death could take place during palliative care consultations[101].

A feeling of forgiveness has also been described in different forms: to resolve bitter feelings[103], to forgive and be forgiven[99] and to right the wrongs[99].

Discussion

Spiritual issues arise frequently in the care of dying patients, yet health care professionals may not recognize them, may not believe they have a duty to address these issues, and may not understand how best to respond to their patient's spiritual needs. Several studies have shown that the majority of primary care physicians believe they should listen to and support patients through their spiritual and existential concerns, yet, literature indicates also that primary care physicians infrequently practice this conviction, citing multiple barriers to spiritual discussion[107]. Most patients however, would like to be able to address spiritual concerns with their physicians if they become gravely ill[107].

Today, patients may not have an established, or a formally expressed, faith connection that can help in time of crisis. They may, however, require assistance to address issues and questions that are not necessarily recognised as 'spiritual'[104]. Spiritual need is multifaceted, and involves an individual reflecting on any part of the personal story.

Spiritual need is also multilayered and the depth of the patient's need depends on how they interpret their present circumstances, the privacy of their surroundings and how the patient relates to the healthcare professional present with them at that moment. It also depends on the patient's physical and psychological state and on the personality and the ability of the patient to articulate thoughts and feelings[104]. However, it could be suggested that the real training for spiritual care is not primarily intellectual, and asks for a hard and often painful process of self-emptying to make space for others[104]. The primary spiritual act is the expression of empathic concern. If sincere, nothing more may be needed[110]. Shortly, spiritual care involves "being" rather than "doing".

Results suggest the importance of a broader focus on the spiritual more than the religious in providing care to patients at the end of life[98]. Perhaps, it may not be the task of the health care team to give patients this meaning, value, or reconciliation, but to facilitate patients' encounters with the meaning, value, and relationships that are already present as givens in the individual existential situation of their dying[110]. Most of hospice staff identify a variety of needs as spiritual: requests for a favourite object, to be creative, to pray, talk about faith, death and dying, to have a religious ceremony, to talk about experiences, to deal with unfinished business and to have company[104]. To help in assessing and responding to a patient's spiritual needs, most staff said that they would like the opportunity to have reflective sessions with colleagues[104]. Primary care physicians can identify the patients desiring an empathetic listener for their spiritual concerns as well as those who would prefer to speak to their physician versus a chaplain or someone else with appropriate screening[107]. More active roles can be leaved to those who have more specific training in this area such as hospice chaplains. Being able to discuss a wide range of spiritual issues with chaplains during visits was viewed very positively by patients[106].

Remarkable was the finding by Hermann[103] that helping to care for others, to contribute in one way or another, was an important spiritual need of many patients even though they were sick and perhaps close to death. Dying patients also wanted to remain involved in decisions and choices about their lives as actively as possible and related the need to stay as independent as possible[103]. Of great importance were the needs to laugh, see people smiling, think happy thoughts and experience the beauty of nature[98, 100]. More difficult to value are the more traditional spiritual (i.e. religious) approaches: in one study the need to pray was viewed as the most salient spiritual need[100] where in another study values as reading religious or inspirational texts are seen as less important than family's closeness, friends and smiles [98]. Above all, needs that could be fulfilled by patients independently were met at a higher level than those that required the cooperation of others[100].

Conclusion

Spirituality is a much broader concept than religiosity and more related towards searching for meaning, moral or biographical contexts besides religious beliefs and ideas. Obviously, in end-of-life care there is a need for spiritual approach, but often not properly addressed by health care workers. However, an honest expression of empathy, "being" rather than "doing", might be a good start.

Health care workers could facilitate the expression of spiritual needs in dying patients just by empathic listening and by addressing them to other staff members with more specific training (as chaplains) if appropriate.

Even at the end of life, people want to be "of value": to help others, to contribute whenever possible. They prefer a positive attitude as for example laugh and beauty.

4.4.2 Palliative care needs in specific diseases

4.4.2.1 Palliative care needs in patients suffering from cancer

Material

This section is based on 27 papers reporting on specific palliative (supporting) needs for patients suffering from incurable cancer disease, their informal carers and/or professionals:

- Two reviews: the contribution of reflective narratives of palliative care professionals as other sources of evidence on patients' needs[111] and needs assessment of patients suffering from malignant wounds[84];
- 17 papers with quantitative data of which 16 surveys and 1 paper based on computerized clinical records[112];
- 6 papers with qualitative design[95, 96, 113-116].

The description of all papers is in appendix.

Results

Palliative care needs for patients suffering from advanced cancer diseases are summarized and grouped following the main 5 dimensions: biological needs, psychological needs, social needs, spiritual needs and health care related needs.

BIOLOGICAL NEEDS:

Management of physical challenges

- *pain*:[117],[118, 119], 67% experienced pain as a problem[120], most patients have access to effective analgesia at home[115], but 59% still suffer from pain[81], while 54-62% has nursing care needs necessary to reduce pain sufficiently[112]. In a hospice setting, pain improved over time[119];
- *Fatigue*:[117], 90% complaints of fatigue[120], where 18% wanted more professional attention[120];
- *Dyspnoea*: 43% complaints of breathlessness[81], where 16-18% has nursing care needs[112]. In a hospice setting dyspnoea showed a negative trend over time[119];
- *Appetite*: 45% complaints of appetite loss/pyrexia[81], where 1-2% of patients suffering from *dysphagia* had nursing care needs[112];
- *vomiting*: 41% complaints of vomiting[81], where 6-8% had nursing care needs[112]. 4% needs a *feeding tube*[112];
- *Edema*: 3-9% had nursing care needs[112];
- *Incontinence*: 8-9% had nursing care needs[112];
- *Constipation:* 6-10% had nursing care needs[112];
- *Seizures:* 2% had nursing care needs[112];
- Ostomy/wound care: 5% had nursing care needs[112];
- *Impaired mobility*:[119]18-33% had nursing care needs[112];
- Consciousness[119];
- *Memory*: 66% had difficulties in remembering what is told[120];
- *Sleep*[94];
- *Sexuality*[120].

Globally, needs for symptom control were unmet in 27%[121] to 62%[94], while fatigue and pain were the most common symptoms[120] and "quality of life" was the most manifest deterioration during the last month of life[122].

Lack of pain control was more frequent among non-English speaking compared to native speakers[118].

Knowledge

How more problems, how bigger the need for information[120]; 39%[123] of respondents felt a need for additional information[124] and one fifth (21%) reported unmet informational needs[117, 120, 125]. Patients whished information on treatment options and alternative or complementary care[120, 123].

The face-to-face format was the preferred approach (66%) in informational needs, while 19% would have appreciated extra written information[123].

The attendance of a family member or friend is frequently mentioned: most patients wanted to be with a member of the family when the diagnosis was disclosed[126].

Carers seem to have more informational needs then patients[117].

People with a language barrier often rely on children (44%) to interpret. Some who had a professional interpreter (17%) felt that it had been helpful[127].

Only half of people with a language barrier were aware of their diagnosis versus 99% of native speaking people. Often (44%) they relied on children to interpret. Only 30% of patients without translator did understand their diagnosis clearly. Some who had a professional interpreter (17% to 23%) felt that it had been helpful[118, 127].

PSYCHOLOGICAL NEEDS

Emotional support on:

- *fear*: more than 70% has fear (for metastasis, physical suffering, death, treatments), 25% needs more professional attention for it[120];
- *frustration*: 80% (because they couldn't do what they did before)[120];
- *depression*: 71% has a depressed mood, more than 20% was suffering *from a mood disorder (60% not recognised by GPs)*[81]. There is a higher prevalence of mood disorders in people with a language barrier .[118]Women, patients living alone and single patients had higher proportions of unmet needs for emotional support (resp. 68% versus 40%; 91% versus 46% and 70 versus 42%)[94].

Coping

- 85% has difficulties with the unpredictability of the future, and 25% needs more professional attention for it[120];
- Patients felt unable to share distress with family, friends or professionals[115];
- Patients actively withhold reality of suffering from their loved ones to avoid burdening and distressing them[81] while others report they would contact friends and family, rather than a professional[95];
- The possibility to deny[114].

Psychological support

Between 10%[125] and 54%[121] of patients have unmet needs for psychological support. Nearly two thirds (64%) of patients needs nursing care for psychological support[112]. On the opposite, only a minority report a need for psychosocial care[128].

Osse et al. described patients' difficulties for accepting the disease and expressing their disagreement[120]. Patients have the feeling they lose control over their body and life (65%)[120].

Fungating wounds are caused by tumour infiltration of the skin, gif of a smell and exudate. This may lead to loss of control over bodily function, and a progressive loss of self-image. Palliative wound care, comprising the combination of symptom control and wound dressings, could restore the body boundaries, resulting in a patient's regain of autonomy[84].

In a hospice setting psychological problems (guilt, stress, fear, anger, anxiety, grief, and spiritual distress) are perceived as severe, whereas physical, social, health related and environmental problems were perceived as mild.[119]

Patients with unmet needs showed significantly higher psychological distress[94].

Psychological support for family

Furthermore, patients worry about how carers would cope[115]. The psychological support of family members requires nursing care needs in 73% of the cases[112].

Information provision and Communication

A timely and sensitive disclosure of diagnosis and a similar communication at each new phase of the disease are needs clearly expressed by the patients[126, 129]. One third of them complain about a lack of communication [124, 128].

SOCIAL NEEDS

Management of daily living

More than 85% of the patients experienced a problematic management of daily living, while 65 to 81% expressed to be in need for nursing care needs helping to overcome some barriers in daily living[120, 124]. Other authors also mentioned a need for assistance with activities of daily living[95, 122] as:

- heavy housework (cleaning, making beds, gardening)[112, 120,94];
- personal transport[120];
- shopping[120].

Almost three patients in four (72%) mentioned difficulties to give tasks out of hands and being dependent on others[120], while access to help could also be problematic as 10% of patients indicated to be in need for more help[128]. More than 6 patients in 10 (62%) had unmet needs for spending time usefully and carrying on some activities[94].

Financial support

Twenty-three percent[130] to 50%[127] of patients wanted more professional attention about extra expenditures[120].

Administrative support[120, 124]

Ethno-specific needs

The transporting of the body back to the home land has been mentioned[127], while patients with ethno-specific needs complain about poor professional support[127]. Patients who do not speak English fluently receive less optimal care. Successful management of palliative care requires a sensitivity to cultural differences, assessment of the patient's priorities and accurate identification of the symptoms.[118]

SPIRITUAL NEEDS

In general, unmet existential concerns were expressed in 54% of patients[121]. To sum up shortly, following spiritual needs were also mentioned in the literature:

- *Dignity*[113];
- *Divine*: for some patients, only religion did provide comfort occasionally[115]. Contact with the church was also important[124];
- *Hope:* the need for hopeful messages at all stages[129];
- *Meaning and purpose:* to feel joy and meaningfulness[94, 120, 122];
- *Resolution/death:*
  - Help with one's final responsibilities[114];
  - Awareness and acceptance of one's imminent death[114, 120];
  - Preparation has to be monitored[131].

HEALTH CARE SERVICES NEEDS

Home care

Most of palliative patients (50-70%) may prefer to die at home in the comfort of familiar surroundings[132]. However, this is not always possible since 25-50% of family carers would have been able to manage the patient at home if home respite services had been available[132]. For patients living alone, a 24/24 home assistant should be standing by[124, 130].

Easy access to care

Ten percent of palliative care patients indicate to be in need for more care than actually delivered[128]; some also complain about difficulties getting a second opinion besides the need for quickly responses to acute care when necessary[128].

Health care setting

Most patients would be informed by a doctor, if possible the family doctor[126].

Only 17% had received an explanation regarding the palliative care unit[126]

Coordination of care

Coordination of care has to be monitored[131] and here, inter-professional communication is of high importance[124, 133] but almost one patient in three (31%) mentioned a lack of communication between health care workers in the end of life care[128].

Discussion: needs of palliative patients suffering from cancer

The central concern of palliative cancer patients is "taking charge", meaning that these people are able to define and actualize their needs, with the position of control depending on their preferred means of achieving such outcomes[113].

The management of daily living and nursing care needs are frequent and create a feeling of dependency. Unmet needs also exist within these categories but concern a minority of palliative care patients.

Directing their own lives, one's own health and health care and directing matters related to be loved ones were expressed as important[96]. Patients felt a tension between the need to accept help and the desire for autonomy[95]. Patients expect from themselves to stay active and involved in events, even though they are in the final phase of their lives. They try to go on with their life, despite of the illness[114].

Palliative cancer patients are often dissatisfied with the communication process, especially at the disclosure of the initial diagnosis: playing it straight, staying the course, giving time, showing you care, making it clear, pacing information are important attributes. The same sensitivity is necessary at each new phase[129]. Patients have a need to discuss issues around death and dying, for some of them talking about death is very important, as it brings satisfaction and rest. Others ones do not wish to talk about death, or at least not too much and not with anybody[114]. It varies not just between individuals, but also for the same person at different times[95].

Conclusion

Unless the birth of the palliative care paradigm in the cancer area, today, cancer patients still experience a huge need for information and support. Since the diversity of any cancer expression in the human body, biological needs may differ even so. More than the simple need for explanations and understanding of the disease trajectory, there is a tremendous need for a sensitive and empathic delivery of this information. Also in the psychosocial and spiritual dimensions of care giving unmet needs remain. People suffering from end-stage cancer disease want to live independent as long as possible in their own surroundings and prefer to die at home where coordination and comprehensiveness of care do matter.

4.4.2.2 *Palliative care needs in patients suffering from heart failure*

Chronic heart failure affects approximately 10% of those aged 70 years and older in the UK[134]. The incidence of heart failure has been persistently raising, in part because of improved survival rates of those with cardiac disease as a result of new drugs and technological advances, and also because of the aging population[134]. With a mortality rate suggested to be 31-48% at one year from diagnosis and 76% at three years, heart failure has become a major cause of death[135].

The impact of chronic heart failure is wide-ranging affecting physical, psychosocial and spiritual aspects of an individual's life and raising issues of mortality, uncertain future, lifestyle modifications and complex medication regimes[134]. A major difficulty in caring for people with end stage heart failure is anticipating or predicting the trajectory of the disease process[134]. Often, death comes unexpected even in symptomatically stable patients, explaining an incidence of sudden death up to 50% in patients with NYHA class two and three[134]. Lacking any indication of an imminent death, confusion may arise as to when the heart failure is considered a terminal illness[134]. As such, people with chronic heart failure may live with more disability for a longer time than those with cancer and have to cope with uncertainty of dying suddenly[136].

Material

Initially seven papers were selected but two of them were excluded after reading. The five papers finally selected are described more in depth in appendix:

- One review[134] on spiritual care in end-stage cardiac failure;
- One prospective survey[137];
- Two studies[135, 136] with semi-structured interviews to explore the experiences of older adults with chronic heart failure;
- One prospective study with three-monthly interviews[108] with end-stage heart failure patients and their informal carers.

Results

Palliative care needs for patients suffering from advanced heart failure are summarized and grouped following the main 5 dimensions: biological needs, psychological needs, social needs, spiritual needs and health care related needs.

BIOLOGICAL NEEDS

Management of physical challenges

- *Breathlessness*[135, 136], most troublesome problem in 55% of patients[137]
- *Angina*[137]: most troublesome problem in 32% of patients[137]
- *Oedema*[135, 136]
- *Palpitations*[136]
- *Pain*[135]
- *Headaches*[136]
- *Constipation*[135]: most troublesome problem in 3% of patients[137]
- *Insomnia*[135, 136]: most troublesome problem in 11% of patients[137]
- *Fatigue*[135, 136]: 27% of patients[137]
- *Loss of energy*[135]: most troublesome problem in 27% of patients[137]
- *Falls*[136]
- *Anorexia*[135, 136]
- *Difficulty in walking*: most troublesome problem in 23% of patients[137]

Taking care for co-morbidity[108]

Multiple medications

- Diuretic medication[135]

Knowledge[136]

- Prognosis of the disease[135]

Seventy percent of these physical problems and 85% of specific cardiac problems could be documented in the nursing notes[137].

PSYCHOLOGICAL NEEDS

Emotional support on

- *Fear*[108, 134-136]
- *Anxiety*[134, 135], especially after an acute episode as myocardial infarction or sudden onset of pulmonary oedema[136]
- *Frustration*[108, 135, 136]
- *Depression*[134-136], most troublesome problem in 15% of patients[137]

Safety feelings

- Monitoring: knowing that the heart function was being monitored[136]

Information provision and Communication

- Better communication from their physician[135]
- Ways in which they could help themselves[136]
- Changing experiences from peer patients[136]

Preservation of autonomy and self esteem[108, 135, 136]

Twenty-six percent of the psychiatric problems could be documented in the nursing notes[137].

SOCIAL NEEDS

Help for activities of daily living[135],

More help was needed for household tasks according to 6% of respondents, washing and dressing (3%), cooking (1.5%), getting to the toilet (1.5%) or help with looking after other family members or children (1.5%)[137].

Need to remain as independent as possible[136]

Rely on others for help as aids for bathing and toileting, home help and financial help[108, 135] could be seen as the most troublesome problem in 20% of patients[137].

Prevention of social isolation[108]

Patients suffering from end stage heart failure requested for a prompt access to community support[108], also for their partners[135].

SPIRITUAL NEEDS

Love – belonging – respect:

- Continuation to give and receive love[108, 134]
- not be seen as a burden by relatives and friends[108, 135, 136]
- feel useful[108]

Divine

- Support of the church and in prayer[108]
- Affirmation of faith[135]

Hope – Peace

- hope and purpose[108, 134-136]

Meaning – Purpose

- The search for meaning[134]
- someone to listen to patient's life story and being comfortable in talking about dying and what gives meaning in life[108, 134, 135]

HEALTH CARE RELATED NEEDS

Globally, people suffering from end-stage heart failure asked for an improvement of the quality of their care[108].

Primary health care

Patients suffering from end-stage heart failure requested for an easy access of services[135] and primary health care. Within the final 4 weeks of life, 26% of patients had not seen their GP[137] and support from the district nurse was experienced only by 8%, from the physiotherapist also by 8%, from the dietician only by 5% [137]. Besides, the need of a psychologist in the multidisciplinary team was also described[136].

Early referral to community and social services through relevant healthcare professionals was requested[135], only 6% experienced any support from the social worker[137].

Respite care

People mentioned respite or provision of day care services[135].

Discussion: needs of palliative patients suffering from heart failure

Palliative care needs of patients living with heart failure are similar to those living with cancer, and yet there are fewer services available to them[135]. None of the patients in Horne's study[135] was referred to any specialist palliative care service. Despite expert medical care the most common symptoms experienced in patients with end-stage heart failure were breathlessness and an extreme lack of energy. Fatigue is the predominant symptom and breathlessness the primary reason for calling out the doctor or an ambulance[135]. Not being able to do even small tasks or get out of the house pervaded many of the patients' lives and influenced changes and experiences of loss in every aspect of daily living[135]. Difficulties in walking were identified as a major challenge in many patients[135]. Having to be dependent on others impacted on their role and those of carers, often causing an emotional impact on patients' lives[135].

However, patients face the challenges presented to them with stoicism. Some sources of support as GP, nurse and family tended to be underutilized by patients worried about being a burden or unable to reciprocate support provided[136].

Spiritual concerns and needs of people living with heart failure are different from those living with lung cancer, reflecting a different illness trajectory of gradual physical decline punctuated by episodes of acute deterioration and often sudden death[108].

Conclusion

Palliative care needs of people suffering from end-stage heart failure do not differ significantly from those of cancer patients. While there might be some more specific, heart related biological needs, all other dimensions may reflect the same comments as seen in cancer patients: the need for a sensitive information delivery, for living at home as independent as possible, for spiritual support and coordinated home care.

4.4.2.3 Palliative care needs of patients suffering from respiratory diseases

According to WHO, COPD is currently the fourth leading cause of death in the world, accounting for 16% of all deaths in the UK[138] and 5% of total Dutch mortality[139]. Further increases in the prevalence and mortality of the disease can be predicted in the upcoming decades. Survival figures of patients suffering from COPD are worse than for many common tumours, yet the process and experience of those dying from this disease has received surprisingly little attention: little is known about the needs of patients witch chronic lung diseases at the end of life.

The last phase of life for COPD patients can be very long and indistinct since periods of stability or slow deterioration intersperse with potentially fatal acute exacerbations requiring hospital admission. Because of this unpredictable trajectory in end of life COPD patients, it is not easy making right prognoses, identifying precisely the start of the terminal phase of the illness, and introducing end of life discussions at an appropriate time[140]. As such it remains very difficult to determine what type of supportive care is most appropriate at what time.

Material

The 7 papers finally selected all report on specific palliative needs for patients suffering from end stage respiratory diseases (not lung cancer), mainly chronic obstructive pulmonary disease (COPD). One article explored the needs of patients with cystic fibrosis who are in the palliative phase of the illness[141]. All papers are detailed in appendix.

- Two reviews: Habraken et al.[139] reviewed heath care needs in end-stage COPD using Bradshaw's classification of needs. Jefferson[141] highlighted difficulties that might be encountered in the care of patients with end-stage cystic fibrosis;
- One survey[140] on healthcare needs of end-of-life COPD patients who deceased, using interviews of informants;
- Four last studies using qualitative methods[138, 142-144].

Results

Palliative care needs for patients suffering from end-stage respiratory diseases are summarized and grouped following the main 5 dimensions: biological needs, psychological needs, social needs, spiritual needs and health care related needs.

BIOLOGICAL NEEDS

Management of physical challenges

- *Breathlessness*[139]: "very much" present in 95%[143], in last year of life treatment received in 98%[140] though experienced as "very distressing" in 76%[138] and present in 91% during the final week of life[138];
- *Cough*: "very much" present in 31%[143], in last year of life treatment received in 80%[140] though experienced as "very distressing" in 46%[138] and present in 52% during the final week of life[138];
- *Pain*: "very much" present in 39%[143], in last year of life treatment received in 72%[140] though experienced as "very distressing" in 56%[138] and present in 63% during the final week of life[138]. 84% of patients with cystic fibrosis frequently reported pain with a marked increase in suffering in the terminal stages[141];
- *Mouth problems*: "very much" present in 55%[143], experienced as "very distressing" in last year of life in 19%[138] and present in 48% during the final week of life[138];
- *Anorexia*: no appetite "very much" present in 23%[143], in last year of life treatment received in 81%[140] though anorexia experienced as "very distressing" in 15%[138] and present in 64% during the final week of life[138];
- *Thirst*: "very much" present in 24%[143];
- *Constipation*: "very much" present in 19%[143], experienced as "very distressing" in last year of life in 65% and present in 25% during the final week of life[138];
- *Insomnia*: "very much" present in 23%[143], in last year of life treatment received in 77%[140] though experienced as "very distressing" in 42%[138] and present in 51% during the final week of life[138];
- *Fatigue*: "very much" present in 50%[143], and treatment received in last year of life in 96%[140];

- *Low mood*: in last year of life treatment received in 77%[140] though experienced as "very distressing" in 57%[138] and present in 55% during the final week of life[138];
- *Weakness*: "very much" present in 47%[143];
- *Sickness*: experienced as "very distressing" in last year of life in 39%[138];
- *Confusion:* experienced as "very distressing" in last year of life in 21%[138] and present in 26% during the final week of life[138].

PSYCHOLOGICAL NEEDS

Emotional support on

- *depression or anxiety*[139] in 90% of COPD patients, though only 4% received further assessment and treatment[142], resulting in feelings related to a sense of loss, and often connected to being unable to undertake roles that had once been an accepted part of life[143]. An overt fear of dying was only expressed by a quarter of patients, with particular fears of dying alone[144];
- *avoidance responses* as denial, distraction or suppression or sensitising responses when the sole focus of interests only is the illness[141].

Information provision and communication

Almost 8 patients out of 10 suffering from end-stage respiratory diseases (78%) received not enough information regarding prognosis or future management and as such felt unprepared for the current poor state of health[139, 142]; 30% felt that diagnostic information had been lacking or given insensitively[142]. Half of patients wanted further information, sometimes for managing their lives, half did not – either feeling that further information would not help, or through fear of what that information might be[144].

Coping

Thirty-one percent expresses a wish to die sooner, of these less than 20% expressed a wish for euthanasia[138].

SOCIAL NEEDS

Practical needs

Since great impact of the disease on daily life[139] and low level of social functioning[143] by restricted mobility[144], more help for maintaining social contacts was needed in 55% (help from social services, meals on wheels, help with household tasks, disability pension)[138, 140].

While 74% with COPD[142] to 87%[143] had any aids and appliances to help cope with their illness as orange badge for disabled parking (>50%), wheelchair (± 35% - 41%), bath aid (34% - 32%), chair lift (16%), walking aid (± 12% -64%) or sanitary aid (± 10%), 72% of patients reported a lack of information regarding the possible social benefits and services they could receive[139, 142, 143].

More of the patients with COPD (50%) then with lung cancer (32%) felt that they could benefit from a better provision of aids and appliances.

Thirty-six percent of patients was dissatisfied with the extent of the professional help from social services and other social agents[139, 142]. The nature of the performed task did not reflect the emotional and social needs of the individuals[143].

Also support needs of informal carers were hardly acknowledged or addressed[140].

Finances

Eighty pecent received some financial assistance from state benefits[143]; 40% felt that the financial support came late in the illness trajectory and was delayed from when they had first become eligible (often 2 – 4 years after diagnosis)[142].

SPIRITUAL NEEDS

It is important when caring for people who are terminally ill to be sensitive and to accommodate religious and spiritual needs[141].

HEALTH CARE RELATED NEEDS

Hospital care

Almost 40% of informants felt that deceased subjects who had been submitted to hospital had been discharged too soon[140]. Seventy-two percent of end-stage COPD patients die in hospital, while zero% in hospice. In hospital, only 43% of relatives were present at the deceased's death while 63% of who were not present would have liked to have been[138].

Palliative care services

Authors mentioned a lack of access for patients with end stage COPD disease[138, 142].

Primary care

Rates of contact with health professionals and planned interventions were low, and housebound patients were less likely to have had contact despite the greater severity of disease implied by their immobility[140]. Only 13%[140] to 39%[138] of patients suffering from end-stage COPD reported having received any nursing help. Of those who reported not having received nursing care at home, 35% mention some unmet needs for such care and those having received some nursing help at home, over a quarter mentions some additional unmet needs[138, 139]. More informants of subjects who died at home rather than in hospital felt that they died in the right place[140].

Discussion: needs of palliative patients suffering from respiratory disease

On the whole, "care" was evaluated well, though satisfaction with care did not always reflect care/service delivery that was appropriate to the needs of these people[143]. Most patients were even "very satisfied" about the medical care stating that they felt they were receiving all the treatment available, but that such treatment was limited in what it could offer to meet their physical and wider needs[142]. Though a majority of participants were in receipt of practical aids and financial benefits, most had to struggle to achieve this level of support[143].

Patients with severe COPD might benefit from a palliative approach. An obvious disparity between COPD patients and lung cancer patients is that patients with lung cancer had already access to specialist palliative care services whereas those with COPD did not have an equivalent system of support. Therefore, the patients with COPD experienced a lack of regular needs assessment at home and their palliative care requirements remained unrecognised[142].

Most of end-stage COPD patients have a very poor quality of life in terms of emotional, social and physical functioning besides a high prevalence of unrecognised psychological disorder and unmet information needs. The complexity of patients' information requirements and the demonstrated failure to meet them confirms the primacy of communication skills in every day practice. Besides, a lack of knowledge on normative need became visible, showing that the knowledge about health care needs in end-stage COPD is still developing, and has not been implemented yet. Therefore, in guideline development, there should be more attention for patients' needs of care in the end-stage of the disease[139].

Patients with chronic (obstructive) lung diseases are more likely to be admitted to hospital acutely. The focus on acute exacerbations means that interventions are directed at crisis management, rather than reducing baseline symptom levels, with the result that people are always experiencing a high level of symptoms[143]. As death may not be predicted there may be little discussion of end-of-life decision making or care with either the patient or relatives. These sensitive discussions may need to occur in the context of a period of stability, rather in one of crisis[138]. The emphasis on acute care also has led to a fragmented service with obvious gaps within community care[143].

These needs are particularly visible in a lack of social contacts, a lack of (prognostic) information, a lack of attention for emotional problems and in a lack of possibilities to die at home[139].

Conclusion

Palliative care needs of people suffering from end-stage pulmonary disease neither differ significantly from those of cancer patients. With respect to pulmonary treatment, people understood that unless remaining suffering, all available treatments were given. When lung cancer patients might benefit more from palliative care, this is not always the case in COPD patients. The difficulty in chronic pulmonary patients is to define the end-stage given the numerous exacerbations and hospital admissions where the focus is on crisis intervention, rather than quality of life.

4.4.2.4 Palliative care needs of patients suffering from muscular- and neurodegenerative diseases

Muscular and neurodegenerative diseases are all characterised by a progressive trajectory with no known cure. Recently, medical technology and science contributed to improved survival rates for people with these degenerative diseases of which the impact on daily life is substantial. But lifespan of these patients is limited with long periods of dependency. Here, life is characterised by a continuous readjustment to an ever changing level of ability, striving for a better quality of life, without any hope of healing or even cure.

The most appropriate timing to offer a palliative approach is here a sensitive issue given the length of these disease trajectories and the common correlation between palliative care and end-of-life issues. Likewise, the extent to which a palliative approach to care may be helpful for these patients and their caregivers, however, has not yet been well documented.

Material

The 12 papers selected for this section refer to specific pathologies (alphabetically):

- Motor Neuron Diseases[145] and more specifically Amyotrophic Lateral Sclerosis[146, 147];
- Huntington's disease[148, 149];
- Multiple Sclerosis[150];
- Muscular dystrophy[151, 152];
- Parkinson's disease[153];
- Systemic sclerosis[154];
- and a combination of these[155, 156].

The results are based on these 12 papers of which: 2 clinical reviews[145, 149], 3 surveys[146, 155, 156], 6 qualitative studies[147, 148, 150-153] and 1 case study[154].

Results

Palliative care needs for patients suffering from these end-stage muscular- and neurodegenerative diseases are summarized and grouped following the main 5 dimensions: biological needs, psychological needs, social needs, spiritual needs and health care related needs.

BIOLOGICAL NEEDS

Management of physical symptoms

- *Speech*[153] and *communicating*[146] facilities;
- *Ventilatory support*[146, 152];
- *Fatigue and tiredness*[155, 156];
- *Insomnia*[146];
- *Pain*, experienced as frequent and severe[146];

- *Discomfort* other than pain[146].

For 76% of patients[146], the major goal of care was relieving pain and discomfort as much as possible, even if it meant shortening of life.

PSYCHOLOGICAL NEEDS

Support on

- *Anxiety and depression*[146, 155, 156].

Information provision and communication

Information need to be provided in a timely fashion with sensitivity to the individual and the needs of families, but too much information following diagnosis was considered stressful[147, 148].

Empathic illness announcement was shown to take time and support, and was challenging for the whole family[147, 148, 150, 153].

Addressing end-of-life issues need to be done in due time, ranging form dilemmas relating to the physical effects of deterioration to major ethical decisions associated with choice of care setting and (dis-)continuation of treatment[149].

Coping

People suffering from life threatening musculo- and neurodegenerative diseases need special attention for their coping with accommodating losses (especially personal independence and employment) and incorporating unwished changes into their lives (giving up work, having to modify lifestyle,…)[150].

SOCIAL NEEDS

Practical needs

- Management of daily living activities as personal care, finances, medications, hygiene, dressing, toileting, bathing, shopping, cooking, …[146];
- Housekeeping[146, 155, 156];
- Transportation for social activities, shopping, and support groups …[155, 156];
- Socialising and staying connected[153].

Informal carers suggested that sometimes professionals have little knowledge and experience of the specific needs of their beloved ones[148] where especially practical support from many sources are so necessary[153].

Individual wellbeing related more to the importance of social support than to physical function. Here, people with advanced motor neuron disease were significantly more likely to nominate life domains in relation to the psychosocial and care aspects of their illness as important to their wellbeing as opposed to physical functioning[145].

There also appears to be a need for a sibling support group both during the chronic illness trajectory and in bereavement[152] where, a good support network among parents was considered particularly important[152].

Finances

- Finances/bills/accounts[146, 155, 156];
- Monetary difficulties and frustrations with the funding system i.e. for home modifications[148, 153].

SPIRITUAL NEEDS

Love – belonging – respect

- respect to losses and compromises that patients encounter[150];
- Confiding in someone (stronger for relatives than for patients themselves)[147]

Meaning and purpose

- Defining meaning and purpose of suffering since mainly negative thoughts related to death are prominent for patients and limited future perspectives for relatives[147];
- Trustful future perspective because of a general sense of struggle with costs of mediations, equipment, transport and necessary home modifications[148] patient involvement.

Resolution and death

- Advance directives[146, 152].

HEALTH CARE RELATED NEEDS

Comprehensive care

Patients suffering from end-stage muscular and neurodegenerative diseases urge coordination and collaboration of clinical and social care, with ongoing communication between palliative care professionals and disease specialist advisers[149]. They plead for early access to expert multidisciplinary care, with competent professionals[147], empowering patients and their families through the introduction of information that may lead to managing future care needs[149], besides suitable supportive care interventions, appropriately skilled health professionals, and supportive care environments as the disease progresses[153].

Especially for the management of rare diseases it is necessary that all carers bear adequate levels of expertise and education[152] and have the ability to use agreed standards of care and planned care pathways so that a vital proactive care management is possible[149]. An ongoing evaluation of care is imperative[149].

Patients clearly wanted one physician who could provide the entire medical care needed[152].

Home care

Home services were identified as a major source of support[148]. Patients request for continuity of home care workers, familiar with them and having the trust of the family as the disease progresses and the families' needs increase[148]. Hardly to understand for family carers was the reluctance by care agencies for their carers to become emotionally attached to their clients, leading to permanent rotation of carers[152].

Informal carers need to replenish their reserves to continue in the care giving role[148].

Respite care

Respite care will be satisfactory if characterised by availability when needed and providing an excellent standard of care[148].

Palliative care

Patients suffering from end-stage muscular and neurodegenerative diseases request clearly defined and appropriate easy accessible palliative care services[150, 152].

Discussion: needs of patients suffering from muscular and neurodegenerative disease

Individuals and their family members endure many losses and challenges associated with chronic muscular- and neurodegenerative diseases. Patients make every effort to manage on their own and try to find their own coping strategies in order not to depend on help but the need for an increasing practical and emotional support is apparent. Some authors recommended involving palliative care services early but events that might trigger the introduction of palliative care are rarely described[155]. So, challenges remain about how and when a palliative approach to care might best be offered to individuals with muscular and neurodegenerative diseases whose illness trajectory may be long and uncertain.

At the end of their disease trajectory, ill and dying patients value adequate pain and symptom management, control, independence, strong relationships, and completion. They seek to prepare for death, contribute to others, and avoid prolongation of dying. In global, chronic and incurable patients may also benefit from more aggressive symptom control in the terminal period. Though most patients receive morphine, dyspnoea, pain and insomnia remain striking prevalent. For every symptom except confusion, over half of the patients experienced moderate to severe levels of the symptom in the last month of life. About one in three caregivers expressed dissatisfaction with some aspect of symptom management[146]. Because of caregiver burden, depression of family caregivers is a particularly significant concern.

The required supportive care for patients and their informal carers falls into two main categories of care providing:

- providing psychological support such as care education and counselling, including accurate information;
- flexible and individualised practical support, including financial support, ranging from in home support with constant carers and prevention of social isolation, to various levels of short- and long-term residential care, including high level care during the last phase of life.

Services most frequently received by patients and equally reported by carers were community rehabilitation, home care and respite care. The four support services that rated high in importance by both carers and patients were: information about disease, equipment for daily living, reliable and ongoing dependable support workers and financial assistance for care[155]. It is important to consider both patients' and their caregivers' views on the needs as far as accommodation, respite and day care are concerned, since these views might be different or even opposing.

Services may be required over many years of caring, but they should also be available at short notice as crises cannot always be predicted.

Two key issues that should inform service provision are

- the need to ensure that both psychological and practical supportive care are adequately choreographed and flexible enough to suit individual circumstances;
- the need for service providers to demonstrate the expert knowledge and care required such as behaviour management, family support, nutrition, swallowing, and communication as well as the provision of a safe, comfortable environment that remains homelike.

In this sense, real helpful nurses and doctors were those who provided useful information and were their when needed, for people and their families. An individual case management approach is likely to be most useful in catering for the differences among individuals[148] seeing that patients and their close relatives should be viewed as individuals with their own individual preferences[147].

Conclusion

People suffering from end-stage muscular- or neurodegenerative disease also feel the need for palliative care. Characteristic for these diseases is the length of the suffering without any specific treatment asking for considerable psychological support. Symptom control seems to be problematic. The rarity of the disease asks for particular coordination and collaboration between all health care providers. Comparable with other patients in end-stage suffering, also these people ask for maximal independency and adaptations in their homes making it possible for living there lives there.

4.4.2.5 *Palliative care needs in patients suffering from neurological diseases*

In this section palliative care needs in different neurological settings are described. The population includes patients with intellectual disabilities, patients with dementia (including Creutzfeldt-Jacob disease) and patients with stroke, another neurological cause of dependency with physical (and sometimes intellectual) disability. An illness with intellectual disability raises difficulties as symptoms may be ignored because of unclear expression although those patients and their relatives need adapted palliative care support[157].

Dementia is a progressive irreversible clinical syndrome evidenced through a set of symptoms lasting for at least six months, which classically include a decline in memory with consequences that impair functioning in daily living[158]. There are many types of dementia resulting from a variety of disorders but Altzheimer's disease is the most common form.

Prevalence of dementia increases with age (from 1 in 1000 at age 40 – 65 years to 1 in 5 over age 80 years) and the median length of survival from diagnosis to death is 8 years[159]. The number of patients suffering form dementia is expected to double over the next 50 years[159]. The disease trajectory of dementia makes identification of the terminal phase very difficult, but it is often hallmarked by increasingly frequent infections, disability and impairment[159]. The disease affects older people who already accumulated many other co-morbidities, resulting in an overall poor health status[159].

Creutzfeldt-Jacob disease (CJD) is a rare specific variant of dementia (estimated incidence of 0.5 – 1 new case per million). Clinical features are rapidly progressive dementia, myoclonus and cerebellar and visual dysfunction, resulting in death within a few months of onset. Rapid deterioration in clinical condition, stays in multiple care settings and late diagnosis are common and may occur in a short time, resulting in a confusing and stressful experience for the person and the family involved.

Stroke is the third most common cause of death with 150.000 people having a stroke in the UK every year. It is the single most common cause of physical or mental disability, with more than 300.000 people living with moderate to severe disabilities caused by stroke[160]. Preferences of stroke patients and their families in relation to palliative care are largely unknown[160].

Material

Initially, 7 papers were selected in this section: 6 came from the UK/Ireland[157-162] and 1[163] from Australia.

- 5 papers were reviews of literature:
  - palliative care needs of people with intellectual disabilities[157, 162];
  - palliative care needs for people with dementia[158, 159];
  - palliative care after stroke[160].
- Two qualitative studies on patients suffering from CJD[161, 163].

More details on these papers are in appendix.

Results

INTELLECTUAL DISABILITIES, DEMENTIA AND CREUTZFELDT-JACOB

Palliative care needs for patients suffering from intellectual disabilities, dementia or CJD are summarized and grouped following the main 5 dimensions: biological needs, psychological needs, social needs, spiritual needs and health care related needs.

Biological needs

Management of physical symptoms

- *Pain*[158, 159, 161, 163]
- *Discomfort characterized by non-verbal pain* indicators using vocalisation, grimaces, bracing, rubbing, restlessness and verbal complaints[159, 162]
- *Dysphagia*[158, 161] necessitating careful assessment of the swallowing reflex to reduce the risk of aspiration[163]
- *Pyrexia*[163], even in the absence of diagnosed infection, causing or exacerbating agitation and restlessness
- *Profuse sweating*[163]
- *Dehydration*[158]
- *Mouth care*[163]
- *Shortness of breath*[163], perhaps exacerbated by muscle spasms in neck and face
- *Incontinence*[158, 161] causing agitation, restlessness and distress[163]
- *Constipation*[163]
- *Insomnia*[158, 161]
- *Tremor*[158]
- *Apraxia*[158]
- Slowness of movement[158]
- *Deafness*[161]
- *Cortical blindness*[161]
- *Myoclonic jerking*[161, 163]
- *Extrapyramidal signs* as seizures[163]
- *Spasticity* and hyperreflexia[161, 163]
- *Sensory disturbance*[163]: hypersensitivity to touch and environmental noise. Therefore, a quiet and restful environment where soft, familiar, classical music may have a place[163] can be favourable

Regular medication review might be advantageous to withdraw superfluous medication[159].

Knowledge

- Information about rare diseases[161, 163]

Psychological needs

Importance of early[163] support on

- Depression[158, 161]
- Various levels of awareness[163]
- Hallucinations[158, 161]
- Delirium[158]
- Paranoia[158]
- Aggressiveness[158, 161]
- Anxiety[158, 161]
- Frustration[158]
- Family distress[161, 163]
    - people were shocked, anxious and upset by the rapid deterioration[163]
    - fear of inheriting CJD[163]

- o desperation[163]

Information provision and communication

- Unequivocal information[163]
- Communication[158, 159, 161, 162]
- Understanding by carers of alternative communication manners as non-verbal signs and behaviours[162]

Bereavement support[158]

Families of people suffering from rapidly progressive intellectual disabilities were assessed as being at high risk of developing complicated grief reactions because their traumatic experience[163].

Social needs

Practical needs

- Activities of daily living[158]
  - o shopping[158]
  - o food preparation[158]
- Personal care[158]Prevention of social isolation[159]

Finances

- Finances[158, 159]

Spiritual needs

Love – belonging – respect

- Dignity[158, 161]

Divine

- Religious aspects of care[158, 159]

Resolution and death

- Less advance care planning in patients with dementia compared to those without[159]

Health care related needs

Comprehensive care

Patients and their carers request for a multidisciplinary approach[158, 161] and the use of clinical care pathways[158, 159, 163], besides a substantial educational level of all health care providers[159]. There is an important need for continuity of care with consistency in assessment and intervention[163].

All health care providers need emotional support for themselves[162] and opportunities for debriefing and counselling[161, 163] besides reflexions on positive experiences[163].

Primary care

Primary health care providers are necessary to communicate with the family helping to overcome the problems associated with receiving inconsistent information[163].

Home care

After all, informal carers as family and friends[158, 159] are in need for support. The aim of home care must be the delivering of hospice quality palliative care in the patients' residence[159].

Respite care

- Respite care[159]

STROKE

Stroke mainly induces physical disabilities, sometimes coupled with intellectual ones.

Biological needs

Management of physical symptoms

- *Pain:* 5% of stroke patients had moderate to severe pain at one year after stroke and was reported as 'constant' in 14 of the 16 patients[160]
- *Incontinence*[160]

Psychological needs

Importance of early support on

- Low mood[160]
- Family distress: 88% reported adverse effects on their life[160]

Information provision and communication

- Unequivocal information[160]

Social needs

Practical needs

- Personal care: 43% of deceased patients required help with personal care[160]

Finances

- Finances[160]

Health care related needs

Home care

Only a third of caregivers felt the experience that having cared for their beloved ones themselves had been rewarding[160].

Discussion: needs of palliative patients suffering from neurological diseases

This discussion mostly describes palliative care for people with intellectual impairment as much less papers described needs for stroke patients.

Needs for the dying person with dementia has been a relatively neglected topic in relation to policy, planning, practice development, and training. Especially, the identification of the palliative phase is important here for a number of reasons: to plan care, to prepare the family and carers for the end of life and make provision for adequate terminal care[159].

There are significantly gaps in professional knowledge, skills, and expertise[158]. Major deficiencies in palliative care for people with dementia are poor symptom management, lack of advanced care planning, poor access to specialist palliative care, difficulty in predicting prognosis, and lack of clinical research[159]. Palliative care needs of patients with dementia are often poorly addressed; symptoms such as pain under treated while these patients are over subjected to burdensome interventions[159].

Communication efforts are necessary to understand people with intellectual disabilities who cannot express themselves properly especially in terminal phases of illness. A lack of meaningful communication can lead not only to poor quality of life but also a state of malignant social psychology[158], defined as a state diminishing the essence of personhood. The consequence is that the person's psychological needs are overlooked, communication becomes a low priority and care becomes a physical, task-oriented exercise leading to a bearing on the way the person feels and behaves[158]. Research showed that an awareness-context of the experience of chronic trauma related to separation, loss, powerlessness, displacement and homelessness is possible for a person with dementia[161].

For rare conditions as CJD, there is a need to develop clinical guidelines for health professionals and families to help understanding the rapid trajectory of the illness and providing successful palliative care[163].

Similarities exist between mental health and palliative care, particularly in relation to the psychosocial care approaches and the collaborative or partnership model[161]. Multidisciplinary working however may be inhibited by suboptimal communication between palliative care teams and specialists[160]. Also after stroke, a comprehensive service should include an integrated multidisciplinary team able to support caregivers[160]. A paucity of data exists in regard to the distinction between provision of palliative care needs and services for patients who die in the acute phase of stroke and for those patients who die later[160]. The physical care needs of stroke patients, in terms of the nature of palliative care interventions required, are likely to be very similar to those of patients with other conditions[160].

Conclusion

People with intellectual disabilities who accessed palliative care were unlikely to be offered the full range of services. Complementary therapy and hospice day-care were rarely offered[162].

4.4.3 Palliative care needs in a specific group: children and their carers

Today, there is growing recognition that too many children suffering from an advancing disease still undergo painful procedures and go through the symptoms without adequate relief, despite the fact that modern medicine has the means to relief their pain and improve most symptoms[164]. The needs of children with life threatening conditions and their families are unique and require special consideration to enable the appropriate delivery of multidisciplinary care that aims to relieve suffering and improve quality of life[165].

4.4.3.1 Material

The selection and description of papers is in appendix. Results were based on eleven papers covering different research methods and leading to a broad spectrum of palliative care needs for children and their carers:

- three reviews:
  - a literature review on palliative care in different phases of adolescence[166];
  - principles and model of care that emerged at a specialist's centre for adolescent care[167];
  - psychosocial and spiritual needs of children living with a life–limiting illness[168].
- three surveys[169-171];
- two qualitative studies[171, 172];
- three studies with mixed design techniques[165, 173, 174].

4.4.3.2 Results

According to the holistic concept of palliative care, the palliative care needs for children are summarized and gathered together in 5 dimensions: biological needs, psychological needs, social needs, spiritual needs and health care related needs, each dimension divided in different sub-dimensions if appropriate. Donneley's[173] included the following clusters of needs in his model based on concept mapping methodology: 1) pain, 2) decision making, 3) medical system access and quality, 4) dignity and respect, 5) family-oriented care, 6) spirituality and 7) psychosocial issues. Those 7 groups were included in the five domains used in the description of this literature review. This overlap explains why we kept our model that covered a broader scope of topics.

Biological needs

MANAGEMENT OF PHYSICAL CHALLENGES

- *Pain* management[168, 171, 175], effective in less than 30%[166], mean importance score of 4.76 [SD 0.595] for children and 4.85 [SD 0.414] for adolescents on a 5 point Likert-type scale[174]
    - effective: importance 4.90 / 5.00 and feasibility 4.07 / 5.00[173]
    - consistent: importance 5.00 / 5.00 and feasibility 4.22 / 5.00[173]
    - comforting athmosphere: importance 4.90 / 5.00 and feasibility 3.67 / 5.00[173]
- *Fatigue* (57–86% of patients)[166]
- *Reduced mobility* (76% of patients)[166]
- *Poor appetite* (71% of patients)[166] and gastro-intestinal problems controlled in only 10%[166]
- *Nutritional management* for child: unmet need according to 84% of carers for children with no-cancer disease[165], supported in the home: importance 3.70 / 5.00 and feasibility 4.22 / 5.00[173]
- *Dyspnea* (6-21% of patients)[166]
- *Sexual relationships* in adolescents[166], mean importance score of 3.56 [SD 1.019] for adolescents on a 5 point Likert-type scale[174]
- Involvement of adolescents themselves[167] or parents[175] in making decisions concerning the patient's treatment and care

Keeping the child comfortable was mentioned as an unmet need according to 86% of carers in non-cancer group[165] (importance 4.50 / 5.00 and feasibility 4.00 / 5.00)[173]. Also administering medications to the child was unmet according to 86% in non-cancer group[165] where assistance with medical management of child was unmet according to 87% of carers in non-cancer group[165].

Knowledge

- Information about the disease:[168], mean importance score of 3.30 [SD 1.002] for children and 4.13 [SD 0.869] for adolescents on a 5 point Likert-type scale[174]

Psychological needs

SUPPORT ON

- Fears and anxiety[165-168]
- Guilt[168, 174]
- Sadness over losses[168]
    - loss of control over owns body
    - loss of personal identity
    - loss of interpersonal relationships
- Depression[165]

INFORMATION PROVISION AND COMMUNICATION

A sensitive and satisfactory provision of medical information had a mean importance score of 2.97 [SD 1.154] for children and 4.16 [SD 0.852] for adolescents on a 5 point Likert-type scale[174].

- Having access to more disease specific information including palliative care: unmet need according to 50% of cancer group[165]
- Knowing what changes were made to child's treatment regime: unmet need according to 82% of family in non-cancer group[165]
- Knowing ways to deal with changes in child's ability/activity levels: unmet need according to 41% of carers of cancer group[165]

Parents of children in their last phase of life indicate an importance on the possibilities to participate in the decision making process of treatment and palliation.

- Children own control over treatment decisions: mean importance score of 3.66 [SD 0.943] for children and 4.61 [SD 0.589] for adolescents on a 5 point Likert-type scale[174]
- Knowing what treatment child receiving: unmet need according to 93% of family in non-cancer group[165]
- Explanations of care options, benefits and burdens: importance 4.50 / 5.00 and feasibility 3.78 / 5.00[173]
- To have a say in the treatment plan: importance 4.50 / 5.00 and feasibility 4.00 / 5.00[173]
- Assessment of personal goals of care: importance 4.30 / 5.00 and feasibility 3.89 / 5.00[173]
- Assessment of perceptions of burdens and benefits of care: importance 3.90 / 5.00 and feasibility 3.44 / 5.00[173]
- The right to say "no": importance 4.50 / 5.00 and feasibility 3.89 / 5.00[173]

They indicate a need for an open respectful communication with the health care team…

- Clear, adequate and caring communication regarding treatment or prognosis[167, 168, 171, 172, 175]
- Unequivocal information and recommendations[172, 175,168] mean importance score of 3.98 [SD 1.046] for children and 3.94 [SD 0.954] for adolescents on a 5 point Likert-type scale[174]
- Not being dismissed nor patronized by staff members[171, 175]
- Structured conversations: mean importance score of 3.20 [SD 1.062] for children and 3.87 [SD 1.007] for adolescents on a 5 point Likert-type scale[174]
- Directly with the child when appropriate[168]
- Being informed of changes in child's condition: unmet need according to 59% of families of cancer group[165]
- Preparation that bad news is coming[175]
- Sensitive delivery of bad news[168, 171, 175]
- Timely discussions about end-of-life decisions: mean importance score of 3.71 [SD 1.047] for children and 4.11 [SD 0.900] for adolescents on a 5 point Likert-type scale[174]
- Straightforward non-technical language[167, 175]
- A familiar person to deliver difficult news about diagnosis, treatment and prognosis[171, 175]

… and request even so an open communication with relatives and friends

- Ability to talk freely about fears and feeling: mean importance score of 4.58 [SD 0.692] for children and 4.63 [SD 0.599] for adolescents on a 5 point Likert-type scale[174], with a competent professional: family focused care: importance 4.20 / 5.00 and feasibility 3.89 / 5.00[173]
- Assistance with telling parents / siblings his concerns: mean importance score of 4.06 [SD 0.876] for children and 4.11 [SD 0.847] for adolescents on a 5 point Likert-type scale[174]
- Assistance with talking to friends: mean importance score of 3.43 [SD 1.011] for children and 3.60 [SD 0.909] for adolescents on a 5 point Likert-type scale[174]

BEREAVEMENT SUPPORT

- Evidence based, integrating loss and grief theory[168, 170]
- Consistent follow-up[166, 175]

- Continued contact with hospital staff after the child's death by phone, mail, or in person[170, 171, 175]
- Targeted specially to fathers or siblings[170]
- Assistance with funeral arrangements: mean importance score of 2.44 [SD 1.092] for children and 3.22 [SD 1.062] for adolescents on a 5 point Likert-type scale[174]

COPING

- Help to cope with child's condition: unmet need according to 50% of carers in cancer group[165]
- Supportive counselling: mean importance score of 3.48 [SD 0.947] for children and 3.99 [SD 0.812] for adolescents on a 5 point Likert-type scale[174]
- Play therapy that focuses on illness-related topics: importance 3.70 / 5.00 and feasibility 3.89 / 5.00[173]
- Self relaxation skills mean importance score of 3.23 [SD 0.969] for children and 3.53 [SD 0.931] for adolescents on a 5 point Likert-type scale[174], importance 3.20 / 5.00 and feasibility 3.67 / 5.00[173]

Social needs

NORMAL LIVES

Dying children and their families are in need for living lives as normal as possible[172] (mean importance score of 4.24 [SD 0.879] for children and 4.05 [SD 0.959] for adolescents on a 5 point Likert-type scale[174]), but seen as unmet need according to 31% of carers of cancer group[165], importance 4.20 / 5.00 and feasibility 3.22 / 5.00[173].

- Being relaxed at home, having contacts with siblings, enabling other siblings' activities to continue, being able to have friends visits, spending time together as a family[172]
- Companionship: mean importance score of 4.16 [SD 0.971] for children and 4.42 [SD 0.733] for adolescents on a 5 point Likert-type scale[174]
- Join sports and summer camps[169]
- Have trips and experiences[167]
- Knowing about school/day care options: unmet need according to 91% in non-cancer group[165]
- School interventions: mean importance score of 3.33 [SD 1.130] for children and 3.34 [SD 1.094] for adolescents on a 5 point Likert-type scale[174]
- Sit exams[167]
- Peer group socializing[166], importance 4.10 / 5.00 and feasibility 3.78 / 5.00[173], importance 3.90 / 5.00 and feasibility 3.56 / 5.00[173]
- Facilitation of preferences/goals for social interaction: importance 3.60 / 5.00 and feasibility 4.00 / 5.00[173]

Also siblings are in need for appropriate attention[166, 168, 175]

- Kindness and attention from staff[165, 175]
- Clear and unambiguous information on the disease status of their sibling[166]
- Access to playgrounds during hospital visits[175]
- Support groups[175]
- Taking part in the leaving process and the preparations of the funeral[166]

… as are the parents of the sick children themselves

- Support in personal relationships aiming to prevent divorce and separation[165]

- Parents who are mentally healthy and functionally under stress: importance 4.30 / 5.00 and feasibility 3.33 / 5.00[173]

FINANCIAL

- Knowing what financial assistance was available: unmet need according to 25% of cancer group[165]

CULTURAL

- Cultural sensitive care: importance 3.60 / 5.00 and feasibility 3.44 / 5.00[173]

Spiritual needs

LOVE – BELONGING – RESPECT

- Being accepted as you are[175]
- Clearly valued as an individual: importance 4.40 / 5.00 and feasibility 3.67 / 5.00[173]
- To be assured that (s)he is important and will be remembered: importance 4.60 / 5.00 and feasibility 4.22 / 5.00[173]
- Knowing (s)he won't be forgotten and will still be loved after death: importance 4.30 / 5.00 and feasibility 3.89 / 5.00[173]
- Privacy: importance 4.10 / 5.00 and feasibility 4.00 / 5.00[173]
- Maintain a sense of self: importance 4.50 / 5.00 and feasibility 4.00 / 5.00[173]
- Confidentiality: importance 4.20 / 5.00 and feasibility 4.11 / 5.00[173]
- Respect for spiritual issues[166, 168], mean importance score of 3.23 [SD 1.044] for children and 3.61 [SD 0.936] for adolescents on a 5 point Likert-type scale[174], importance 4.10 / 5.00 and feasibility 4.00 / 5.00[173]
- Preservation of the integrity of the parent-child relationship[168]

DIVINE

- Faith[168]
- Prayers: importance 4.70 / 5.00 and feasibility 4.78 / 5.00[173]

POSITIVITY – GRATITUDE – HOPE/PEACE

- Honesty: importance 4.60 / 5.00 and feasibility 4.00 / 5.00[173]
- Hope[175]
- Focus on the child's hopes/dreams: importance 4.10 / 5.00 and feasibility 3.67 / 5.00[173]
- Love: importance 4.70 / 5.00 and feasibility 4.78 / 5.00[173]
- Pleasant distractions from the situation: importance 3.90 / 5.00 and feasibility 4.00 / 5.00[173]
- Fun: importance 4.40 / 5.00 and feasibility 4.00 / 5.00[173]
- Laughter for release: importance 3.80 / 5.00 and feasibility 3.78 / 5.00[173]

MEANING AND PURPOSE

- Assessment and support of concerns around meaning, loss, and spiritual issues: importance 3.60 / 5.00 and feasibility 3.67 / 5.00[173]
- Create a personal legacy: importance 3.70 / 5.00 and feasibility 3.44 / 5.00[173]

APPRECIATION OF BEAUTY

- Art and music: importance 3.70 / 5.00 and feasibility 3.67 / 5.00[173]
- Creative expression: mean importance score of 3.69 [SD 1.006] for children and 3.68 [SD 1.002] for adolescents on a 5 point Likert-type scale[174]

RESOLUTION / DEATH

- To tell their stories[175]
- Opportunities to discuss such tragic events as the death of a child[175]

Health care related needs

QUALITY OF CARE

- Strictly followed standards in procedures and policies by care providers (as hand washing procedures and compromised immune system policies)[175]
- Honest, clinical accurate, compassionate and available care givers[175,171], importance 4.30 / 5.00 and feasibility 3.67 / 5.00[173]
- Knowing health care professionals are sincere about caring: unmet need according to 80% of family in non-cancer group[165]
- Consistent care givers[165], mean importance score of 4.29 [SD 0.963] for children and 3.94 [SD 1.043] for adolescents on a 5 point Likert-type scale[174], importance 4.20 / 5.00 and feasibility 3.11 / 5.00[173]
- Choice of where to die: mean importance score of 3.89 [SD 0.998] for children and 4.56 [SD 0.692] for adolescents on a 5 point Likert-type scale[174]

ACCESS OF CARE

- Ready access to staff[165, 168], also out of hours: unmet need according to 33% of participants in cancer group[165]
- Access to palliative care from the time of diagnosis without a time constraint: importance 4.60 / 5.00 and feasibility 3.44 / 5.00[173]

HOSPITAL CARE

- Managing travel and other distance issues: unmet need according to 81% in non-cancer group[165]
- Not spending hours and hours in clinics and waiting rooms: importance 4.10 / 5.00 and feasibility 3.22 / 5.00[173]
- Unlimited access to family as desired by the child: importance 4.40 / 5.00 and feasibility 3.67 / 5.00[173]

INTERDISCIPLINARY AND COMPREHENSIVE CARE

- Interdisciplinary care requiring everyone to work as a team in a focused way for each individual[166-168]
- Coordinated healthcare provided in a timely, convenient, and pleasant environment: importance 4.20 / 5.00 and feasibility 3.56 / 5.00[173]
- Knowing whom to direct questions about care: unmet need according to 44% of families in cancer group[165]
- Truth with colleagues and others[167]
- More paediatric trained nurses: importance 3.80 / 5.00 and feasibility 3.00 / 5.00[173]
- Empowerment of non-specialist staff[165, 172]
- Workforce planning (recruitment and retention of carer staff, community regard for care staff, adequate salaries for carers who often work 'unsociable hours' marketing of this caring profession, job prospects and managing inconsistent demands for services)[165]
- Care for the health care provider: importance 3.90 / 5.00 and feasibility 3.44 / 5.00[173]
    - Staff members need time to debrief after a patient's death and desired for ongoing support services and educational opportunities[171]

- Quality of life: importance 4.90 / 5.00 and feasibility 3.78 / 5.00[173]

COMMUNITY CARE

- Collaboration with community agencies in the provision of bereavement support[170]
- Long term accommodation services (especially related to non-cancer illnessess)[165]

HOSPICE CARE

- Community hospice programs need to be prepared to serve pediatric patients[165, 175]

HOME CARE

- Ability to transition in or out of the hospital as needed: importance 4.00 / 5.00 and feasibility 3.89 / 5.00[173]
- Trusting the health care system and have thorough information about how to care for child at home: unmet need according to 39% of families in cancer group[165]
- Ability for doctors and nurses to make home visits: importance 3.40 / 5.00 and feasibility 3.22 / 5.00[173]
- Family focused care: importance 4.40 / 5.00 and feasibility 4.00 / 5.00[173]
- Parent support: importance 4.10 / 5.00 and feasibility 3.78 / 5.00[173]
- Home care
  - To feel safe and secure[166, 168, 172], importance 4.20 / 5.00 and feasibility 3.67 / 5.00[173]
  - Being able to remain in familiar surroundings: importance 4.20 / 5.00 and feasibility 3.67 / 5.00[173]
  - As much time at home as possible (as little time in the hospital): importance 4.30 / 5.00 and feasibility 3.67 / 5.00[173]
  - Parents need control over outsourcing care possibilities[172]
  - Out-of-hours support where families were wary of using the services for fear of overstretching the little staff available and losing the service[172]

RESPITE CARE

- Available respite care[165]

4.4.3.3 *Discussion: needs of palliative patients - children and adolescents*

Palliative and end-of-life care for children and adolescents is qualitatively different from care for adults because of children's unique developmental needs, the untimely loss of human potential, the family's central role, complicated issues as pain control and symptom management, and the legal and ethical status of children[174]. A major difference that exists between adult and paediatric palliative care is the reality that children, despite serious and life-limiting illnesses, will often continue to progress through normal developmental stages. This means that a child's understandings of the illness will change over time and the issues causing distress will also change over time[168]. Parents and medical team members may not be prepared for changes or growth in cognition and emotion, and may continue to interact with a child at an earlier developmental level[168].

The three distinct populations of children who stand to benefit from improvements in palliative care are the following:

- those who are born without an expectation of survival to adulthood but who may live a long time with substantial suffering;
- those who acquire illnesses such as cancer;
- and those who suffer relatively sudden death caused by trauma[164].

In each of these categories, child and family needs differ.

Dying children and their families are in need for comprehensive services that offer a continuum of care based on a specific understanding of children's developmental needs and the specific psychosocial needs of not only the child but also the family system[174]. However, in most health care institutions serving children at the end of their lives, the transition from curative to palliative care lacks a comprehensive, coordinated and evidence-based approach[175].

After all, while medical treatment is essential in the management of patients with life threatening diseases, other aspects of their life should not be overlooked. A diminished social life is one of the major consequences of chronic illness and repeat hospitalizations. For children and adolescents, exclusion from school and recreational activities such as sports and summer camps are responsible for many of the psychological consequences of chronic illness as low-self-esteem, lack of confidence, and withdrawal[169].

The uncertainty about life prognosis caused anxiety for the families[172]. Preventable errors in procedures and/or careless comments disturbed families long after their child died[175]. Poor communication of important information could haunt parents and complicate their grief even years later[175]. Because many staff members reported feeling inexperienced in delivering bad news, an hypothesis could be made that the insufficient preparation of the staff members contributed to the families' negative experiences[171].

Care providers' duty in palliative care is to ensure as far as possible, that whilst painful, they ensure that no unresolved agenda remains and that the possible suffering as death approaches is therefore minimized[167]. As such, in palliative care practice it is common for doses to be escalated in a stepwise manner to control symptoms. The primary intent to control symptoms must be paramount[172]. Authors noted a discrepancy between high levels of pain described by parents and their belief that their child's pain had been treated "adequately" or "well" [175].

High quality paediatric palliative care programs need to be created to address all these specific physical and psychosocial needs of those children, mainly dying from cancer[174]. Today, WHO (1989) and the Australian Association for Hospice and Palliative Care (1994) have both provided definitions for provision of palliative care which state that support should continue to be offered to the family in their bereavement following the death of the patient[170].

The needs are as varied as the children and the families, no two situations have been the same or even similar. The most important factor is to carefully assess family needs and respond to their needs, not to what can be believed their needs should be[174]. Major attention should be given to the acquisition of maximal autonomy and decision-making competence and psychosocial and spiritual issues should be addressed[166]. A multidisciplinary team involving medical and nursing staff experienced in working with adolescents should take care of the child and his family to ensure a high quality of life and to give time to say goodbye[166]. It is important that health care providers continue to be involved in service provision once a child had died[170].

Helping children to die well and assisting families in coping with this devastating experience is the responsibility of health care professionals. Accomplishing this mission depends on the accurate identification of the physical, psychosocial and spiritual needs of dying children and their family members[168]. Every child and family has a unique experience of the end-of-life journey. From each experience, practitioners learn lessons about the physical, psychosocial and spiritual needs at the end of life that offer insights when caring for future families[168]. Lack of knowledge about these particular needs, besides lack of information about available services, patient dependency and carer fatigue may delay access to appropriate supportive and palliative care services for families of dying children especially with non-cancer conditions[165].

The death of a child is considered to be the most traumatic experience a family can suffer. Grief associated with the loss of a child as acknowledged as particularly intense with a high risk of complicated bereavement[170]. Bereavement support has been associated with reducing the likelihood of complicated grieving following a child's death[170].

Very little difference might exist between needs of families who chose to care for their child at home or in hospital care. Being able to spend time with their children was important, while aspects of care that made families feel safe and secure were equally important[172]. In the concept map dignity and respect form the most central cluster suggesting that these values should receive explicit attention in paediatric palliative-care program planning and evaluation[173].

A hospital liaison to community hospices, home care agencies, and families would be a beneficial addition to the services provided already[175]. Family members expressed the preference for one caregiver to be "in charge" throughout all phases of treatment[175]. The lack of a trusting bond with a primary caregiver was identified as a major source of dissatisfaction[175].

However, the focus of all families was on living normal lives, rather than dying[172].

4.4.3.4 Conclusion

Needs of children in palliative care are always distressing. A unique feature in the palliative care setting for children is the intense involvement of parents and siblings. Besides, children grow up and adaptation of the care process to their evolution is necessary. On the other hand, illness might move back the affected child in earlier emotional or even physical phases.

The social environment (home) and connections (as school and summer camps) in childhood seems of special importance. Therefore, even more than in other palliative care situations, continuum and coordination of care are imperative. Information provision is needed towards the child himself and his/her family as well, with specific communication skills.

Family members need time with their child, irrespective of the preferred place of death. After the child's departure bereavement support is hardly requested.

Palliative paediatric care programmes help to address all these needs properly.

4.4.4 Palliative care needs in miscellaneous settings

In this section remaining papers are considered, all reporting on palliative care needs in different patients and settings which could not be classified in the other chapters.

4.4.4.1 Material

In this section 31 papers were selected.

Eight papers (n=8) reported on specific palliative (supporting) needs for patients suffering from an incurable non-cancer disease, their informal carers and / or professionals:

- 3 reviews[176-178] listing biological and psychosocial needs;
- 5 studies with a mixed qualitative and quantitative design including patients suffering from end-stage heart failure, renal failure or respiratory disease[179], patients with chronic critical illness in intensive care units[180, 181], residents of aged care facilities[182].

The remaining 23 articles did not specify patient groups: 8 reviews[183-190], seven studies with a quantitative design[43, 191-196], four studies with a mixed qualitative and quantitative design[92, 97, 197, 198] and four studies used a purely qualitative approach: Wenrich[93, 199-201].

The details of these studies are in appendix.

4.4.4.2 Results

Palliative care needs of these patients are grouped following the main 5 dimensions: biological needs, psychological needs, social needs, spiritual needs and health care related needs.

Biological needs

MANAGEMENT OF PHYSICAL CHALLENGES

Prevention and relief of suffering is the chief goal of palliative care in a multidisciplinary setting that focuses on improving quality of life[188]. Patients with a non-cancer palliative diagnosis demonstrated a considerable symptom burden[43, 176, 179]. Physical symptoms as pain, dyspnoea, anorexia, vomiting and peptic ulcers are comparable or even more distressing than in cancer patients[177]. It was reported that two patients in three had difficulties to tolerate their physical complaints[176].

- Pain[177, 185, 191, 194, 197,196]: 2 patients in 5 had severe pain half of time in last 3 days[176], 71% of palliative residents of aged care facilities had pain[182], 86% of residents experienced pain during their last 3 months, 19% needed more treatment for pain[192]. Among patients aged 80 and over there were fewer interventions for pain[195];
- Dyspnoea[177, 191, 194, 197]: one patient in 4 had moderate or severe dyspnoea in the last 3 days[176], 32% of palliative residents of aged care facilities had dyspnoea[182], 75% of residents who died experienced dyspnoea at the end of life[182, 192]. Among patients 80 and over there were more interventions for dyspnoea[195]. Twenty percent of residents experienced suffocation during their last 3 months of life[192];
- Anorexia[177, 196] and dysphagia[194]: 51 – 57% of palliative residents of aged care facilities had dysphagia or anorexia[182, 192]; 4 – 8% of patients needs a feeding tube[194]. There is a significant age difference where compared to younger patients (< 60 year of age) aged people (> 70 years of age) do complain more from anorexia (49% versus 60%)[196];
- Nausea / vomiting[177, 194]: 20 – 26% of palliative residents of aged care facilities had nausea/vomiting[182, 192];
- Constipation[194, 196]: 75% of palliative residents of aged care facilities had constipation[182, 192];
- Fatigue / weakness[177, 196]: 55% of palliative residents of aged care facilities had weakness[182]: 52% of home residents had weakness in the last 3 months of life[192];
- Insomnia[186]: 25% of palliative residents of aged care facilities had insomnia[182, 192];
- Drowsiness: Patients >70 years had a lower prevalence[196];
- Oedema[194];
- Incontinence[191, 194, 197]: 59% of home residents had incontinence in the last 3 months of life[192];
- Urinary tract infections: patients over 70 had a higher prevalence[196];
- Bedridden more than 50% of time[191, 197].

INFORMATION

The need for more information on the expected disease trajectory is a priority for carers of patients with non-cancer diseases[97, 184]. In addition, there is also a need for information on the nature of the disease, changes in disease status, potential treatments and complications besides alternative treatments[92, 180, 181].

Depending on the underlying disease, information is requested on[92, 180, 181]:

- pain management[92],
- ventilator liberation[92, 180, 181],
- CPR / resuscitation[92],
- survival[92, 180, 181],
- functional recovery[180, 181],
- acceptable quality of life[92, 180, 181].

Physicians are the preferred sources for all this information provision[184].

Psychological needs

There is a generally accepted need for psychological support for patients in the last phase of life[97] since these patients feel a intense psychological distress[176, 177, 179], even more then cancer patients[177].

EMOTIONAL SUPPORT[199]

- Anxiety[177, 182, 196]: Patients 80 years and more experienced less interventions for anxiety[195];
- Depression[177, 191 43, 179, 182, 197]: higher prevalence in patients aged over 70[196];
- Feelings of guilt towards family[179];
- Acceptance[179];
- Compassion[199].

One third of dying nursing home residents needed more care for emotional and spiritual needs[192].

Prisoners felt lonely, hopeless and remorseful, because a substantial problem of funding and provision of enough (independent) health care workers; therefore, there is not enough emotional support in prison[190].

COPING[196]

Patients who were aware of the imminence of death emerged a positive attitude, expressing this as "*how can we make the best of it?*". They needed less diagnostic tests and treatments and had more informal care[202].

PSYCHOLOGICAL SUPPORT FOR THE FAMILY

The need for psychological support for the family and the informal carers was described[176] besides anticipatory grief[194].

INFORMATION PROVISION AND COMMUNICATION SKILLS

There is a clear need for sensitive, honest, unhurried and optimistic[92, 184, 188] information provision in understandable terms. A "multidisciplinary family meeting" might be an effective communication strategy[92, 180, 183, 184, 193]. Personal involvement on choices[97] and control[92] of people 80 years of age and older was problematic: there was significantly less communication concerning the goals of care with these persons, but more with their families[195]. Moreover, aged people experienced less possibility to participate in decisions about medical therapy[195] and their wishes in relation to their death[179]. Inter-professional communication and coordination was also seen as important[97, 124].

Social needs

MANAGEMENT OF DAILY LIVING

Most (87%) palliative patients need any kind of assistance or practical help[177] in the management of daily life[97, 179, 191, 196, 199, 203]. Palliative patients in prison need more nursing support[190].

Access to community activities was also mentioned as a social need[179] in the prevention of social isolation[177]. Patients were concerned about becoming dependent on others[92] and how their disease would affect the family carers[92] (mostly women as informal care providers)[191]. Extensive support towards these family carers is also imperative[179].

Other needs for daily living included:

- Body care / personal care[191]: unmet needs in 18,2%[191, 197,192];
- Transportation[191, 197, 203];
- Housekeeping[191, 203]: unmet need in almost 1 patient out of 4 (23%)[197].

ADMINISTRATIVE SUPPORT

Advanced AIDS patients needed client advocacy[203].

FINANCIAL SUPPORT

About 1 family out of 5 spend more than 10% of the household income on healthcare costs, depending of the care needs; 10-16% had to sell assets, take out a loan or obtain an additional job[179, 197]. For this reason they could discuss euthanasia or physician-assisted suicide[97, 197].

Others expected a serious financial burden because of their disease[92, 179-181, 197]. Emergency financial services are needed for advanced HIV patients in underserved populations (8-27%)[203].

ETHNO-SPECIFIC NEEDS

Ethnic minority patients expressed basic human needs rather then cultural-specific ones, such as religion, diet or family involvement. This suggests that stereotypical cultural care may not always be appropriate, as micro-cultures and individual diversity within cultures exist.[201].

Spiritual needs

Most GPs have a high awareness of the potential spiritual needs of their dying patients, and consider that they have a role providing care, but lack time and appropriate strategies to introduce the subject as part of their consultations[93]. Less than 40% of patients think that doctors should discuss spiritual issues[92].

As stated above, 30% of dying nursing home residents needed more care for emotional and spiritual needs[192].

Most patients want hope and positive attitude[199]. Patients need that their GP would consider them as a whole person with his/her unique interests or personality[199].

Health Care related needs

HOSPITAL CARE

Almost 1 patient out of 5 (19%) in residence care for aged people who died during study course had been hospitalized[182]. Specific curative treatment was maintained in 28% of patients[43]. Compared with cancer patients, aged people with non-cancer diseases had a significantly shorter stay in the hospital and were more likely to be discharged to a nursing home[195].

ACCESSIBILITY OF CARE

Most advanced HIV patients needs typically 5 medical services: ambulatory/out patient care, mental health services, oral health care, on site pharmaceuticals and laboratory services. Some needed more services. Mental and oral care services were not identified by staff. It is important to include a core set of services in a multidisciplinary approach in any program targeting AIDS patients from underserved populations[203].

HOME CARE

GPs and community nurses have a key role in the coordination and continuity of care[43, 124,97]. Compared to cancer patients, non-cancer patient were less likely to die at home or in a hospice despite of their preference. they were more likely to die in a hospital or a residential home[176].

HOSPICE CARE

Only 4% of residential aged people were involved with specialist palliative care[176] or a palliative care service[182].

4.4.4.3 *Discussion and conclusion: miscellaneous settings*

Palliative care needs in miscellaneous settings are very similar to those described in other chapters. Obviously, many palliative care needs are "universal", irrespective of disease or setting. Yet proportionally fewer resources are used to alleviate suffering in these patients than for patients with cancer[82]. In practice, an integrated approach to palliative care is essential also for these patients[97].

4.5 DISCUSSION AND CONCLUSIONS: NEEDS OF PALLIATIVE PATIENTS

This systematic literature search aimed to inventory needs in palliative patients suffering from different diseases and treated in different health care settings. To that end, different instruments assessing palliative care needs were found and mentioned in the text. It should be noticed that some of them (as the well known RAI-PC)[e] have been missed and would have required a specific search strategy that was not within the scope of this review. Needs of healthcare personnel, informal carers or services were out of the scope of this research project. We used different databases (PubMed, Embase, Cinahl, BNI, and Psycinfo) and searched for quantitative as well as qualitative data. Palliative care needs could be identified in five different disease groups (cancer, chronic heart disease, respiratory diseases, muscular and neurodegenerative diseases, neurological diseases) in children and for all palliative patients in the spiritual domains.

The authors created their own multidimensional framework to inventory all palliative care needs instead of using an existing taxonomy, as for example Maslow's[76] or Bradshaw's[78] taxonomy. The classification of needs was more adapted if linked to a well known and comprehensive approach as the bio- psycho-social model[204].

In general, palliative care needs are similar between patients at the end stage of any of these diseases. Palliative care provided to meet these needs can be seen as an example of holistic (bio- psycho- social, spiritual) and comprehensive (hospital, community, home, respite) care. All patients' needs were described using these different axes. Biological needs differ depending on the underlying disease, but the common need for all these patients is to reduce the physical complaints. More similarities exist in the remaining axes: globally, there is need for stepwise delivered information depending on patient's demand and for sensitive communication, psychological support for patients and their informal carers, family members or siblings. Practical support for activities of daily living should answer to recurrent social needs whose fulfilment would give to terminally ill patients an opportunity to live their lives as long as possible within a social framework. Patient's spiritual perceptions in all its dimensions (religious or not) also require a special attention. Though patients in an end stage of their disease request for a single, well known and trustful care giver (mostly their GP), they are very sensitive for collaboration and shared expertise between caregivers, irrespective of the care setting (hospital, home, hospice,…).

Most striking results were the bid for humour and positive thinking in the palliative care setting and the efforts of dying patients in order to avoid being a charge for their family care givers.

Although most of these needs are common to all patients and seem to be generic for the palliative care setting, the implementation of palliative care requires a tailored expertise, where individual needs assessment is performed by a trained health care provider aiming for high quality personal care giving. Optimal control of symptoms is important, besides continuity of care, communication and coordination.

As a result of the literature search it is quite impossible to state if the different needs are generally met or not. Meeting a need depends hardly on the individual perspective. A patient may assert that an imperative need was met whilst (informal) caregivers or acquaintances might report at the same time on that specific element as completely missing in the care delivery.

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[e] RAI PC: Resident Assessment Instrument – Palliative Care

Perhaps, this might be explained by the emotional commitment and subjective interpretation of different signs and signals by relatives and carers.

Difficulties often arise to define the terminal stage of the chronic disease trajectory and to start palliative care for diseases other than cancer. In the treatment of cancer, mostly, a relative stable episode is followed by rapid decline and distinct nearing end that triggers more intensive palliative care. This is not the case for other chronic diseases with unexpected exacerbations as for example heart failure or chronic pulmonary diseases. Their trajectory is much more unpredictable, making it more difficult to start palliative care appropriately. Similar results were reported in the survey further described in this report.

The results presented in this literature study are quite exhaustive as a result of the systematic comprehensive literature search in different databases with a large selection of quantitative and qualitative research papers. A content saturation encountered in the final lists corroborates this comprehensiveness.

Nonetheless, some critical points remain. First, most selected papers were published in English, besides some papers in French and Dutch. It is striking that research was mainly performed in USA, UK and the commonwealth besides the Scandinavian countries and the Netherlands, while research from other Western countries was seriously under represented. It is not clear if this is the result of a lack of research or of a publication selection bias.

Second, we did not perform any structured quality assessment of the selected papers as the papers were mostly descriptive quantitative and qualitative research results. Instead of focusing on the quality of these papers mainly published in peer reviewed journals, we tried to be as complete as possible in our search for palliative care needs.

Third, focus of research was patients' needs in terminal illness. As such, literature focusing on families' needs, (home) carers' needs, different health care services' needs or even pure medical topics as treatment options for any physical complaints was not considered.

Fourth, literature demonstrates a relation between (unmet) healthcare needs and the healthcare delivery within a healthcare system. For that reason, we added an additional axis in our bio- psycho- social and spiritual framework related to the health care system. As such, there might have been an advantage focusing the literature study on both aspects ("palliative care needs" and the "health care system") at the same time. However, by stressing solely on the palliative care needs and not on the health care systems, the mutual relation between both could not be described.

Therefore, a cautious interpretation of the results is necessary. The inventory is based on different types of research where needs were described according to different perspectives: sometimes distinct needs were described and assessed; sometimes the existence of unmet needs was reason for research. Some authors were interested in the patient's perspective; others one's described the carer's perspective on patients' needs. Our search reported all these different needs, independently of the source of information. Differences as mentioned here could not be traced in our summary tables in appendix.

Finally, a palliative care need mentioned in the literature does not always imply a professional intervention. On the contrary, often, the informal carers and the social framework are sufficient for assisting the patient through these needs. On the other hand, this illustrates the importance in the palliative care setting of the informal care giving which could be substantially supported.

5 DIVERSITY AND EFFECTIVENESS OF CARE MODELS FOR PATIENTS WHO NEED PALLIATIVE CARE

5.1 INTRODUCTION

Many health care structures are inadequate in meeting the needs of terminally ill patients and reducing the cost of care at the end of life[205]. Shortcomings in the medical, psychological, spiritual and practical domains of care have been described by experts[206] and researchers[207]. Many people die subsequent to unwanted care, in unrelieved pain with few or no discussion about their preferences for treatment[208].

Over the last 20 years specialized palliative care services grew worldwide, initially focusing on terminal cancer care, but increasingly including patients with cancer and other terminal diseases that are at earlier stages of their disease trajectory. This growth has occurred not only in terms of the number of specialist palliative care units, but also in the range of models of organization. Assessment of the effectiveness and value for money offered by palliative care models in different settings is now of prime concern to each health care system.

5.2 METHODOLOGY OF THE LITERATURE REVIEW

5.2.1 A review of systematic reviews

This chapter is based on a review of systematic reviews. The choice of this methodology allows both the assessment of systematic reviews on elements that cause diversity in palliative care models, as well as the individual models that are included in the reviews.

Formal meta-analytic pooling methods were not applicable due to the heterogeneity of interventions and outcomes included in the different reviews. This literature review is therefore a structured narrative synthesis including a discussion of the studies' characteristics and results.

This review of systematic reviews is to our knowledge the first one to provide a comprehensive overview of elements that create a picture of diversity in palliative care models and evidence on the effectiveness of these models in different health care settings.

5.2.2 Research question

The main research question of this literature analysis is: "What types of care models do exist for patients who need palliative care and what evidence is available on the diversity and effectiveness of these models?"

A palliative care model or program has been defined for this project as: "A service of professionals that provides or coordinates comprehensive care for patients who need palliative care" (adapted definition from Zimmermann et al. 2008)[209]. This definition is in line with the WHO (2002) definition[30] of the concept of comprehensive palliative care described in the first part of the literature review on definitions.

5.2.3 Search strategy

Four databases (i.e., MEDLINE, COCHRANE database of Systematic Reviews, the Cumulative Index to Nursing and Allied Health Database-CINAHL and EMBASE) were searched for papers published in English, Dutch and French between January 1990 and October 2008. This 1990 cut-off was chosen since most palliative care programmes were developed after the initial WHO definition of palliative care: "The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is the best quality of life for patients and their families"[210].

The search terms used referred to palliative care and focused on interventions in palliative care (health facilities, health personnel, health care organisation) and their evaluation. The search terms and detailed search strategies are in appendix.

5.2.4 Inclusion and exclusion criteria

This literature search included studies that described the evaluation of health care models for palliative patients.

Systematic reviews were rejected based on the following criteria:

- Title: references that did not deal with patients who need palliative care or were case reports, personal views, historical reviews, editorials, letters and duplicate entries.
- Abstract: other papers than systematic reviews.
- Study: systematic reviews were rejected if they did not report on a comprehensive approach to care that evaluated structural and/or organizational aspects and/or outcomes of palliative care. Studies that evaluated (the impact of) only one component of comprehensive palliative care on only 1 aspect of quality of life (e.g. impact of pain medication on pain) were consequently rejected.

Individual **studies** within the systematic reviews were rejected if:

- the study design was not a trial or an intervention study (i.e., papers that only provided a description of the service provision without any evaluation were rejected);
- the study did not provide sufficient information on clinically relevant elements including the type of care provided, the health care providers, the setting and the outcomes;
- the study did not include adults aged 18 plus;
- the study was published before 1990;
- the full text article was not available in official databases;
- the study was published in another language than English, French or Dutch;
- the study was not conducted in Western countries.

5.2.5 Data analysis

The review of systematic reviews followed the guidelines outlined by Grimshaw et al.[211] based on the Cochrane Effective Practice and Organization of Care Group (EPOC) Standards. A standardized form with 12 items (see form in appendix) has been created to assess the components and the effectiveness of palliative care models. This template was based on the data reviewer form proposed by the EPOC Group[212].

The items analysed in individual studies are:

- Country in which the study was conducted,
- Presence of a conceptual background,
- Type of research design,
- Type of objectives,
- Prognosis of the patient population,
- Type of care models in different settings,
- Type and number of populations targeted,
- Type and number of caregivers,
- Type and number of interventions,
- Type and number of needs addressed,
- Type of outcomes measures,
- Results on (cost)effectiveness.

5.2.6 Assessment of methodological quality

One reviewer (L.B) independently assessed articles for eligibility, extracted data and assessed the study quality. Any doubts on eligibility of the studies were discussed with the KCE project manager. The methodological quality appraisal of the reviews used the QUOROM (Quality Of Reporting Of Meta-analyses) statement checklist[213]. Researchers added to the results of the checklist a global critical appraisal that completed the answers to the 20 items (see appendix). The researchers did not perform the assessment of the methodological quality of the individual studies included in the selected systematic reviews. On one hand the source of papers (systematic review) had been selected e.g. on methodological grounds. Furthermore, efficiency and time constraints did not allow performing this huge additional task.

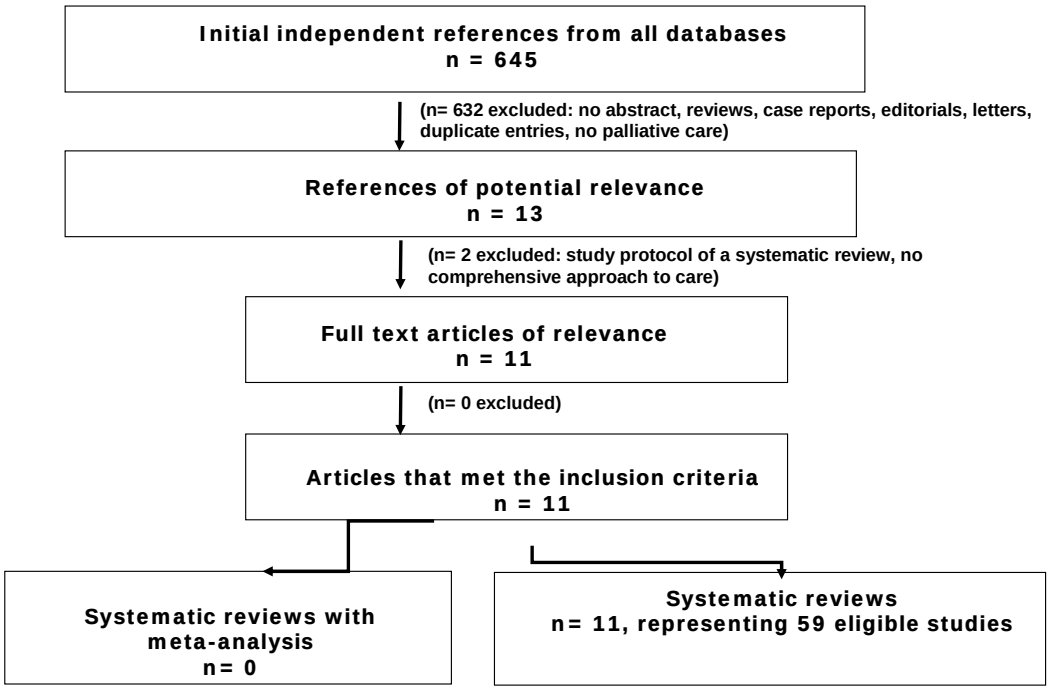
5.3 RESULTS

5.3.1 Selection of papers - flow diagram

The initial search identified **645 citations**, published between January 2000 and October 2008 (Medline database 366 hits, Cochrane Database 136 hits, Cinahl 71 hits and Embase 72 hits). After scanning titles of the citations and abstracts, 13 systematic reviews were selected for further screening and full text articles were retrieved. After examination of full text articles, 2 papers were excluded: the first one was a Cochrane protocol[214] and the second one was a review of papers on palliative care in GP without any focus on organization models[215]. Eleven (n=11) systematic reviews were included in the review[209, 216-225]. None of the systematic reviews presented a meta-analysis.

The 11 systematic reviews had a total of 187 references according to the inclusion criteria of the individual systematic reviews. One hundred (n=100) of these references were rejected following the criteria described above. After removing duplicate entries from the remaining 87 references a total of **59 studies** were selected for further analysis[205, 226-242105, 243-282].

QUOROM statement flow diagram: Selection and inclusion of studies in the review.



5.3.2 Characteristics of the studies selected in the analysis

Summary tables with the description of all included individual studies are in appendix to this chapter.

The paragraphs below summarize the design and objectives of the studies, the countries, the types of settings, the existence of a conceptual background, the target populations, the prognosis of the patients, the caregivers involved in the study, the types of interventions, the needs addressed by the care model, outcomes measures, impact on cost-effectiveness.

Type of research design

The most frequent designs were randomized controlled trials (49%; n= 29).

The other studies (41%; n=24) had different types of observational and descriptive research designs including e.g. prospective study designs, cross-sectional designs, interviews, and medical chart review processes. Controlled trials without randomization were used in only 10% of the studies (n= 6).

Objectives of the studies

Measurement of (cost)effectiveness was the goal most commonly cited in the different studies with only very few studies specifying other types of goals. Only 24% (n=14) of the studies reported on their objectives in terms of improvement in efficiency and/or coordination and/or, continuity and/or quality of care.

Countries where the studies were conducted

The countries where the studies were conducted are presented in the table below. Most studies were conducted in the UK and the US (both: n= 22), followed by Australia (n=5) and Norway (n=3). The researchers did not identify any study conducted within the Belgian health care system.

Table 2: Countries where the studies have been conducted

Countries	Number
US	22
UK	22
AUSTRALIA	5
NORWAY	3
THE NETHERLANDS	2
IRELAND	2
SWEDEN	1
ITALY	1
SCOTLAND	1
TOTAL:	**59**

Types of settings

The most common setting for the study of palliative care models is the home care setting (42%; n=25), followed by transmural care systems (31%; n=20) and the hospital setting (24%; n=14). The National Council for Public Health Care in the Netherlands described transmural care as follows: 'Healthcare, geared to the needs of the patient, provided on the basis of co-operation and co-ordination between general and specialized caregivers, with shared responsibility and specification of delegated responsibilities'[283]. In this review transmural care systems refer to service offerings that include two or more care settings involved in the organisation of palliative care services (e.g. hospital teams providing care at the patient's home or supporting caregivers in primary care).

Only one study was conducted in nursing homes[235].

One UK study analysed the impact of management in day care centres on symptom management and quality of life[242].

Table 3: Type of settings

Type of setting	Number of studies
HOME CARE SETTING	23
TRANSMURAL CARE SYSTEMS	20
HOSPITAL	14
NURSING HOME	1
DAY CARE	1
TOTAL:	**59**

Presence of a conceptual background

A conceptual background was mentioned in only 5 studies:

- definition of 'Quality of Medical Care'[230],
- 'Palliative Care Model/Hospice Model of Care'[232, 233],
- 'Trajectory Framework for Palliative Medicine'[261],
- 'Stress Process Model'[262].

Those studies relied on these conceptual models to define and guide the content of the care model presented.

Target populations

Cancer patients were mostly targeted in the different studies, including patients with e.g. breast cancer, lung cancer and prostate cancer. Twenty-six studies (44%) exclusively targeted cancer patients. Patient with HIV/AIDS were specifically targeted in 10 studies (17%). A limited number of studies targeted neurodegenerative diseases (n=3) or patients with heart failure (n=2). Multiple pathologies were targeted in 13 studies (22%). Five studies (8%) did not describe their patient population in detail and applied broad categories, e.g. 'geriatric patients with a chronic and life threatening disease'.

The type and number of the different pathologies (target populations) were similar when comparing the studies conducted in different settings (home care, hospital care, integral systems, day care and nursing homes). As an example, cancer patients were targeted in 65% of the studies dealing with home care (n=23), compared to 71% and 65% of the studies that were conducted in hospitals (n=14) and transmural care systems (n=20).

A full overview of the differences between studies conducted in the different settings is provided in appendix. These differences include pathologies, caregivers, needs, outcomes measured and results on effectiveness.

Table 4: Type of populations

Type of populations	Number of studies
CANCER PATIENTS	26
MULTIPLE POPULATIONS	13
AIDS	10
NEURODEGENENERATIVE DISEASES	3
HEART FAILURE	2
RESPIRATORY DISEASES	0
NOT SPECIFIED	5
TOTAL:	**59**

Prognosis of the patient population

The prognosis of the patient population was defined in 20 studies (34%). This prognosis ranged from less than 2 weeks to over one to five years life expectancy. One study defined life expectancy under a broad heading as 'limited life expectancy'. An overview of the different prognoses described in the studies is provided in the table below.

Table 5: Prognosis of the patient population

Prognosis of the patient population	Number of studies
TWO WEEKS OR LESS	2
TWO MONTHS OR LESS	1
MORE THAN THREE MONTHS	1
SIX MONTHS OR LESS	6
TWO TO NINE MONTHS	2
AT LEAST SIX MONTHS	3
LESS THAN ONE YEAR	3
ONE TO 5 YEARS	1
LIMITED LIFE EXPECTANCY	1
NOT SPECIFIED	39
TOTAL	**59**

Type and number of caregivers

A large variety of caregivers executed different tasks in the different care models. Multidisciplinary teams were present in 41% (n=24) of the studies. These teams consisted of different caregivers including nurses, home health aides, housekeepers, physical therapist, occupational therapist, mental health counsellor, primary care managers, assistants, social workers, volunteers, coordinators, secretaries, physicians, specialists, administrators, dieticians, occupational therapists, health technicians and welfare rights workers. Multidisciplinary teams consisted of a minimum of two persons over a maximum of 12 persons.

Nurses were the lead-persons in 41% (n=24) of the care models. Different labels were used including oncology nurses, advanced practice nurses, nurse case managers, clinical nurse specialists and nurse facilitators. Other caregivers who were less frequently involved as lead-persons to the different care models were family doctors (n=4), social workers (n=2) and clinical pharmacists (n=1). These caregivers often worked in liaison with multidisciplinary teams. Four studies did not report on the type of caregivers involved in the study.

The type and number of caregivers were similar between settings. However, nearly all models of transmural care systems relied on a multidisciplinary team. Nurses often had a leading role in studies conducted in home care settings compared to studies conducted in hospitals and transmural care systems (74% compared to 26% and 20%).

Table 6: Type of caregivers

Type of caregivers	Number of studies
MULTIDISCIPLINARY TEAMS	24
NURSES (CLINICAL NURSE SPECIALIST, ONCOLOGY NURSES, NURSE CASE MANAGERS, ADVANCED PRACTICE NURSES, etc)	24
FAMILY DOCTORS	4
SOCIAL WORKERS	2
CLINICAL PHARMACISTS	1
NOT REPORTED	4
TOTAL	**59**

Type and number of interventions

The different care models tested a wide variety of interventions. The most common ones were different types of nursing services including practical aid, counselling, education and coordination of services.

Other services provided were:

- Case management: including a supplementary level of care monitoring and direction provided by a nurse case manager. The case management encompassed comprehensive assessment, care planning, review of subject needs and services, ongoing case manager observation and monitoring of

subject reports of service quality, close follow-up of patient progress and service delivery was provided through telephone calls and home visits[268];

- Coordination of care: locating and arranging linkages to medical, practical and psycho-social services[252];
- Liaison activities between e.g. the family doctor and a multidisciplinary team[269], hospital and out-patient clinics[234];
- Hospital at home including practical home nursing care for up to 24 hours a day[243];
- After hours support and weekend nursing care with the aim to supplement existing community nursing provision[229];
- Technical medical help at home, including taking blood samples, sputum culture[266];
- Bereavement support[247];
- Psychological counselling[279];
- Educational activities for patients, such as health literacy, which is the capacity to understand basic health information[238];
- Educational activities for community staff including bedside training[252];
- Educational activities for family caregivers, including how to discuss experiences and expressing feelings towards sick relative[105];
- Development of a treatment plan[250];
- Advanced care planning services to identify patients' preferences with regard to palliative care[274];
- General palliative care services (not specified);
- In-home palliative care services or hospice at home care[205];
- Needs assessment in patients by clinical nurse specialists with the aim to develop an individual treatment plan[245];
- On demand telephone follow-up[246];
- Comprehensive team care[269].

Overall the studies lacked a clear description of the type, number and intensity of the services provided. A service that was labelled with an identical name could include different services. For example 'case management' was operationalized in the study of Nickel et al.[268] as comprehensive assessment, care planning, review of subject needs and services, ongoing case manager observation and monitoring of subject reports of service quality, close follow-up of patient progress and service delivery through telephone calls and home visits.

Other authors (e.g. Topp et al.[278]) described this intervention as the following list of interventions: assessment of resources and the coordination of care between inpatient, outpatient and home care settings, assistance with communication of patient information throughout the health care system, assessment of patient/family educational needs, recommendation or provision of appropriate education, evaluation and feedback regarding critical thinking and delegation skills among care providers, suggestions to other health care providers and hospital administrators for improving customer satisfaction/ patient outcomes, functioning as a patient advocate with liaison between patient/family and the health care team to ensure that patient needs were met.

Overall, the type and number of interventions did not differ in function of the setting where they were applied.

Type and number of needs addressed

The needs addressed in the different studies largely varied. Biological needs were addressed in 53% of the studies. Psychological, social and healthcare related needs were addressed in 56%, 42% and 42% of the studies respectively. Spiritual needs were less frequently addressed (24%), as well as family caregiver needs (14%). A total of 37% studies did not specify at all the needs they addressed.

Almost all studies that reported the needs that were addressed mentioned multiple needs: only 3 studies focused on a single need. The content of the different categories of needs differed between studies. For example, psycho-social needs could refer to anxiety and depression whereas other studies focused on patient insight (i.e an understanding of the consequences of the disease on e.g. life expectancy, symptom control) and dimensions of quality of life, as well as psycho-social needs in informal caregivers.

Biological, psycho-social, social and health care needs were mentioned in nearly half of the studies. On the opposite, spiritual needs were mentioned in one out of five studies only (n=12).

The type and number of needs addressed in the studies were similar but their importance still varied according to their type. For example, biological needs were frequently addressed in all settings i.e., 12 studies conducted in home care settings (52% of 23 studies), 6 of the 14 studies in hospital and 10 studies with transmural care systems (n=20). Greater differences were noted for social needs: 12 studies in home settings (n=23) mentioned these needs, versus 5 studies in hospital (n=14) and 9 studies in transmural care systems (n=20). Spiritual needs showed the greatest differences as they were mentioned in 8 studies in home care settings (out of 23 studies), 3 studies with transmural care systems (n=20) and only one study in the hospital settings (n=14).

Type of and number of outcomes measures

Outcomes measures were grouped in four categories:

- Biological outcomes: complications, pain and symptom control were the most frequent biological outcomes that were mentioned. Functional status (e.g. activities of daily living), survival/mortality and symptom free survival were other types of biological outcomes.
- Psycho-social outcomes: satisfaction with care was one of the most frequent outcomes mentioned in this category. Quality of life, cognitive status, anxiety and depression, psychological distress, patient preferences were also analysed.
- Economic outcomes included the use of health care services and resources, and the related cost.
- Other outcomes included the use of specific health care services, the communication between patient and provider, the carers' satisfaction and problems, the place of death, the length of stay in hospital and other settings, readmission rates, accessibility of care, the caregivers' health.

Psychological outcome measures were used in two thirds of the studies (40 out of 59) whereas biological outcome measures were used in 32 of the 59 studies. Economic outcome measures were also used in half of the studies (n=30).

When comparing the different settings the type and number of outcome measures are similar, with the exception of psycho-social outcome measures that were used more frequently (87%) in studies conducted in home care settings compared to studies conducted in hospital settings (70%) or applied in transmural care systems (66%).

Impact of the models on outcome measures

Due to the large heterogeneity of the different care models there is no consistent evidence with regard to the (cost)effectiveness of the different care models. As a consequence it is not possible to conclude if care models conducted in home care, hospital or transmural care settings produce better outcomes when mutually compared.

In all care models, the greatest effectiveness is reported for psychological outcome measures. This might be partly explained by the fact that this measure was frequently applied in the studies (68%). Effectiveness on biological outcome measures was shown in only 22% of the studies that applied this outcome measure. There is limited evidence with regard to the effectiveness of care models in economic terms: only 3 out of 10 studies provided positive outcomes for these measures.

Other positive outcomes of palliative care models are 'satisfaction of the informal caregiver', 'place of death', family morale, family insight, family anxiety, and number of unmet needs that were discussed in some care models.

No positive effect on any outcome measure was reported in respectively 26% (home care studies), 42% (hospital care studies) and 50% (transmural care systems studies).

5.4 GENERAL DISCUSSION AND CONCLUSIONS

This review of systematic reviews focused on the diversity and effectiveness of care models for patients who need palliative care.

5.4.1 Palliative care models found in the systematic reviews

From the large number of studies that were identified in the different systematic reviews, only a limited number of the studies met the inclusion criteria. This finding demonstrates that a) care models that focus on comprehensive care delivery have been scarcely researched, and b) there are only a limited number of studies with adequate study designs in this field that have evaluated the effectiveness of different care models.

Overall, care models in the different studies are not clearly labelled in the sense that it is not clear who is the lead-caregiver or what are the key objectives defined for every respective model. Clear objectives of the studies in terms of improvement in coordination and/or, continuity and/or quality of care could only be defined for a small number of studies.

Since there is no clear labelling of the different care models in the literature, care models in our review are classified based on the setting in which they are conducted, being care models in home care, hospital care, nursing homes, day care and transmural care systems. The latter models include service offerings organized in multiple settings, mostly home care and hospital care.

The concept of hospice care is not presented in this review as a separate model of care since the authors did not retrieve any study on hospice care that met the inclusion criteria. According to the official definition of the MESH thesaurus, hospice care refers to the specialized treatment provided to a dying person whereas palliative care encompasses earlier stages of an incurable disease, as described in the definitions section. However, the International Association of Hospice and Palliative care uses both terms as synonyms and twelve papers had hospice care in their keywords. Hospice and palliative care models might have different organization models depending on the country. For example, hospice care in the U.S is mostly provided in long-term care facilities or at the patient's home. In the UK hospice is seen as one part of the specialty of palliative care and no differentiation is made between 'hospice' and 'palliative care'.

A key conclusion of this review is that care models for patients who need palliative care presented an important heterogeneity in terms of conceptual backgrounds, settings, objectives, patient prognosis, caregivers, interventions, outcome measures and results on effectiveness of care. As a consequence, no conclusion can be drawn from this literature review that one particular model of care is superior to another care model in terms of (cost)effectiveness or efficiency of care.

5.4.2 Target populations of the palliative care models

5.4.2.1 Specific pathologies

The literature review highlights the presence of multiple target populations, with many care models focusing exclusively on patients with cancer. Till recent date a rather limited number of studies have targeted patients with heart failure, neurodegenerative diseases, respiratory diseases and HIV or AIDS. Only a quarter of the studies targeted multiple pathologies at the same time. This focus on single patient populations mirrors the organisation of medical care in hospitals. In this context it is important to analyse if the needs of these particular patient populations differ or not. Previous parts of this study have identified similar needs across different patient populations who need palliative care for what concerns psychological, psycho-social and spiritual needs.

5.4.2.2 *Minor role of the prognosis*

An important conclusion is the poor link between the prognosis and the type of palliative care model. First, a limited proportion of studies mentioned the prognosis as an inclusion criterion. Palliative care models seemed rather intended to answer the needs of palliative patients, independently of their prognosis. Moreover, when the prognosis was mentioned, its large variability (up to 5 years) showed that this criterion had little validity: the chapter on definitions underlined its poor predictive value in the long run. This variability in life expectancy was neither linked to the type and number of interventions provided or other components of the different care models.

5.4.2.3 *Patient needs*

Almost all care models targeted multiple needs, in the different domains. This indicates that biological, psycho-social, spiritual and health care related needs are recognized as important needs that require attention in palliative care. Spiritual needs however were addressed in only a minority of the studies.

It is also important to note that needs of family caregivers were mentioned in only a limited number of studies. This finding is surprising since informal caregivers play a major role in the care of patients who need palliative care[284, 285].

5.4.3 Caregivers in the palliative care models

Almost half of the studies have appointed nurses as lead-caregivers to address the multiple needs of the target population(s). Nurses received different labels to characterize their interventions, including e.g. nurse case managers, home hospice nurse and advanced planning nurse. The other half of the studies mentioned teams as providing care to patients, in particular in models that involved different settings. The papers do not systematically describe who are the core and the additional members of the team. Core members are often nurses and doctors. Additional members of the team include e.g., certified nursing assistants, home health care aides, volunteers from the community (largely untrained but some being skilled medical personnel), chaplains and housekeepers. A liaison between a single caregiver and a multidisciplinary team was for example presented as a form of palliative care organization.

The presence and importance of health professionals other than doctors contrast with the Belgian situation, in particular in home care settings. As an example, three quarters of the GPs who answered to the web survey, described in part 3, identified themselves as care coordinators for palliative patients.

5.4.4 Interventions experimented in palliative care models

The type and number of interventions applied by multidisciplinary teams and individual care providers largely varied between care models. However, many studies did not provide sufficient details on the interventions and the related implementation strategies. Interventions ranged from managing the physical symptoms to treating depression in patients with advanced disease or caring for dying patients. Much of the interventions largely went beyond medical care as they also targeted other complex psychological, social, and spiritual needs of patients and their caregivers.

5.4.5 Outcomes under study

The type and number of outcomes strongly varied between studies. Psycho-social outcome measures were mostly used, irrespective of the setting, and were represented in a high number of studies that reported on positive outcomes with regard to the effectiveness of care.

Another outcome measure that was frequently used was users' satisfaction: numerous instruments were used to assess this outcome and often found a positive effect of the interventions. Many studies also reported on positive results with regard to the effectiveness of interventions in the different care models on control of symptoms, comfort of the patient and psycho-social outcomes (e.g., quality of life, communication, anxiety, spiritual well-being). Positive outcomes on e.g. costs, length and frequency of hospital stays, place of death were reported in only a minority of the studies.

Despite these positive results, a substantial number of care models could not demonstrate the effectiveness of the model under study, neither for the primary nor for the secondary outcome measures. In this context the comparison between care models does not allow any firm conclusion on which care model produces the best outcomes.

None of the studies explicitly presented their outcome measures as structure, process or outcome indicators of high quality palliative care. Research on indicators in palliative care should therefore contribute to the standardisation of the assessment of palliative care models.

A finding similar to the needs section refers to the scarcity of studies that focused on outcomes related to family caregivers. Caregivers' well-being or health for example was studied in only a limited number of studies, although family caregivers play a major role in the care of palliative patients.

5.4.6 Lessons to learn for Belgium

5.4.6.1 Choice of a palliative care model: no superior models

An important conclusion of this literature review is that there is no evidence that a specific care model is superior to another one. The diversity of care models that were analysed in the literature review are already available in Belgium i.e., home care models, hospital care models, linkages between specialized and first line of care (through mobile teams), palliative care in nursing homes, palliative care units (hospices) for dying patients and day care centers. In the context of these models a wide range of interventions can be implemented in relation to the patients' needs, depending on the available caregivers, settings, stages of the disease and especially the preferences of the patient and family caregivers.

The question of opportunity of day care settings in Belgium can not be solved as only one paper analysed the outcomes in this setting. Unfortunately, the study focused only on biological (symptoms) and psychological (quality of life) outcomes and found little effect. However one major role of these structures is the positive effect on the informal caregivers but as in most studies their outcomes were not considered in the design of this study.

5.4.6.2 Shaping a palliative care model

The implementation of a care model implies a preliminary clear definition of objectives and outcome indicators. Current projects on indicators in palliative health care should serve as an example to the design and evaluation of palliative care models in Belgium. The diversity and effectiveness of care models for patients who need palliative care highlight the need for a conceptual framework that provides a comprehensive overview of attributes of high quality palliative care linked to quality/performance indicators at the structure, process and outcome level of care.

5.4.6.3 Lead caregiver: potential for new avenues

The presence of a multidisciplinary team is a common feature of most care models, in particular for models that operate across different settings. The composition of the palliative team however varies. Literature shows that specialized nurses play a central role e.g., in the role of case managers or for specialized care, for example in case of chemotherapy. If nurses in the future are to take leading roles in palliative care in Belgium, a redefinition of tasks and responsibilities is required since general practitioners nowadays fulfill leading positions in palliative care, at least in the first line of care.

5.4.6.4 Patients' needs at the heart of the organization

The target populations of the studies have been mostly defined according to the palliative status of specific pathologies. In Belgium, access to palliative care depends on the prognosis whose rationale has been questioned in previous parts of this study. A common denominator to both situations is the spectrum of patients' needs. Common needs exist, independently of the pathologies and of the prognosis. The common goal of palliative care models is to provide the right answer to this broad range of needs.

This highlights the importance of adequate broad training programs for health care professionals first to identify the needs, thereafter to answer them in various domains (medical, social, psychological and spiritual). Delegation to other professionals is a possibility for some specific problems but health care professionals have to keep a holistic view of the care and avoid splitting up the care according to the multiple patients' needs.

5.4.6.5 Informal caregivers: key for care models at home

This review highlighted a gap in the literature with respect to needs and outcomes of informal caregivers. The latter have been hardly studied whereas available studies show that most patients wish to die at home, where family caregivers are often strongly involved.

Key points: Literature review on palliative care models

- **No palliative care model could be identified as giving better outcomes than other models;**
- **Care models described in systematic literature reviews were heterogeneous in terms of objectives, caregivers, target populations and interventions;**
- **Most care models were organized either in home settings or as transmural care models between settings;**
- **Multidisciplinary teams were mostly involved, with different caregivers: however nurses were most often the leading persons;**
- **The most frequent outcomes were satisfaction and psychosocial outcomes; some papers did not find any effect of the model under study on the outcomes previously defined;**
- **Most care models are organised according to the patient's needs; one missing point is often the attention to informal caregivers.**

Part three: Epidemiological surveys

This part describes different surveys:

- A web-based survey among general practitioners to analyse their perception of palliative care and their experience with palliative care services;
- A follow-up of palliative patients followed by their GP at home (or in replacement home setting);
- A follow-up of palliative patients in nursing homes;
- A follow-up of palliative patients in hospitals.

6 WEB-BASED SURVEY AMONG GENERAL PRACTITIONERS IN BELGIUM

6.1 OBJECTIVES

The aim of this survey is to analyse the personal view of GPs about palliative care.

6.2 METHODOLOGY

6.2.1 GPs sampling

The initial aim was a sample of 1000 GPs who would fill out the web-based questionnaire. The collection of GPs' mail addresses was difficult: neither both scientific societies (Domus Medica and Société Scientifique de Médecine Générale) could provide any email address for privacy reasons.

6.2.1.1 Recruitment of Dutch-speaking GPs

First, the researchers contacted the chairs of GP circles in March 2008: all chairs (N=190) received an email containing the URL of the web-based questionnaire. They were asked to spread this among the GPs within their circle. After one week all chairs were contacted by phone in order to give them more information. Almost half of them did not forward the mail. The most frequent reason was that they did not believe that the GPs would answer. After further explanation most of them agreed to send the mail.

Secondly, emails were sent to groups of GPs using available GP lists:

- all GPs from the department of general practice of Gent University (N=31),
- all vocational trainers of the same department (N=55),
- vocational trainers belonging to the interuniversity centre for vocational training in general practice (Interuniversitair centrum voor huisartsen opleiding-ICHO, N=2200),
- some Community Health Centres (N=6)
- Other known Dutch speaking GPs in this study in order to get a snowball effect by asking everyone to send it to colleagues.

6.2.1.2 Recruitment of French-speaking GPs

Finding email addresses was more complicated in the French speaking part of Belgium, given the absence of available mailing lists. The researchers first sent mails to chairs (n=47) and participants (n=741) of RAMPE (course on palliative care organised by the "Société Scientifique de Médecine Générale". From this group, 12% (95/788) of the GPs filled the questionnaire. Other mails were sent to all GPs and vocational trainers from the UCL centre for general practice.

The "Unité de Socio-économie de la Santé" (SESA) from UCL provided post addresses of all French-speaking GPs. All of them (except RAMPE participants) received a letter containing the URL of the website (N=5210). 2.8% (147/5210) were undeliverable. The response to this letter was disappointing: only about 150 doctors filled out the questionnaire after this mailing.

Finally, known GPs were contacted and asked to send the URL to colleagues (N=130).

6.2.2 Development of the questionnaire

The design of the web-based questionnaire is based on a literature. It is important to note that the research about the definitions of palliative patients is mainly done in the UK and USA. Some items might not be applicable to the Belgian situation. Nevertheless the following results were introduced in the questionnaire.

The literature makes a difference between 'general palliative care', under the responsibility of all caregivers, and 'special palliative care' provided by specialists belonging to a multidisciplinary team[38, 286-290].

Barriers for GPs to perform palliative care are split up into tree different topics i.e., barriers connected with the person of the GP, barriers connected with the patient or the family and barriers connected with the health care system[51, 286, 287, 290-299].

Barriers associated with the person of the GP are:

- difficulties in omitting cure into care, problems accepting the fact that the patient will die, palliative care seen as a personal failure[292];
- communicative problems in talking about end of life issues or dying with the patient and/or his or her family[293, 294, 296, 297];
- lack of knowledge about palliative care services and palliative treatment[286, 291-295];
- fear of losing control or of negative financial consequences by referring the patient to palliative care[51, 294, 295] ;
- earlier bad experiences[294].

Barriers associated with the patient or the family are:

- distress of patient and family confronted with end of life issues[51, 292-298];
- patient or family may experience referral to palliative care as hopelessness[290, 292, 295, 298];
- lack of or wrong information about end of life and the possible palliative treatment options[292, 297, 298].

Barriers associated with the health system are:

- criteria to start palliative care imposed by the system (e.g. time before death)[291-295, 299];
- financial consequences[291, 293, 294, 296].

The web questionnaire was based on these results and discussed within the research group. A pilot study allowed last changes in the questionnaire (final version in appendix 4.1).

6.3 RESULTS OF THE WEB-BASED SURVEY

The initial aim was a sample of 1000 GP participants. At the closing date (22 July 2008) 909 GPs had responded. Web-based surveys seem therefore promising tools but two major problems were identified i.e. finding email addresses and referral to a URL address in a post mail.

6.3.1 Characteristics of the GP participants

GP participants were 637 Dutch–speaking and 272 French-speaking GPs. Two thirds of them (64%; 573/895) were male.

The mean age was 44.3 years, with the following age distribution:

- 21.9% (192/875) younger than 30 years;
- 17.8% (156/875) aged between 30 and 40 years;
- 23.8% (208/875) aged between 40 and 50 years;
- 28.6% (250/875) aged between 50 and 60 years;
- 7.8% (68/875) older than 60 years.

This sample included 909 GPs out of 11 389 (8%) GPs registered in the RIZIV/INAMI statistics as having a clinical activity[300]. The participants to this study were slightly younger (44.3 versus 48.8 years) and there were fewer men (64% versus 81%) than in the population of GPs who work full time.

Half of the participants (48.8%, 425/871) worked in single-handed practices. One fifth (20.4%, 178/871) worked in a duo-practice, 21.4% (186/871) in a group-practice, 8.3% (72/871) in a Community Health Centre and 1.1% (10/871) ticked 'other'.

Nearly half of the GPs (44.2%, 351/795) stated that they had some formal training in palliative care. "Formal training" included a large diversity of continuing medical education sessions i.e., from one evening to a one-year formal course. Learning about palliative care during medical curriculum or reading about the topic was not considered as a training.

Three out of five GPs (59.6%, 484/812) had palliative patients at the moment they filled out the questionnaire. Mean number was 1.6 palliative patients per GP: 37.2% (134/360) had 1 palliative patient; 33.1% (111/360) had 2 patients, 17.5% (63/360) had 3 palliative patients and 12.2% (44/360) had more than 3 palliative patients when they filled the questionnaire.

6.3.2 Descriptive results

The questionnaire consisted of three parts:

- The first one dealt with the possible distinction GPs make between palliative, terminal and dying patients;
- The second part analysed the knowledge of the GPs about the palliative services in Belgium, as well as their perception of their own role in the care for palliative patients and their family;
- The last part dealt with possible difficulties GPs encounter in dealing with patients and families in the last stage of life.

6.3.2.1 Distinction between the labels 'palliative', 'terminal' and 'dying'

Most GPs (82.9%, 670/808) made a distinction between 'palliative', 'terminal' or 'dying' patients.

The most important determinant for labelling 'palliative' (for 72%, 507/704) was the 'need for extra care' ('extra' was defined as an additional care to the normal one for the disease).

'Life expectancy' was the most important determinant for 'terminal' (78.3%, 577/661) and 'dying' (79.6%, 506/636) patients. Nevertheless 'the need for extra care' remained an important determinant during the care for people at the end of life.

The estimated (im)possibility for (partial) recovery (the most important criterion in most definitions of palliative care), seem less important in all GP's definitions.

Table 7: Determinants of patient labelling

	Palliative patient % (n/N) (order)	**Terminal patient % (n/N) (order)**	**Dying patient % (n/N) (order)**
Diagnosis	70.5% (496/704) (2)	48.0% (317/661) (3)	29.4% (187/636) (5)
Time before death	49.9% (351/704) (4)	**87.3% (577/661) (1)**	**79.6% (506/636) (1)**
Need for extra care	**72.0% (507/704) (1)**	60.5% (400/661) (2)	51.4% (327/636) (2)
Possibility for (partial) recovery of remission	43.6% (307/704) (5)	44.8% (296/661) (4)	37.4% (238/636) (3)
Life quality	66.3% (467/704) (3)	38.8% (257/661) (5)	31.0% (197/636) (4)

The ranking of items by the GPs varies according to the labelling of the patient. For patients labelled as 'palliative' the need for extra care is most important, followed by the diagnosis. The diagnosis switches to the last position if the patient is labelled 'dying'. Life expectancy becomes a more important determinant as death comes near.

Life quality is important when the patients are labelled 'palliative', less important when they are called 'terminal' or 'dying'.

For the GPs who ticked the box 'life expectancy', the table below shows the link between 'life-expectancy' and the labelling.

Table 8: Life-expectancy according to patient labelling

Life-expectancy	Palliative patient % (n/N)	Terminal patient % (n/N)	Dying patient % (n/N)
More than 5 years	3.4 (19/558)	0.4 (3/698)	0.1 (1/717)
> 1 and <= 5 years	16.1 (90/558)	1.7 (12/698)	0.3 (2/717)
> 3 months and <= 1 year	**48.7 (272/558)**	11.6 (81/698)	3.9 (28/717)
> 2 weeks and <= 3 months	**34.2 (174/558)**	**47.0 (328/698)**	13.5 (97/717)
> 1 week and <= 2 weeks	0.4 (2/558)	**26.5 (185/698)**	**46.0 (330/717)**
> 24 hours and <= 1 weeks		11.5 (80/698)	**25.7 (184/717)**
> 12 hours and <= 24 hours	0.2 (1/558)	1.3 (9/698)	10.5 (75/717)

The WHO palliative care definition emphasized the needs of the patient and his/her family. The questionnaire asked GPs if they thought that the needs of patients differ according to the labelling. Most GPs (77.2%, 575/745) answered positively:

- For 'palliative' and 'terminal' patients, psychological care was the most important, closely followed by physical care;
- For 'dying patients' physical care was more important.

Table 9: Difference in care needs according to patient labelling.

	Palliative patient % (n/N)	Terminal patient % (n/N)	Dying patient % (n/N)
Physical care	76.2 (467/613)	89.8 (543/605)	85.6 (512/598)
Psychological care	91.0 (559/614)	91.6 (560/611)	79.4 (470/592)
Social care	72.4 (443/612)	62.5 (376/602)	50.7 (296/584)
Existential care	66.2 (403/609)	75.9 (460/606)	61.8 (367/594)

6.3.2.2 *Knowledge/use of palliative care services and role of the GP*

Knowledge and use of the existing palliative services

The best known services were: 'palliative home care' known by 96% (652/679) of the GPs, 'palliative forfait' (92.2%, 629/682) and palliative units (89.5%, 614/686). Two thirds (65%, 409/629) of the GPs asked the 'palliative forfait' for at least one patient in 2007. More than a half (55.9%, 343/614) referred at least one patient to a palliative unit. Only 9.2% (60/652) of the GPs used palliative home care teams in 2007.

Table 10: Knowledge and use of palliative services

	% GP who know the service (n/N)	% GPs who used the service in 2007 (n/N)	Within the group of GP who know the service, % who used it in 2007 (n/N)
Palliative support-team in the hospital	73.3 (514/701)	34.7 (243/701)	47.3 (243/514)
Palliative unit	89.5 (614/686)	50.0 (343/686)	55.9 (343/614)
Palliative home care	96.0 (652/679)	8.8 (60/679)	9.2 (60/652)
Palliative referent	46.5 (319/686)	21.3 (146/686)	45.8 (146/319)
Palliative day care	38.2 (259/678)	6.9 (47/678)	18.1 (47/259)
Palliative forfait	92.2 (629/682)	60.0 (409/682)	65.0 (409/629)
Volunteers	63.3 (435/687)	29.1 (200/687)	46.0 (200/435)

Role of the GP in palliative care

GPs largely agreed on the fact that taking care for palliative patients is an essential GP task. For 93.4% (665/712) this is a very important task, enriching their profession (89.4% 638/713; and their life (82.1%, 570/694). Many GPs (89.3%, 634/711) wanted to share the care for palliative patients with other professionals. The GPs strongly disagreed with the item that care for palliative patients is an exclusive task for specialists (89.7%, 637/710). Many of them (80.9%, 575/711) disagreed when asked if they would like to avoid this task.

An essential role of GPs in the care for palliative patients is listening and being supportive to the patient (96.8%, 686/709) and to family members (95.2%, 674/708).

Moreover GPs give themselves a role of contact person for other care-givers (88%, 622/707). Giving medical information and the coordination of the medical treatment remains central (75%, 528/704).

Determinants to start palliative care

The most important determinants for starting palliative care within general practice were the demand from the patient (87.1%) and/or the family (80.7%). The necessity for support was another determinant (important for 85.9%, 582/678 of the GPs). Many GPs also considered starting palliative care when other care givers were asking for, although 29.9% (204/682) said that this aspect had no positive nor negative determination in the start of palliative care.

GP's knowledge of the services for palliative care was an important determinant for 82% (554/676) of the GPs to start palliative care.

GPs stated that criteria as life expectancy, social situation, socio-economical class, degree of education, age of the patient, knowledge of patient/family about palliative care, did not play a role as determinants for starting palliative care.

6.3.2.3 Difficulties when caring for palliative patients

Talking with the patient and the family

For 38% of the GPs (255/671) talking with patients about end of life issues was difficult. Half of them (49.9%, 335/671) had no problems while 12.1% (81/671) did not know. Talking with family members seemed to be easier: 61% (408/669) did not find this difficult, 25.1% (168/669) did, and 13.9% (93/669) did not know. Half of the GPs (52.9%, 352/665) talked with every palliative patient about coming death, 22.1%, (147/665) did not and 25% (166/665) did not know.

Most doctors (87.7%, 518/591) agreed that they made an evaluation of the emotional strength of the patient before talking about end of life issues. Less GPs (69.4%, 461/664) assessed the emotional strength of the family. Many GPs (68.9%, 453/657 for patients and 53.1%, 313/589 for family members) considered their evaluation of the emotional strength of patients/family members as a determinant for talking about end of life issues.

Barriers by family members concerning talking about end of life issues determine the conversation with the patient for 50.5% of the GPs (338/667). Nevertheless 26.6% of the GPs (178/667) did not take the meaning of the family into account. If talking about end of life issues was a taboo for the patient and/or the family, one third of the GPs (33.4%, 222/665) respected this taboo, 40.8% (271/665) did not respect the taboo and talked with the patient, while 25.9% (172/665) did not know what to do.

Problems for starting palliative care

Most GPs did not experience any problem in dealing with aspects of their own work (time management, little support, care 24 hours a day). Palliative care can be demanding but this does not prevent them from starting it (78.4%, 516/658):

- 80.7% (535/663) said to have no problem with giving palliative care even without any support from other caregivers,
- 80.9% (537/664) did not care about providing care 24 hours a day,

- 82.7% (548/663) did not fear the lack of time.

Most GPs did not see palliative care as their own medical fail (91.1%, 625/657). They were not blocked by the fact that they would like to give hope (93%, 610/656) nor by their own religious or moral conviction (97.4%, 639/656). Difficult or unclear administrative procedures did not stop GPs (74.8%, 495/661 and 75.1%, 497/662 respectively) for starting palliative care neither did lack of knowledge hinder them (74.9% 493/663). Bad experiences had no influence on future start of palliative care (94% 616/656).

The results concerning factors connecting to patients or family members were more heterogeneous. If the patient was not aware of his/her condition, starting palliative care seemed difficult for 66.9% (445/665) of the GPs while 23.1% (154/665) would do it anyway. Similar results were seen if the family was not aware of the condition of the patient (26.1%, 173/663 would do it anyway, 62%, 411/663 found this difficult). Half of the GPs (52.1%, 346/664) had difficulties starting palliative care if the family did not want the patient to be informed, while 32.2% (214/664) did not see this as a barrier.

Table 11: Statements

Statements	% GPS agree (n/N)	% GP do not know or neutral (n/N)	% GP disagree (n/N)
I find it difficult to talk about end of life issues with patients	38.0 (255/671)	12.1 (18/671)	49.9 (335/671)
I find it difficult to talk about end of life issues with family members	25.1 (168/669)	13.9 (93/669)	61.0 (408/669)
Sometimes I feel that the family is hindering me to be honest with the patient	50.5 (338/669)	22.9 (153/669)	26.6 (178/669)
If the family do not wish that I am honest with the patient and I feel their wish is correct, I follow their advice	21.1 (141/665)	26.0 (173/665)	52.8 (351/665)
I talk with every palliative patient about coming death	52.9 (352/665)	25.0 (166/665)	22.1 (147/665)
I assess the emotional strength of the patient before talking about end of life issues	87.7 (518/591)	10.0 (59/591)	2.4 (14/591)
I assess the emotional strength of the family before talking about end of life issues	69.4 (461/664)	19.0 (126/664)	11.6 (77/664)
My assessment of the emotional strength of the patient is determining my talking or not about end of life issues	68.9 (453/657)	18.4 (121/657)	12.6 (83/657)
My assessment of the emotional strength of the family is determining my talking or not about end of life issues	53.1 (313/589)	22.6 (133/589)	24.3 (143/589)
If death is a taboo, I respect this taboo and will not talk about it	33.4 (222/665)	25.9 (172/665)	40.8 (271/665)
If the patient is not aware of his condition, I have difficulties with offering palliative care	66.9 (445/665)	9.9 (66/665)	23.1 (154/665)
If the family is not aware of the condition of the patient, I have difficulties with offering palliative care	62 (411/663)	11.9 (79/663)	26.1 (173/663)
I have difficulties offering palliative care if the family does not want the patient to be informed	52.1 (346/664)	15.7 (104/664)	32.2 (214/664)
I have difficulties offering palliative care if I am not supported by other caregivers	9.8 (65/663)	9.5 (63/663)	80.7 (535/663)
I have difficulties offering palliative care because I fear I have to be available 24 hours a day	10.3 (68/664)	8.9 (59/664)	80.9 (537/664)
I have difficulties offering palliative care due to lack of time	8.0 (53/663)	9.4 (62/663)	82.7 (548/663)
I have difficulties offering palliative care, because I fear resistance of the patient and/or family	5.7 (38/663)	14.9 (99/663)	79.4 (526/663)
I have difficulties offering palliative care due to unclear administrative procedures	11.5 (76/662)	13.4 (89/662)	75.1 (497/662)
I have difficulties offering palliative care, due to complex administrative procedures	9.8 (65/661)	15.3 (101/661)	74.8 (495/661)
I have difficulties offering palliative care, due to own lack of knowledge about palliative services	11.4 (76/663)	14.2 (94/663)	74.9 (493/663)
I have difficulties offering palliative care, because this period will be emotionally stressing for me	9.7 (64/658)	11.9 (78/658)	78.4 (516/658)
I have difficulties offering palliative care, because I experience the lack of medical treatment as a fail	1.4 (9/657)	3.5 (23/657)	91.1 (625/657)
I have difficulties offering palliative care, because I want to give hope for recovery	1.5 (10/656)	5.5 (36/656)	93 (610/656)
I have difficulties offering palliative care, due to previously bad experiences with palliative care	1.5 (10/656)	4.6 (30/656)	93.0 (616/656)
I have difficulties offering palliative care, due to my own religious and/or spiritual conviction	0.6 (4/656)	2.0 (13/656)	97.4 (639/656)

6.3.3 Multivariate analyses

6.3.3.1 Dependent variables

Multivariate analysis was performed in order to get an idea of possible predictors of the results. Since the questionnaire dealt with several topics, principal component analysis was used as a reliable way to make subscales.

We first divided the questionnaire in several subdivisions:

- Distinction between palliative, terminal and dying: one item.
- Knowledge about palliative services: 6 items
- Perception on task/role of the GP: 11 items
- Difficulties in caring for palliative patients: 25 items

The internal consistency of the variables that questioned the knowledge of the GP was 0.784: if the GP knew one service, the chance that he/she knows other services was large. For the multivariate analysis (regression analysis), the sum-score of the scores on the different variables of knowledge was used.

The questions concerning the task/role of the GP had an internal consistency of 0.774 (46.69% explained variance). Sum-scores were used as well.

Since the questionnaire consisted of multiple questions, principal component analysis using SPSS 1.6 (rotation method: Varimax with Kaizer Normalisation) was performed to look for internal consistency between the questions. PCA showed 5 factors: total explained variance was 55.9%; (for details see appendix)

- Factor 1 (9 variables): Difficulties with organisational aspects (explained variance 24.6%; α=.870)
- Factor 2 (4 variables): Hindered in communicating diagnosis (explained variance 9.6%; α= .767)
- Factor 3 (5 variables): Personal perspectives (explained variance 9.3%; α = .702)
- Factor 4 (3 variables): Assessment of emotional strength of patient and family (explained variance 6.8%; α = .702)
- Factor 5 (3 variables): Taboo (explained variance 5.6%; α = .539)

Sum-score of the variables of every factor was used in the multivariate analysis.

6.3.3.2 Independent variables

Multivariate analyses were performed, with following independent variables:

- Language,
- GP gender and age,
- Practice organisation (single handed versus group),
- Having followed a training in palliative care or not,
- Number of palliative patients at the time of the research.

6.3.3.3 Results of the multivariate analysis

Distinction between palliative, terminal and dying patients

Doctors with training in palliative care make a distinction between palliative, terminal and dying patients (N=776; odds ratio 2.462).

Knowledge (N=857)

Being trained (t=5.090, sign .000), French speaking (t=4.531, sign .000) and not single handed working (t=2.427, sign .015) had a positive effect on knowledge.

Task (N=660)

Linear regression analysis was performed with the sum-score of the task/role items. Having followed a training in palliative care (t=2.865, sign .004) and having more palliative patients (t=2.291, sign .04) are the two significant variables. GPs with training found palliative care an essential task, enriching their life and their profession. They wanted to share the care with other professionals as well as to be the coordinator towards the patient. They did not agree that palliative care was task unique for specialists.

Difficulties due to organisational aspects of the palliative care (N=625)

Linear regression was performed with the sum-score of factor organisation. GPs without training palliative care (t=-8.244, sign .000), working in the Dutch speaking part of Belgium (t=-7.679, sign .000), younger (t=-2.445, sign .01) and having less palliative patients (t=-2.236, sign .02) had more problems in dealing with the organisation of the care for palliative patients.

Hindered in communication diagnosis (N=643)

GPs working in the Dutch speaking part of Belgium (t=-13.628, sign .000) and not working single handed (t=3.188, sign .002) are more likely to have difficulties to start palliative care when the patient/family is unaware of the diagnosis or when the family is hindering honest communication with the patient.

Personal perspectives (N=635)

GPs without training in palliative care (t=-4.115, sign .000) and female doctors (t=2.965, sign .003) are more likely to report problems connected with their own ideas (I have difficulties talking to patients/family about end of life, palliative care is a personal failure, I like to give hope, contradictory to moral and ethical assumptions)

Assessment of emotional strength of patient/family (N=569)

French speaking GPs (t=3.422, sign .001), single handed working GPs (t=-3.131. sign .002), GPs with more palliative patients (t=2.092, sign .037) and female GPs (t=2.077, sign .038) are more likely to assess the emotional strength of patient/family and to take into account this assessment.

Taboo (N=645)

GPs without training (t=-3.493, sign .001) and single handed working (t=-2.044, sign .041) are more likely to follow the taboo about death or to follow the wish of the family not to talk.

Significant associations between training in palliative care and the GP's perception

Having training in palliative care was often a significant independent variable in the regression analyses. Having training was associated with a better knowledge of most palliative care services. This variable was also associated with a positive view on the role of the GP profession in palliative care. On the opposite, having training had an inverse relationship with GPs' difficulties linked to the care of palliative patients. Having training was associated with less difficulty to talk with patients, to talk with the families (even if death was a taboo). This training facilitated the care of palliative patients: any barrier to offer palliative care (e.g. for emotional, administration, availability reasons) was inversely associated with training in palliative care.

Significant associations between GP language community and the perception of palliative care

The variable 'language' was also frequently significantly associated with the statements of the GPs. French speaking doctors have a better knowledge of the palliative services. Dutch speaking GPs report more difficulties concerning the care, they report problems due to organization as well as to communication. Dutch speaking GPs have difficulties when families are hindering them in honest talking with the patient. French speaking report to assess the emotional status of the patient and the family and to lean on this assessment in their communication with patient and family.

Significant associations between type of practice and GP perceptions

GPs working single handed had less knowledge about palliative care services. They were more likely to assess the emotional strength of the patient and the family and respected more taboos. A contradictory finding was that not single handed working GPs report more hindering by the family in honest communication.

Significant associations with age/gender of the GP

Being older was linked to a better knowledge of services of palliative care. To some extend female GPs report more difficulties in caring for palliative patients.

Table 12: Significant association between dependent and independent variables

	Language	Gender GP	Age GP	Solo or not	Training	Nr palliative patients
Knowledge	sign .000 (French)			sign .015 (solo)	sign .000 (training)	
Task/role					sign .004 (training)	sign .04 (more pt)
Difficulties organisation	sign .000 (Dutch)		sign .01 (younger)		sign .000 (no training)	sign .02 (less pt)
Hindered	sign .000 (Dutch)			sign .002 (solo)		
Problems due to personal perspective		sign .003 (female)			sign .000 (no training)	
Assessment emotional strength pt	sign .001 (French)	sign .038 (female)		sign .002 (solo)		sign .037 (more pt)
Taboo				sign .041 (solo)	sign .001 (no training)	

6.4 DISCUSSION

To the best of our knowledge this is the first national study about the perception and experience of GPs with palliative care in Belgium. Nearly one tenth of all GPs in Belgium having a practice, participated to this study.

The most important results of this web survey are:

- The training in palliative care influences the way GPs perceive and fulfill their task with palliative patients;
- Clear and honest communication with patients at the end of their life is not easy;
- GPs like to care for palliative patients despite difficulties.

6.4.1 Prevalence of palliative patients

About half of the GPs have at least one palliative patient at a given time, with a mean number of 1.6 patient per doctor. Although this prevalence might have been biased by the interest of the GP who answered, it is in line with the results of the survey in the home setting. In the Senti-Melc study in 2006, 174 general practitioners reported 798 non sudden deaths, a mean of 4.5 patient per doctor[28, 301]. No numbers are found about the group labeled as palliative patients.

An extrapolation based on about 11400 active GPs in Belgium[300] would mean that 8100 GPs currently care for approximately 13000 persons that they consider as palliative patients. The survey with the description of palliative patients in home (replacement) settings gave an estimate of 0.7 patients per participating GP i.e., a total population of 8000 patients for all active GPs. The estimation ranges therefore between 8000 and 13000 palliative patients cared by GPs.

This figure depends on the GP assessment of the palliative status of patients. This range of point prevalence estimates is still high in comparison with the number of "forfaits" paid each year by the INAMI-RIZIV: 13097 patients only benefited from a "forfait" (of maximum two months) during a whole year period (2007[302]).

6.4.2 Definitions by GPs: difference between "palliative" and "terminal/dying"

Most GPs make a distinction between the definitions of 'palliative', 'terminal' and 'dying' patients. In general GPs call a patient 'palliative' when he/she is at the end of his/her life and has needs that exceed the usual care for his/her disease. This can be psychological support, as well as medical treatment like pain management. In contrast, GPs often label the patients "terminal" or "dying" according to time before death: 'terminal' when the GP estimates the survival time between 2 weeks and 3 months, 'dying' when the estimated survival time is less than 2 weeks. However, the literature review on definitions highlighted the difficulty to give an accurate survival prognosis, except near the end of life. Linking palliative care to time before death may not be a good option and leads to late start of palliative care for patients at the end of their life: the recent study from the Christian Sickness Funds found that one out of five patients dies within the week after a demand for palliative forfait[303].

6.4.3 Perception of palliative care by GPs: role of training

The most important factor linked with a positive perception of palliative care is the training of the GP in this specialty. Doctors with training see palliative care as an essential task that enriches their profession as well as their live. They report less difficulty in communicating with patients and their families. They are more likely to talk with patients about death, they are less influenced by families who do not want the patient to be informed about his/her condition. They have, as expected, more knowledge about the possibilities within palliative care. The literature dealing with the positive influence of training on the practice of palliative care is mostly done among nurses[304]. Alvarez et al. found in a systematic review of training within general practice only 18 articles. The quality of the included studies was rather poor and the author strongly advised research designs with objective outcomes including patient opinion[305]. Peretti-Watel et al. compared family physicians with less training and less experience to oncologists. General practitioners reported more difficulties in talking about end of life issues and felt more uncomfortable with palliative patients[306]. This author also suggested training as a possible solution.

Most GPs consider palliative care as an essential task, enriching for their profession and personal life. They want to engage and seem little hindered by the fact that palliative care is time consuming, nor by their own religious or ethical conviction. They like to be the coordinator of the care for the patient, but want to share this with other caregivers.

Important tasks are to listen and to give support to the patient and his/her family members (WHO definition). Nevertheless medical treatment, for the disease as well as for pain management, also remains important.

Authors stated that the perception of GPs of palliative care was influenced by the number of patients they care for[306]. In this survey, the number of palliative patients did not appear as a significant variable linked with the perception of palliative care. One hypothesis could be that the number of patients at a given time was not representative of the whole experience of the GP.

Age, gender and practice organisation were not often significant in multivariate analysis. The only results seen were that younger, female, solo working doctors signalled to encounter more problems in the care for palliative patients. Difficulties mentioned by younger GPs (knowledge of services, administrative procedures, talking with the patient) could inspire further educational training in the faculties. No study on the influence of the gender of the health professional in palliative care has been found. Studies about the relation between gender and communication in general describe female doctors as more engaged in partnership-building, more interested in psychosocial aspects of health, less directive, more explicitly reassuring and encouraging[307].

6.4.4 Importance of communication with patients

Communication with patients and families at the end of life is very important. The literature about needs concluded to the need for stepwise delivered information and for sensitive communication with patients and their informal carers. Clear communication with the patient is not only beneficial for the palliative patient and his/her family but as well for the well-being of the caregiver[308]. However, only half of the (motivated) GPs in this survey talk with every patient about dying and many GPs report problems communicating with patients and families. Sometimes the communication with the patient is hindered by the family and Dutch speaking GPs seem to be more sensitive about their influence.

6.4.5 Palliative care services: known but hardly used

GPs know most palliative services. Nevertheless it is striking to note that some of these services were hardly used during the preceding year. One hypothesis could be that palliative care is sometimes unnecessary if usual care and family support are adequate. A second hypothesis is the late identification of the palliative status by the GPs. A last option should be that doctors who have problems with talking about end-of-life issues would not start palliative care in order to avoid talking about it. These hypotheses would need further analysis using a qualitative design.

6.4.6 Limitations of the web survey

The first limitation refers to potential selection biases, as GPs who participated were probably more interested in palliative care. Moreover, a subgroup of French-speaking respondents followed specific palliative training ("RAMPE" group). Multivariate analyses were used to overcome this problem.

Secondly, this web survey did not include specialists who still care for a large proportion of palliative patients.

Finally, there is a potential gap between the perception of the GPs and the reality. As illustration, it might be that the GP experiences communication problems that are not noticed by the patient whilst patients of GPs who do not experience any problem would not be satisfied about the communication with their GP.

Key points: web survey among general practitioners

- **About half of the GPs who participated had at least one palliative patient at the time of the survey;**
- **The GPs who participated to this web survey see palliative care as an essential task for general practitioners;**
- **GPs with training in palliative care have less difficulty to cope with organisational and psychological difficulties when caring for palliative patients;**
- **GPs make a distinction between "palliative" (patient for whom the care needed exceeds the usual care for the disease) versus "terminal" and "dying" patients (terms associated with estimated time before death);**
- **Working with colleagues (duo or group-practice) facilitates palliative care.**

7 SURVEY IN HOME SETTINGS

7.1 STUDY DESIGN

This prospective study has two parts:

- Identification of palliative patients by the general practitioner and description of their characteristics at the beginning of the survey (T1);
- Follow up of the identified palliative patients 12 weeks later (T2).

7.2 METHODOLOGY

7.2.1 Recruitment of GPs

7.2.1.1 Recruitment of Dutch-speaking GPs

Domus Medica randomly selected two samples of 375 GPs out of their database of 7700 Dutch- speaking GPs. We contacted the 750 GPs by phone: 684 could actually be reached after a maximum of three attempts.

From the 684 contacted GPs, 34.5% (236) refused to participate to the study and 65.5% (448) were willing to take part. However, only 44.2% of them (198/448) did fill out the questionnaires, either the one for GPs without palliative patient(s) or the questionnaire at T1 about the palliative patient(s).

Of the total group contacted by phone, the response rate was 28.9% (198/684): 60.6% of the respondents (120/198) included one or more palliative patients, resulting in 164 palliative patients included at time 1. The other GPs (39.4%, 78/198) had no palliative patient.

7.2.1.2 Recruitment of French-speaking GPs

The SESA from UCL provided two samples of 275 French-speaking GPs: 477 of the 550 GPs were actually reached by phone after a maximum of three attempts.

Of the 477 contacted GPs, 47.6% (227) accepted to take part to the study. Two thirds of them (63.4%, 144/227) did effectively fill out the questionnaires, either the one for GPs without palliative patient or the questionnaire about the palliative patient(s) belonging to their practice at time 1.

From the total group contacted by phone, we had a response rate of 30.2% (144/477). One third of this group (36.1%, n=52) included one or more palliative patients, resulting in 75 palliative patients included at time 1. The other GPs (63.9%, 92/144) had no palliative patients at time1 and responded only to the questionnaire about their practice.

7.2.1.3 Final sample of GPs

The initial sample size calculations estimated that the number of GPs should be between 455 and 767 (see appendix). A total of 1320 GPs were contacted by phone: 675 (58.1%) accepted to take part to the study but 342 only filled out the questionnaire. In that group, 50.3% (172/342) had one or more palliative patients, resulting in 239 included patients for time 1. Half of the GPs (170/342) had no palliative patients.

Table 13: Inclusion of GPs and palliative patients

	Dutch speaking	French speaking	Total
N Sample	750	550	1320
Effectively reached	684 (59.0%)	477 (41.0%)	1161 (100.0%)
Acceptance	448 (65.5%)	227 (47.6%)	675 (58.1%)
Refusal	236 (34.5%)	250 (52.4%)	486 (41.9%)
N included GPs	198 (44.2% of the acceptance group)	144 (63.4% of the acceptance group	342 (50.7% of the acceptance group)
N GPs with pall pt	120 (60.6% of the included group)	52 (36.1% of the included group)	172 (50.3% of the included group)
N GPs without pall pt	78 (39.4% of the included group)	92 (63.9% of the included group)	170 (49.7% of the included group)
N pt included T1	164	75	239

7.2.2 Inclusion of palliative patients

The GPs who agreed to participate were contacted by phone with the following question: "Are you at this moment in charge of one or more patients meeting following criteria: "suffering from an incurable, progressive, life-threatening disease, with no possibility to obtain remission or stabilization or restraining of this illness"?". This definition of a palliative patient was the same in the three different settings (GPs, hospitals, nursing homes for the elderly) and is further detailed in the part on hospital survey.

If the GP did not have any palliative patient at the moment, he/she was asked to answer to a short questionnaire about his/her practice.

If the GP was in charge of palliative patient(s), he filled out one questionnaire per included palliative patient.

7.2.3 Development of the questionnaire for the home setting

Questionnaires in the home settings were developed in parallel to the development of the questionnaires in the hospitals as they had the same aims i.e., assessing the prevalence of palliative patients in different settings, the therapeutic project of the health professionals and the follow-up of the patients 12 weeks later.

The final versions of the questionnaires are displayed in appendix. The first questionnaire HA2 collected data about the GP's practice. The first patient questionnaire HA/MG 3a concerned data relating to the patient's socio-demographic characteristics, the diagnoses, the prognosis, the care plan, specific options in relation to palliative care and the most likely future actions for this patient. The second one HA/MG 3b to be administered 12 weeks later was devoted to current therapeutic strategy's changes with special attention to palliative care resource used.

7.3 RESULTS

7.3.1 Results: description and characteristics of palliative patients in the home setting at time 1

7.3.1.1 Description of the participating GPs

342 GPs agreed to take part to the study: 65.2% (221/342) were male and the mean age was 48 years. This mean age is the same as the mean age of the GPs registered in the RIZIV/INAMI statistics as having a clinical activity[300]. There were less men in this sample than in the total Belgian group (65.2% male GPs in this study versus 81%).

Two-thirds (64.2%, 210/327) worked in a single-handed practice, 16.5% (54/327) in a duo-practice, 12.5% (41/327) in a group-practice and 4.9% (16/327) in a Community Health Centre; 1.8% (6/327) ticked 'other'.

One third (36.5%, 174/274) of the included GPs had some training in palliative care.

As stated above, half of the GPs had one or more palliative patients. The GPs with palliative patients had a mean number of palliative patients equal to 1.4 (ranging from 1 to 8 patients).

A comparison between groups with and without palliative patients was conducted using the following variables i.e., language community, gender, age of the GP and having followed a training in palliative care. Only significant differences were found for language (less French speaking doctors had palliative patients) and gender (more female doctors had palliative patients). The characteristics of the practice were different but when recoded into single handed versus others the results were not significant. Having followed training in palliative care showed no significant difference between both groups.

Table 14: Practice features in group GPs with and without palliative patients and in the whole included group

Practice	GPs with palliative patients% (N) (n/N)	GPs without palliative patients% (N) (n/N)	Included group % (N) (n/N)
Single handed	58.6 (99/169)	70.3 (111/158)	64.2 (210/327)
Duo	20.1 (34/169)	12.7 (20/158)	16.5 (54/327)
Group	16.0 (27/169)	8.9 (14/158)	12.5 (41/327)
Community Health centre	3.0 (5/169)	7.0 (11/158)	4.9 (16/327)
Other	2.4 (4/169)	1.2 (2/158)	1.8 (6/327)

7.3.1.2 Description of the included palliative patients in the home setting

The study included 239 patients from 172 general practitioners. Half of these patients (51.7%, 122/239) were men. Mean age was 71.4 years (from 17 to 99 years) with a median of 74 years. A 'palliative forfait' was applied for 58.3% of the patients (91/156).

Three out of five patients (62.7%, 148/236) were married or lived with a partner. One third of the patients (37.2%, 87/236) had no partner (either widow/widower or single).

Most patients (80.5%, 190/236) lived at home, either in their home or with close relatives. One fifth of the sample (19.5%, 46/236) lived in an elderly nursing home.

Most patients (88.8%,198/223) were previously admitted to the hospital, of whom 23.6% (52/220) were previously admitted in intensive care.

Life expectancy exceeded 3 months for 56.6% (124/219) of the patients. For one third of the sample (33.3%, 73/219,) the doctor expected the patient to die within 3 months and 10% (22/219) was expected to die within some days.

7.3.1.3 Diagnoses

Most patients (79.3%, 176/222) had an oncology problem i.e. either a tumor (88%, 155/176) or a hematology problem (11.9%, 21/176). Dementia was the second most common pathology for 3.6% (8 patients). Five patients had respiratory problems (2.3%) and four suffered from cardiovascular disease (1.8%). All other diagnoses counted for maximum 1%.

7.3.1.4 Treatment options

Treatment options were not at all discussed for 13.8% of the patients (30/218). General options about treatment were recorded in 59.1% of the cases (129/218). The options were mostly discussed (87.6%, 113/129) with the patient. For a quarter of them (27.1%, 59/218) the professionals discussed with the family, mostly orally (83%. 49/59). For 27% (59/218) this question was not answered.

Looking more in detail, the health professionals excluded specific treatment options for about half of the group: resuscitation (55.8%, 121/217), renal dialysis (68.7%,147/214), vasopressors (50.5%, 107/212). Only antibiotics were in half of the cases considered (53.2%, 115/216).

Tube feeding and giving fluid were respectively in 40.5% (87/215) and 36% (77/214) excluded. In about 1/4 of all cases, treatment options were neither considered, nor discussed.

Table 15: Treatment options for the palliative patients included

	Resuscitation % (n/N)	Tube feeding % (n/N)	Par-enteral fluid % (n/N)	AB % (n/N)	Blood transfusion % (n/N)	Renal dialysis % (n/N)	Vaso-pressor % (n/N)
Excluded	55.8% (121/217)	40.5% 87/215	36.0% 77/214	22.2% 48/216	47.0% 101/215	68.7% 147/214	50.5% 107/212
To consider	12.9% (28/217)	23.3% 50/ 215	31.8% 68/214	53.2% 115/216	29.3% 63/215	9.8% 21/214	22.6% 48/212
Ongoing		10.2% 22/215	6.1% 13/214	12.0% 26/216	3.3% 7/215	0.5% 1/214	3.3% 7/212
Not discussed	31.4% 68/217	26.1% 56/215	26.2% 56/214	12.5% 36/216	20.5% 44/215	21.0% 45/214	23.6% 50/212

Treatment for the major pathology was stopped for half of the patients (49.3%, 105/213). For 13.1% of the patients (28/213) new or existing treatment options could be considered. For 30% (64/213) a treatment was ongoing and for 7.5% of the patients (16/213) a treatment was established but not yet started.

A referral to a palliative unit was excluded for 29.2% of the patients (62/212). For 5% (10/212) this referral could be considered and the option was not discussed in 20.8% of the cases (44/212).

Half of the patients (48.8%, 104/213) wanted comfort as first choice, 21.6% (46/213) wanted life-prolonging treatment and this option was unknown for 29.5% (63/213). Family members were more clear: 66.8% (143/214) wanted comfort, 21% (45/214) wanted life prolonging treatment and for 12.2% (26/214) this was not discussed.

Eighty patients (48.5%, 80/165) had expressed intentions for their end of life, mostly orally (81.3%, 65/80). 15.9% (25/157) had a demand for euthanasia, mostly orally expressed (68%, 17/25).

7.3.1.5 Planning for the future

Place of palliative care

Most patients and family members (71.8%, 145/202) wished the patient to stay at the same place he/she stayed at the moment of the survey (home or nursing home), mostly (73.1%, 106/145) with the aid of palliative care services.

Five percent (5%, 11/202) wanted to be transferred to the hospital with a palliative support team. A similar number (4.5%, 9/202) wanted to go to a palliative unit and 2.5% (5 patients) wanted to be referred to a nursing home. This item was not discussed for 15.3% of the patients (31/202).

Place of death

This topic was not discussed in about a quarter of the cases (28.1%, 60/213). When discussed, most patients wanted to die in the place where they live (52.1%, 111/213 at home, 10.3%, 22/213 in the nursing home). The idea of the family about the place of death sometimes differed: more family members want the patient to die in the hospital.

Table 16: Patients and family members' preference of place to die

	Patient% (n/N)	Family member% (n/N)
At home	52.1% (111/213)	45.3% (96/212)
In the hospital	2.3% (5/213)	6.1% (13/212)
In a palliative care unit	2.3% (5/213)	1.9% (4/212)
Nursing home	10.3% (22/213)	14.2% (30/212)
Depending on the evolution	4.7% (10/213)	7.1% (15/212)
Don't know, not discussed	28.8% (60/213)	25.4% (54/212)

7.3.2 Results: description and characteristics of palliative patients in the home setting at time 2 -12 weeks after time 1

7.3.2.1 Group of patients who died before T2

Situation

Half of the patients (50.6%, 121/239) died before T2.

- 19.1% (23/121) died in hospital;
- 10.7% (13/121) died in a palliative care unit;
- 53.7% (65/121) died at home;
- 16.5% (20/121) died in a nursing home or residency for the elderly.

Comparison: life expectancy and status of the patient at T2

Half of the included patients died before T2. A comparison with the GP prognosis at T1 shows a discrepancy: 40% of the patients who were assessed to have a life expectancy of more than 3 months died before T2 (12 weeks after T1). 40% of the patients who were expected to die within 3 months were still alive at T2, even for three patients who were expected to die within a few days.

Table 17: Life expectancy at T1 and status at T2

Life expectancy	Alive % (n/N)	Died % (n/N)
3 months and more	59.7 % (74/124)	40.3 % (50/124)
Less than 3 months	39.7 % (29/73)	60.3 % (44/73)
Some days	13.6% (3/22)	86.4 % (19/22)
Missing values	59.0 % (10/17)	41.0% (7/17)

Comparison between the wish for the place to die and the place of death

Eight patients wanted to die in a hospital and 6 of them died between T1 and T2: 2 died in hospital as demanded, 4 died at home.

Five patients expressed the wish to die in a palliative care unit and 2 of them died between T1 and T2: one died in a in a palliative care unit as demanded, 1 died at home.

One hundred and twelve patients (n=112) expressed the wish to die at home and 62 of them died: 44 died at home as demanded, 9 died in hospital, 6 died in a palliative care unit, 2 died in a nursing home.

Twenty-two patients expressed the wish to die in a nursing home and 13 of them died: 11 died there as demanded, 2 died at home.

Table 18: Comparison between the wish for the place to die and the place of death

Wish for place to die (Nr patients)	Nr pt wanting to die in:	Nr pt died before T2	Place of death			
			Hospital	Palliative care unit	Home	Residency
Hospital	8	6	2		4	
Palliative care unit	5	2		1	1	
Home	112	62	9	6	44	2
Nursing home	22	13			2	11

In conclusion, most palliative patients in the home setting died at the place they wanted if they expressed a wish. With the exception of the home situation, if the patient did not die in the requested place, he/she most often died at home. If the requested place was at home this wish was fulfilled in most cases (76%).

If the patient who wanted to die at home died in hospital or in a palliative care unit, the most frequent reason was that either the medical care was to demanding to give this at home[309], either the GP or specialist assessed that the care for the patient was psychologically to demanding for the family[28]. Only in 3 situations the patient and in 2 situations the family asked to make the transfer.

7.3.2.2 Treatment strategy for patients in general practice between T1 and T2

Half of the patients (51%, 98/192) received some treatment or admission to hospital between T1 and T2: 55 patients received 1 treatment, 22 patients received 2 treatments, 15 patients 3 treatments and 4 patients more than 3 treatments (to a maximum of 9). The details of treatments:

- 72 patients were admitted to hospital;
- 51 patients received antibiotics;
- 16 patients had tube feeding;
- 15 patients received parenteral feeding;
- 3 patients were resuscitated;
- 10 patients got a blood transfusion;
- 3 patients received a renal dialysis;
- 3 patients got vasopressors during their stay in hospital.

The most frequent decision when the patient received only one further treatment was an admission to hospital (61.8%, 34/55), followed by getting antibiotics (29.1%, 16/55). Three patients got tube feeding and 2 patients parenteral feeding as only treatment. The patients who were resuscitated, received blood transfusion or renal dialysis always had other treatments combined.

The study analysed the correspondence between excluded treatment options and further treatments. When resuscitation, renal dialysis or vaso-pressors were excluded, the patient never received any of them. Some patients received treatment while those options were excluded at T1: 2 persons received tube feeding, 2 persons got parenteral feeding, 2 persons got a blood transfusion and 7 patients received antibiotics.

7.3.3 Multivariate analyses

Multivariate analysis was performed in order to get an idea of possible predictors of the results.

7.3.3.1 Variables influencing discussion of treatment options.

Independent variables used in the equation were:

- language
- age and sex of the GP
- practice characteristics (working single handed or not)

- GP followed training palliative care or not
- age of the patient
- diagnosis (oncological problem or not)
- life expectancy (more than 3 months, between some days and 3 months, death expected within some days).

Dependent variables were:

- treatment options discussed or not?
- were treatment options discussed with patient or with the family?
- discussion of treatment options: oral or written?

Younger doctors were more likely to discuss the treatment options with patient or family. If discussed French speaking doctors and older GPs more often did this with the family. Written forms were more used with younger patients. No other variables were significant.

7.3.3.2 Variables influencing treatment options between T1 and T2

We looked for possible variables influencing treatment options between T1 and T2. The variables used in part one, Dutch or French speaking, age and sex of the GP, practice organisation, having followed a training palliative care and number of palliative patients at this moment, were non significant.

Age of the patient, diagnosis (oncological problem or not) and status of the patient (more than 3 months, between some days and 3 months, death expected within some days) were introduced as possible predictors of treatment options.

Younger patients received more treatments. The other variables were non significant.

Since admission to hospital was the most frequent intervention, we looked for possible predictors. None of the variables (language, age and sex of the GP, age of the patient, diagnosis and status of the patient) was significant.

7.4 DISCUSSION: PALLIATIVE CARE IN HOME SETTINGS

This survey included about 350 GPs: about twice as many GPs accepted to co-operate but did not fill out the questionnaires. Nevertheless the results of this research give an insight into the Belgian situation, even if the profile of respondents might induce a selection bias. The population under study partly overlap with the populations of the two next chapters as GPs might have patients in nursing homes and/or other persons might be transferred in hospitals.

The results of this part are in line with those of the web-based survey. Half of the GPs who participated took care of at least one palliative patient at the time of the survey. GPs have about one to two palliative patients at the same time. There is a large difference between Dutch and French speaking GPs: 60% of the Dutch GP included palliative patients versus 36% of the French speaking GPs. An explanation might be the different data sources used to find the GP participants in both parts of the country.

Most palliative patients identified by the GPs were older than 70 years and suffered from an oncology problem. Chronic diseases were rarely mentioned in the survey.

GP stated that in about 25% of the cases, disease, treatment options and wishes about place to be and to die were not discussed with the patient, despite recommendations in literature[310, 311]. Written preferences were exceptional. The question is to know if the remaining 75% effectively know the exact content of the patient's wishes.

Curative treatment of the main pathology had been stopped for half of the patients and intrusive future treatments were excluded. Only the administration of antibiotics is mostly permitted, followed by par-enteral and enteral perfusions (considered for one third of the patients). The study from the Christian Sickness Funds found that nearly half of the patients at home received antibiotics during the three last months of life[303].

Most patients want to die at home. Family members do agree to some extent but more frequently consider other options. Probably they feel the limits of their capacity to support and to live with a dying patient. Moreover, GPs might assess this as well in their advice to the patient and the family. Higginson and Costantini showed in their review that patients' preferences, intensity of home care and extended family support were factors strongly associated with home death[57]. In the Senti-Melc[28] study only 47% of the GPs were aware of patients' wish concerning place to die[301] versus 71% in this study conducted 2 years later. When wishes were clarified, nine out of ten patients wanted to die at the place where they lived, in this study as well as in the Senti-Melc study.

Patients mostly want to be comfortable at the end of their life: most of them do not wish treatments to prolong their life. Family members are even more explicit: they want comfort for the patient.

This survey showed that assessing survival time before death is difficult, as mentioned in the part about definition and in the discussion of the results of the web-based questionnaire[56, 309]. The GPs in this survey were often inaccurate in their prognosis, even for some dying patients.

Half of the patients included in the survey were still alive after 12 weeks: this finding illustrates that 2 months of palliative care is inferior to the actual duration of palliative care for half of the patients identified as palliative by their GP.

If discussed, the treatment options were mostly followed, only a small part of the patients received treatments that were previously excluded. This was the case in particular for admission in hospital and antibiotics.

The wish of the patient about the place of death has been followed for most patients, in particular those ones who desired to die at home and in replacement home settings. This is comparable to the Senti-Melc study: 80% of the patients died where they wished to die when the GP knew about this wish[301]. If this wish was not fulfilled, the most frequent reason was that the formal caregiver assessed that either the medical care was too demanding, or psychological aspects would be too demanding for the family. If the patient did not die in the requested place the GP usually triggered the transfer. Sometimes however the patient him/herself changed his/her mind, probably to overcome the problems for the family. The part about the needs of palliative patients indeed showed that palliative patients are sensitive to stay as independent as possible[103].

Key points: palliative patients in home settings

- **Palliative patients at home are mostly old patients who suffer from cancer.**
- **Treatment options are not discussed for a quarter of the patients.**
- **Treatment options were excluded for half of the patients, with the exception of admission to hospital and antibiotics.**
- **When discussed, the wishes for further treatment were mostly followed.**
- **Most patients want to die at home and the reality frequently answers to their wish.**

8 SURVEY IN NURSING HOMES AND RESIDENCIES FOR THE ELDERLY

8.1 STUDY DESIGN

This prospective study has two parts:

- Identification of palliative patients in a sample of nursing homes and residencies by the responsible/nurse of the institution and description of their characteristics at the beginning of the survey (T1);
- Follow up of the identified palliative patients 12 weeks later.

8.2 METHODOLOGY

8.2.1 Recruitment of the nursing homes

Three random samples of 50 elderly nursing homes/residencies were selected out of the database of the Belgian government. If the institution did not accept to participate, a similar institution from the second sample (or if needed from sample three) was selected. Fifty (50) residencies were finally included, 25 Dutch speaking and 25 French speaking ones. The table below shows that service flats are less common in the French-speaking part of the country. The following paragraphs will use the term "nursing homes" for all institutions.

Table 19: Institutions included in the study

	Dutch speaking	French speaking	Total
Nr places	2347	1552	3899
Nr service flats	255	8	263
Total	2602	1560	4162

The first sample size calculations estimated that between 2080 and 7925 elderly people had to be included in order to have a high confidence level (see appendix 4.2). The size of this final sample includes 50 residencies with 4162 places.

After inclusion the researcher filled out one questionnaire on the features of the institution;

8.2.2 Development of the questionnaire

The questionnaires for nursing homes (see appendix 4.3) were similar to those used in hospitals (cf. next chapter).

8.3 RESULTS

8.3.1 Description of participating nursing homes

8.3.1.1 Characteristics of the participating nursing homes

The mean number of beds in the nursing homes is 89 (from 21 to 191 places). The mean number of residents in the Dutch speaking nursing homes is 102 (41 to 180), in the French speaking nursing homes 70 (21 to 191). The occupation rate is high; 88% in the Dutch-speaking and 100% in the French-speaking nursing homes.

In the Dutch speaking part of Belgium 16 out of 25 nursing homes have special care for dementia versus in 7 out of the 25 French speaking institutions. In Flanders 11 homes are publicly supported (OCMW) versus only 3 French-speaking institutions (CPAS). Fourteen homes in the Dutch speaking part versus 6 in the French speaking part are VZW. In the French-speaking part, 15 are private institutions.

8.3.1.2 Palliative care in the participating selected nursing homes

The researchers discussed with the responsible of the nursing home if the team had a formal view on the way to provide palliative care (legal obligation). If yes, the researchers asked if and how this was communicated to the resident and/or his/her family. They also looked at possible documents that could help residents in decision making processes: official documents "Not To Resuscitate", euthanasia and living will.

From the 26 nursing homes (18 in Flanders and 8 in the French speaking part) who have a formal view on palliative care, 23 (17 in Dutch speaking, 6 in the French-speaking part) communicated this to the patient and/or family members, 3 did not. This information was usually explained verbally by a member of the team (17). Seven homes had written documentation (brochure, intranet, quality handbook) for team members, mostly not accessible for residents or family members.

Half of the nursing homes (16 in the Dutch speaking part, 8 in the French speaking institutions) have one or more documents concerning end of life (official forms, living will, "Do Not Resuscitate" (NTR) and euthanasia documents). In Flanders 9 nursing homes have all three documents, 4 have only a NTR document, two have NTR and euthanasia documents, one has only a euthanasia document. In the French speaking part, one nursing home has a living will and an NTR document, three other ones have a living will, 4 have a NTR document and one has a document on euthanasia.

8.3.2 Results of questionnaires 1 at time 1

The researcher checked all patients together with the responsible of the nursing home, mostly a nurse (75.9%) in order to decide if the patient fulfilled the definition of a palliative patient as detailed in the chapter on home setting. All palliative patients were included in the study.

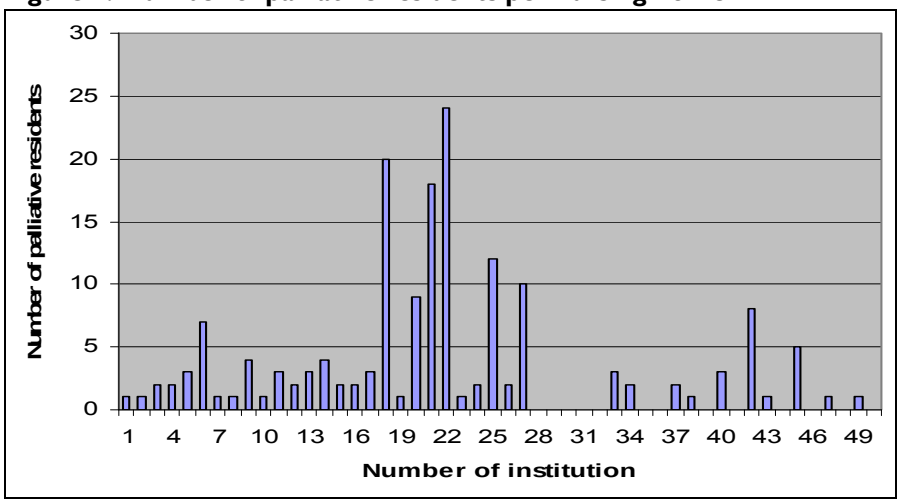
8.3.2.1 Description of the palliative patients in nursing homes

The total number of included palliative patients was 168: 129 Dutch speaking and 39 French speaking patients.

Most palliative patients were female (101/165, 61.2%), with a mean age of 83.8 years (Std 8.6) (from 53 to 103 years). Most of them lived alone, either as widow(er) 103/164 (62.8%), or as divorced or as single 29/164 (17.7%). One fifth of the persons (32/164, 19.5%) were married.

One out of 20 residents (4.3%, 168/3849 residents) was identified as a palliative patient; The prevalence was higher in Dutch speaking institutions (5.2%) than in the French speaking institutions (2.5%). In Flanders, four nursing homes had respectively 12, 18, 24 and 12 palliative patients. In the French speaking institutions the highest numbers were 5, 8 and 10 persons. In Flanders, all nursing homes identified at least one palliative patient. In the French-speaking part, 13 residencies had no palliative patient.

Figure 1: Number of palliative residents per nursing home



8.3.2.2 *Diagnoses*

Many palliative patients (38.1%, 64/168) suffered from dementia as main diagnosis. The second most frequent main pathology was cancer, with an incidence of 16.7% (28/168). Terminal heart failure and cardiovascular disease accounted for 11.3% (19/168) and 15.5% (26/164) respectively.

All other pathologies had less than 5 patients.

8.3.2.3 *Treatment options*

Table 20: Main pathology

Pathology	Dutch speaking % (n/N)	French speaking % (n/N)	Total % (n/N)
Cancer (either tumor or hemo-lymphopathy only 1 case)	14.8% (19/129)	23.1% (9/39)	16.7% (28/168)
Terminal hart insufficiency	13.2% (17/129)	5.1% (2/39)	11.3% (19/168)
CVD	18.6% (24/129)	5.1% (2/39)	15.5% (26/168)
Cardio vascular other than CVD, respiratory, lever, renal pathology, infectious disease	4.7% (6/129)	10.3% (4/39)	6.0 % (10/168)
Dementia	35.7% (46/129)	46.2% (18/39)	38.1% (64/168)
Other degenerative neurological pathology	0.8% (1/129)	7.7% (3/39)	2.4% (4/168)
Other pathology	12.4%(16/129)	2.6% (1/39)	10.1%(17/168)

Before their palliative status, 62% (104/166) of the residents were already admitted to the hospital (from 1 to 10 admissions). Most of them (30.6%, 26/104) were already admitted in intensive care unit, mostly once.

Life expectancy

Most palliative patients (80.6%, 129/160) had an expected lifetime exceeding three months. The death was expected within three months for 15.6% of the patients (25/160) and within a few days for 4 residents. Most palliative patients (70.4%, 114/162) were not informed about their palliative condition, mostly due to cognitive impairment.

- 64 patients suffered from dementia (first pathology as well as in combination with another pathology);
- 27 other residents were not capable of receiving information (mental disorder, coma, mentally handicapped…);
- 14 residents were not informed, whilst capable of receiving information. The reasons were mainly psychological: the resident was not capable to

accept the diagnoses/palliative situation (6), did not want to hear (3) the diagnosis or the family refused the situation to be told (3), the resident denied or was not aware of the situation', a bad contact between the caregivers and resident (1), the resident got the label palliative from the hospital just some days ago (1).

All but one palliative residents got the information from a doctor, mostly the general practitioner (56.2%, 27/48), sometimes in presence or in co-operation with the family or with the palliative referent of the nursing home (29.5%,14/48). Three patients were informed in the hospital by the specialist and one patient was informed by the nurse of the nursing home. For two residents this was unknown.

Options for further treatment

Options for further treatment were registered with the resident in 19.9% of the cases (33/166; 26 written and 7 oral). In 49.4% (82/166) of the cases this was done with family members.

For 6 residents the caregivers took the responsibility for further treatment options, for one resident due to the absence of any family member.

Most treatments were excluded, except antibiotics. In 10 to 20% of the cases, treatment options were neither considered nor discussed with the team, the patient and/or the family. For resuscitation this number was 26%.

Table 21: Treatment options

	Resuscitation % n/N)	**Tube feeding % (n/N)**	**Parenteral fluid % (n/N)**	**AB % (n/N)**	**Blood transfusion % (n/N)**	**Renal dialysis % (n/N)**	**Vasopressor % (n/N)**
Excluded	68.5% 111/162	72.9% 121/166	72.3% 120/166	7.8% 13/166	67.5% 112/166	79.5% 132/166	60.5% 98/162
To consider	5.6% 9/162	6.6% 11/166	11.4% 19/166	74.7% 124/166	11.4% 19/166	3.0% 5/166	14.2% 23/162
Ongoing		9.6% 16/166	6.0% 10/166	16.3% 27/166		0.6% 1/166	11.7% 19/162
Not disc	26% 42/162	10.8% 18/166	10.2% 17/166	1.2% 2/166	21.1% 35/166	16.9% 28/166	13.1% 22/162

In half of the cases (48.8%, 79/162) any further treatment was excluded. Treatment was ongoing in 29.6% (48/162) and for 17.3% (28/162) it could be discussed.

For 64.9% of the palliative patients (72/111) the treatment would be only symptomatic: remission or stabilisation was the aim in 30.6% (34/111), although this is in contradiction with the definition of palliative patient used in this research. For one resident the treatment was only psychological.

For 59.4% palliative patients (98/165) admission to the hospital was excluded. For 7.3% of the residents (12/165) this admission could be an option. For 25% (42/165) hospitalization could be an option but not for the main pathology.

For 75.9% of the residents (126/166) the reference to a palliative care unit was excluded but for 12% (20/166) this could be an option. The most frequent reason was that the residency could give palliative care as good as any palliative care unit.

Only 11.5% (18/157) of the palliative residents had a living will and one resident (0.6%) has an euthanasia document. Half of the palliative residents (54.2%, 91/165) had a "do not resuscitate" document available.

8.3.2.4 *Future expected actions*

Wishes for further treatment

Apart from the specific treatment options (see above), residents and/or family members were asked their general wishes for the future i.e., comfort, life prolonging treatment or do not know. In 62.5% of the cases (102/163) wishes for further treatment were not discussed with the resident.

When discussed, fifty-one patients (31.3%, 51/165) wanted comfort and 6.1% (10/165) wanted a treatment that extends life if possible. Family members definitively wanted comfort (75.9%, 123/162), 8.0% (13/162) wanted a treatment that prolongs life and 11.7% (21/165) did not express any wish.

Place of death

Half of the patients (57.2%, 95/166) wanted to stay in the nursing home, 42.2% (70/166) did not express any wish concerning their place to die.

Family members definitively wanted the resident to die in the nursing home (82.5%,137/166), while 15.6% (26/166) did not express any wish.

The teams of the nursing homes thought that 91.0% (151/166) of the palliative residents would be best off getting palliative care within the ward. Eighty-four% of the caregivers also wanted to take care of family members.

8.3.2.5 *Features of nursing homes with high number of palliative patients*

Five nursing homes included 10 or more patients, four in Dutch-speaking, one in the French-speaking provinces. This was significantly higher than the number of included patients in the other nursing homes.

The first difference between the nursing homes with high versus low inclusion numbers was the size of institution. Nursing homes with high inclusion had 50% more residents (mean 126.5 Std 43.2 versus 80 Std 43). The nursing homes with a high number of palliative patients had no service flats and had a significantly higher number of places for residents with special care (mean 83.7, Std 12.5 versus 37.1 Std 28.5).

Looking at the features of the residents homes with high inclusion more residents had a higher score on the KATZ scale (difference significant for special care KATZ B, C and CD: B: 14 Std 14 versus 10.9 Std 9.7 C: 38 Std 35 versus 9.3 Std 10.3 CD: 30.2 Std 20.5 versus 15.9 Std 16.3).

There was also a significant difference in the mean number of residents with dementia. In nursing homes with high inclusion this number was almost double compared to the other nursing homes (23 Std 26.5 versus 12.2 Std 19.3).

Moreover, all nursing homes with high inclusion had a formal view on palliative care and a formal protocol concerning end of life. They discussed their vision on palliative care and gave information to the resident and/or the family. Moreover they had documents for living will, NTR and euthanasia. All documents were discussed with resident and/or family.

Another difference concerned the pathology: in nursing homes with high inclusion twice as many patients with dementia were included. In the other nursing homes more patients with cancer pathology were included. As a result the mean duration time since the diagnosis was higher in the nursing homes with high inclusion.

Looking at treatment options in nursing homes with high inclusion most medical treatments (except for antibiotics) were excluded in about 80%, versus between 50 and 60% in all other homes. In nursing homes with high inclusion most treatment options were discussed with family members, as expected since more patients suffer from dementia.

It is clear that for the patients in homes with high inclusion, patients and/or family members wanted the patient to stay in the nursing home and to die there. For 80% of the patients a reference to a palliative care unit was excluded. As expected most family members wanted comfort treatment for the patient.

For more patients in wards with high inclusion (78.3% versus 69.1%) a NTR document was filled out. No difference was found for other documents.

8.3.3 Result of questionnaire 2 at time 2 (12 weeks after time 1)

8.3.3.1 Group of patients who died before T2

Of the 168 included patients 45 (26.8%) died before T2: all of them wished to die in the nursing home. Forty-three died in the nursing home, one person died in hospital (transfer was needed due to medical problems). There was one missing value.

8.3.3.2 Comparison between life-expectancy at T1 and T2

A quarter (23.3%, 30/129) of the patients with a life-expectancy more than 3 months died before T2. Three out of five (60%, 15/25) patients with a life-expectancy between 2 weeks and 3 months were still alive at T2. One patient out of 4 who were expected to die within some days was still alive at T2.

8.3.3.3 Treatment interventions between T1 and T2

Of the 124 residents still alive, one was in hospital at T2 and the others in the nursing home: 77 received palliative care, 30 did not have any palliative care.

Most palliative residents (68.4% 106/155) did not get any treatment suggested in the survey between T1 and T2. One quarter (23.9%) of the residents (37/155) received one intervention, 5.8% (9/155) two interventions and 1.9% (3) received 3 interventions. Antibiotics were administered in 36 cases, 13 residents were admitted to hospital, 7 got tube feeding, 5 parenteral feeding and 1 got a blood-transfusion.

Thirteen (n=13) residents were admitted to the hospital although this option was excluded for 6 of them. For the residents receiving antibiotics this treatment option was not excluded. One of 7 persons receiving tube feeding and one of the 5 residents with parenteral fluid had had this treatment option excluded at T1.

Multivariate analysis

Multivariate analysis was performed to identify possible predictors of the results.

VARIABLES INFLUENCING DISCUSSION OF TREATMENT OPTIONS.

Independent variables in the equation were:

- language
- size of the nursing home
- age and gender of the resident
- life-expectancy at time 1
- pathology : dementia or not

Dependent variables were:

- treatment options discussed or not
- treatment options discussed with patient or with the family
- treatment options orally discussed or written down

The evolution from treatment option to effective decision has not been analysed for each treatment given the small sample sizes. Little variations were noted between patients with most treatments either excluded (e.g. dialysis) or considered (e.g. antibiotics) at the beginning of the survey.

Treatment options were more often discussed in Dutch speaking nursing homes. When patients came closer to death, treatment options were more frequently discussed.

Treatment options were more often written down in larger nursing homes (N=104, odds .230) and for younger patients N=104, odds .943). No other variables were significant.

VARIABLES INFLUENCING TREATMENT OPTIONS BETWEEN T1 AND T2

We looked for possible variables influencing treatment options between T1 and T2. Following variables were included in the equation as independent:

- Language;
- Size of the nursing home;
- Age and sex of the resident;
- Life-expectancy at time 1;
- Diagnosis (cancer, heart, CDV and dementia - other diagnosis had too small numbers).

Dependent variables were:

- received treatment or not, between T1 and T2;
- received antibiotics or not;
- admission to hospital: yes-no.

Concerning receiving treatment or not, only language was significant. In French speaking nursing homes the palliative patient got more treatment (N=132, odds ratio=7.864).

Looking more in detail, in nursing homes situated in the French speaking part (N=132, odds ratio=8.821), in larger nursing homes (odds ratio 3.833) and for patients with longer life expectancy (odds ratio .130) more antibiotics were delivered.

No variables were significant in relation to admission to hospital.

8.4 DISCUSSION: PALLIATIVE CARE IN NURSING HOMES

Only 4.3% of the residents were considered as palliative patients by the health professionals. This proportion probably underestimates the true prevalence: however the study did not collect baseline data on all residents that would have given characteristics of residents who died during the study but were not considered as palliative at the beginning of the survey.

In 2009, Belgium had 129.257 places in nursing homes. Considering a full occupation rate (cf. waiting lists) an extrapolation of the proportion of 4.3% to the whole resident population would mean that at least 5500 elderly people might be considered by their caregivers as being palliative patients.

Moreover there are large differences between nursing homes. If the nursing home has a formal view on palliative care and protocols concerning end of life, more palliative patients were included. This could mean that the view on palliative care has a direct influence on the number of palliative patients identified within the nursing home.

Most palliative patients suffered from dementia. However, topics concerning end of life were discussed if possible with the resident or if not with the family: in 2 out of 3 cases the agreements were even written down. This proportion is higher than the results from the survey in home settings.

Most curative treatments had been stopped and future treatments were excluded. In reality, no further treatment was administered for 70% of the patients. Antibiotics, followed by admission to hospital, were the most frequent interventions.

Most palliative patients asked to die in their nursing home and nearly all included residents who passed away died in their nursing home. This is in line with the Senti-Melc study where 93% of the patients died in their nursing home as requested when the caregivers knew about their wishes[28].

Key points: survey in nursing homes

- **Only 4% of all residents are considered as palliative by the health professionals;**
- **Most palliative residents suffer from dementia;**
- **Treatment options are mostly discussed with resident or family;**
- **When clarified, treatment options are mostly followed as well as the preferred place to die.**

9 PREVALENCE AND DESCRIPTION OF PALLIATIVE PATIENTS IN HOSPITALS

9.1 INTRODUCTION AND OBJECTIVES

A large amount of information is available on the hospital inpatients as they near the end of their life. Although place of death and its determinants have been extensively investigated, hospital use and transitions between care settings have been less often studied[27].

Studies that investigate hospital use at the end of life are often limited to specific diagnoses (e.g. cancer), age groups (e.g. the elderly) or settings (e.g. specialist palliative care services). Moreover, little is known about the size of the palliative care inpatient population and about their management in Belgian hospitals.

The primary aim of this study is to estimate the population of palliative patients who stay in short stay and medium stay hospitals and to describe the distribution of these patients according to medical and demographic characteristics and ward category. Other objectives are to measure the agreement on patients' status between the medical and the nursing staff, to describe the care palliative patients receive, use of resources and relationship between the hospital health care teams and the palliative care teams.

9.2 METHODOLOGY

9.2.1 Study design

This prospective study is composed of 3 parts:

1. Identification and prevalence of in-hospitals' palliative patients by interview of the heath care team,
2. Follow up of identified palliative patients (at 14 or 42 days) by interview of the healthcare team,
3. Cross-sectional description of palliative settings in hospitals.

9.2.1.1 Hospital's selection

In this study, 14 hospitals were randomly selected from all acute and medium-term care hospitals in Belgium.

Three criteria were taken into account:

- the type of institution (university, general or specific hospital),
- the total number of beds (> 500 beds, 300 to 500 beds or < 300 beds),
- the geographical locations (Brussels, Flanders or Wallonia).

We grouped the Belgian hospitals into twelve strata and used a random selection based on the hospital official identification number.

9.2.1.2 Hospitals' beds selection

All hospitals' beds were included except neonatology, paediatric wards, obstetrics and psychiatry as such wards are too exceptionally concerned with palliative care. Palliative and intensive care units were not eligible due to their specific care plans.

9.2.1.3 Patients' selection

All patients hospitalized on an eligible bed were included in the first survey. Patients admitted for less than 48 hours were excluded as the proportion of missing data could be too high. In case of in-hospital transfer during the same in-hospital stay, patients were included only once.

In the second survey, only patients identified as "palliative patients" by the nurse and/or the physician were enrolled.

9.2.1.4 Data collection

The survey was conducted in 2008 over a 3-months period (March 15st - July 15st) by two specifically appointed nurses. They had a short training including the presentation of the data collection form and a simulated interview.

Firstly, hospitals and wards received an information letter describing the survey's aim, the methodology, the timetable and the researcher's address and phone number. Then, each ward was visited by one researcher on two different days separated by a period of two weeks for the acute care units and by a period of six weeks for the medium-term care units.

Step 1: Identification of patients

On first day (D1), the researcher interviewed the principal nurse (or if impossible, a nurse in charge of the patient) and the physician who had the most daily contacts with the patient.

For each patient, the nurse and the doctor independently assessed whether the patient met the definition of "palliative patient". When their answers differed, a consensual response was required.

Step 2: Follow up

The second study's part was performed with the help of the same caregivers and with assistance of two structured questionnaires. The first questionnaire was submitted on D1. The second questionnaire took place 14 days (D14) after the first one in acute service and 42 days (D42) in medium-term care service. These delays of 2 and 6 weeks were fixed according to the mean in-hospital length of stay.

In the results section, the data concerning the second questionnaire will be presented with the terms ' at day 14 (42)' as the second questionnaire took place at day 14 for acute beds and at day 42 for non acute beds.

Step 3 Description of the setting

Finally, a self administered questionnaire was sent to the hospital's direction and to the persons in charge of the palliative care team and palliative care unit, if this unit existed in the hospital.

9.2.2 Sample size

The total number of hospital beds to be included in the survey should be greater than 3700 beds. This number corresponded to a confidence of 95% and an accuracy of 5.0% considering a design effect of 2.0. Estimates from the literature showed that 5 to 15% hospitalized patients are palliative patients, i.e. 10% on the average[41, 43, 45, 48, 312]. Taking these parameters into account in the formula to calculate simple and systematic samples multiplied by the design effect, we derived a sample size equal to 2 X 182 = 364 palliative patients. This would lead to investigate 364 / 0.10 = 3640 inpatients. Taking 0.75 as occupation rate meant that 4842 beds should be checked.

9.2.3 Definition of palliative patients in this survey

The definition of the "palliative patient" is based on the operational definition described in the definition section in order to identify the palliative inpatient population. Based on the literature, the researchers decided to identify the palliative patient as "*a patient suffering from an incurable (1), progressive (2), life-threatening disease (3), with no possibility to obtain remission or stabilization or restraining of this illness (4)*".

The term "incurable" allows excluding illnesses for which there is a chance of completely cure, the term "progressive" eliminating the chronic, incurable but stable disease. "No possibility to obtain a remission or a stabilization of the illness" points out the limits or the ineffectiveness of specific therapeutics on the disease's control[39] .

"Life-threatening disease" introduced a notion of survival prediction and fatal outcome[313]. This notion remained imprecise given the difficulty to give an accurate prognosis (see the parts on definition and survey at home), except very close to death[57].

This definition did not encompass any criterion based on the needs. This label was too subjective and would have forced to take into account many factors that are related to palliative care in the perception of care providers[40].

In the results section, the terms "palliative patients" is used for the patients identified as palliative by the physicians and by the nurses.

9.2.4 Survey questionnaires

The physician and nurse had to select patients meeting following criteria: "suffering from an incurable, progressive, life-threatening disease, with no possibility to obtain remission or stabilization or restraining of this illness". This definition was identical in the three different settings (GPs, hospitals, nursing homes for the elderly).

The design of the questionnaires used in the second study's part was based on a literature study done by two physicians specialized in palliative care and by one epidemiology specialist. The first questionnaire concerned data relating to the patient's socio-demographic characteristics, the diagnoses, the prognosis, the current admission, the care plan and the patient's discharge plan. The second one was devoted to specific palliative care resource used (hospital and home based), current therapeutic strategy's changes and patient's discharge (see appendix).

The questionnaires were submitted for review to a number of hospital staff. After adjustment, they were tested on one acute and one medium-term care service.

The self-administered questionnaire was a structured standardized questionnaire. It was only used to collect information about the establishment's structure, the institutional functioning and the palliative activity in the year 2007 (see appendix).

9.2.5 Ethical considerations

All procedures were undertaken to ensure the confidentiality and anonymity of the questionnaire and the voluntary participation of the hospitals. The forms were anonymous and the patient's identity was known only to the hospital staff. Nurses and doctors were asked for consent to interviews. The hospital ethic committees approved the study protocol.

9.2.6 Statistical analysis

Pearson's chi square test was used to detect statistical differences between groups as data gathered were primarily categorical.

Multivariate logistic regression was used to test the effect of some factors on the intention to prolong life, on the referral to the hospital palliative care team and on the discharge status. When testing the intention to prolong life, the covariates introduced in the model were age, sex, status, pathology, prognosis, type of beds and outcome. In the model dealing with the referral to the hospital palliative care team, the same factors and the intention to prolong life were introduced in the model. These factors were also introduced in the model that analysed the outcomes.

9.3 RESULTS

9.3.1 Prevalence of palliative patients in hospitals

The survey was conducted in 14 hospitals (4646 beds) and 2639 patients were included. The medical and/or nursing staff identified 249 patients who met the criteria palliative patients' definition. These patients counted for 9.44% of the total inpatient population.

9.3.1.1 Description of the sample of palliative patients

The next table shows the proportion of palliative patients in function of the region, hospitals, type of hospitals and the type of beds.

Table 22: Proportion of palliative patients in function of the region, hospitals, type of hospitals and the type of beds

	Nb Patients Included	Nb Palliative Patients	% Palliative Patients
Total	2639	249	9.44
Region			
Flanders	624	49	7.85
Wallonie	692	56	8.09
Brussels	534	85	15.92
University Hospitals	789	59	7.48
Hospitals			
G	115	7	6.09
H	87	5	5.75
I	394	36	9.14
J	395	23	5.82
K	101	2	1.98
L	42	1	2.38
M	170	13	7.65
N	409	42	10.27
O	146	32	21.92
P	154	8	5.19
Q	210	18	8.57
R	52	4	7.69
S	63	28	44.44
T	301	30	9.97
Type of hospitals			
Private	1528	153	10.01
Public	1111	96	8.64
With palliative unit (S4)	1614	166	10.29
Without palliative unit (S4)	1025	83	8.10
Acute	2437	212	8.7
Chronic	202	37	18.3
Type of beds			
Surgery (C)	727	16	2.20
Medecine (D)	1015	134	13.20
Geriatry (G)	409	77	18.83
Special Care (Sp)	488	22	4.51

Five factors should be noted about this distribution. The proportion of palliative patients was lower in surgical beds (2.2%), in university hospitals (7.5%) and slightly higher in private hospitals (10.0%). It was also higher in hospitals with a specific palliative care unit (10.3%). Finally, it was significantly higher in Brussels (15.9%). This is partially explained by the higher proportion of palliative patients in one Brussels hospital.

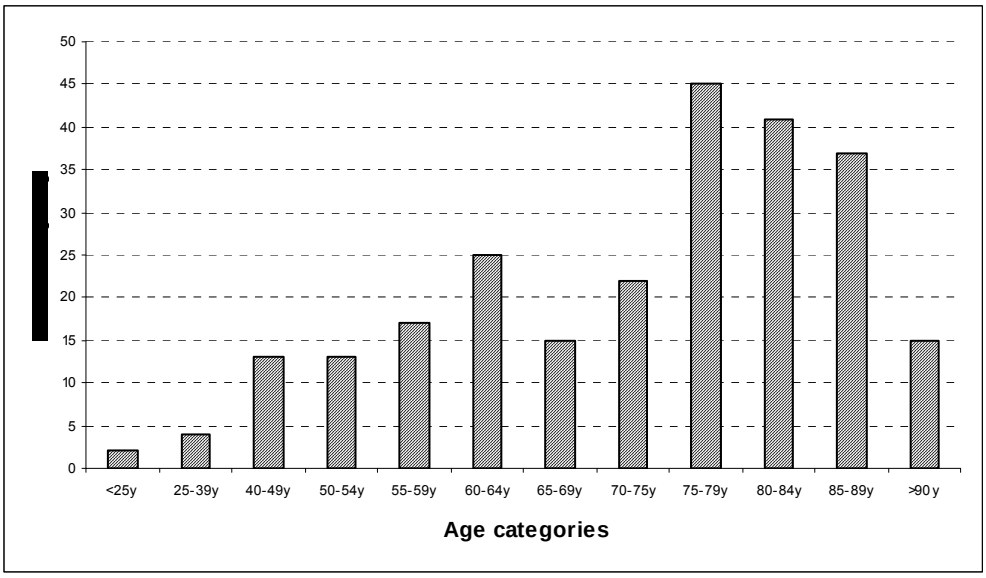
9.3.1.2 Agreement between medical and nursing staffs

The nurses and the physicians who qualified the patients as "palliative" did agree for most patients (207/249, 83.1%). For 28 patients (11.2%), the agreement was obtained after consensus. However, 12 patients (4.8%) were categorized as 'palliative' only by the nurses and 4 patients (0.8%) only by the physicians.

9.3.2 Socio-demographic characteristics of hospitalized palliative patients

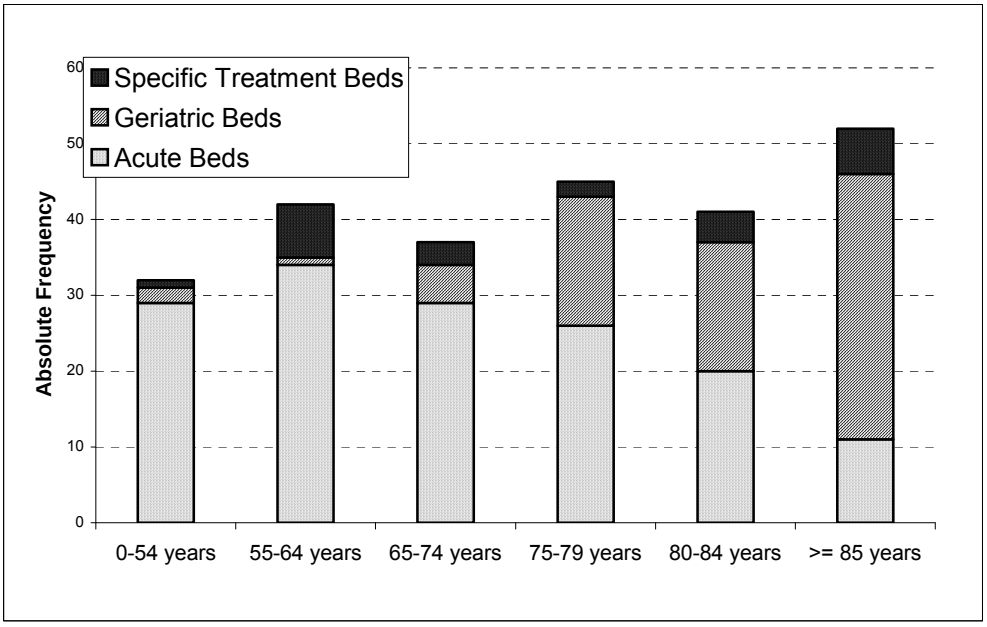
The mean age was 72 years (median 76, minimum 21, maximum 99). The majority were aged over 65 years (175/249, 70.3%) with a great proportion over 80 years (93/249, 37.3%).

Figure 2: Distribution of age (years)



As expected, the proportion of older patients was concentrated in geriatric beds and younger patients in acute beds. In specific treatment beds (Sp), the treatment concerned all age categories (next figure).

Figure 3: Distribution of age among the different type of beds



Forty six percent of patients were male (113/249).

About half of patients (112/239, 46.9%) were married, one third were widowed (79/239, 33.1%), 14 were divorced (5.9%), 34 were single (14.2%) and the social status data were missing for 10 patients.

Seventy percent of patients came from their home (174/249), 10.4% (26/249) from a nursing home and 19.7% (49/249) from another place. Before the current hospitalization, one hundred twenty one patients (69.9%) were living with at least one adult and 47 patients (27.2%) were alone or living with a minor.

9.3.3 Circumstances of admissions

In acute hospitals, 90.0% (188/209) patients were admitted for one specific reason and 10.0% (21/209) for multiple reasons. The most frequent reason was an acute medical complication (168/209, 80.4%) followed by a planned medical or surgical treatment (28/209, 13.4%), a check up (25/209, 11.9%) and a social reason (12/209, 5.7%). More than one reason justified the admission in chronic hospital for 10 patients (10/40, 25%). In these hospitals, 29 patients were admitted for revalidation (29/40, 72.5%) and 12 patients were waiting for a transfer in nursing home (12/40, 30.0%).

Regarding the type of beds, 59.8% of patients (149/249) were hospitalized in acute beds, 30.9% in geriatric beds (77/249) and 9.2% in specific treatment beds (23/249).

More than half of the patients (139/249, 55.8%) were admitted through the emergency department. This proportion was around 61.1% for patients hospitalized in acute or in geriatric beds (respectively 91/149 and 47/77). The admission was planned for 95.7% of patients in specific treatment beds (22/23).

Thirty five percent of patients (88/249) were coming from another wards of the hospital. These proportions were 33.6% in acute beds (50/149), 41.6% in geriatric beds (32/77) and 26.1% in specific treatment beds (6/23).

The nurses' and physicians' team of the ward knew 44% (108/248) patients when they were hospitalized.

9.3.4 Medical characteristics of hospitalized palliative patients

9.3.4.1 Primary diagnoses

The primary diagnoses of patients identified by medical and nursing staff as responding to the definition of "palliative patient" are given in table below. Approximately, half patients (128/249) had a primary cancer diagnosis. The most common non-cancer diagnoses were dementia (32), stroke (17), and cardiac (16), respiratory (16) or hepatic (13) failure.

Table 23: Prevalence of pathologies in palliative patients

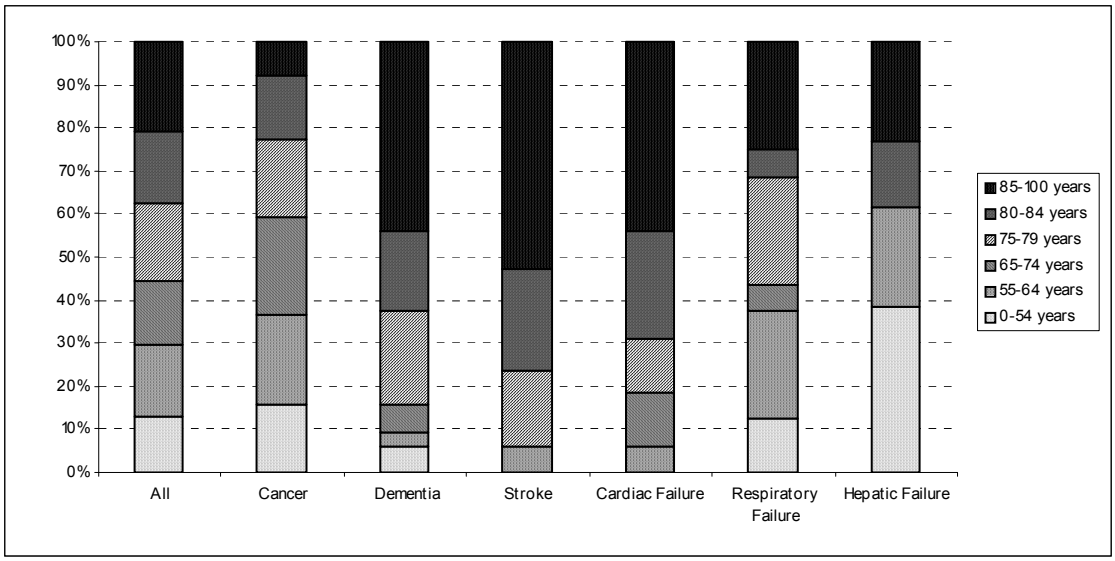
	Nb Palliative Patients	% Palliative Patients
Cancer	128	51.4
Solid tumor	108	43.4
Hematologic cancer	19	7.6
Dementia	32	12.9
Stroke	17	6.8
Cardiac failure	16	6.4
Respiratory failure	16	6.4
Hepatic failure	13	5.2
Neurological degenerative diseases	8	3.2
Other vascular diseases	6	2.4
Renal failure	5	2.0
Infectious diseases	2	0.8
Other diseases	6	2.4
TOTAL	249	100

In case of cancer, respiratory or hepatic failure, patients were mainly hospitalized in medical wards (D-beds). The proportions were respectively 63.3% (81/128), 75.0% (12/16) and 53.9% (7/13). In case of dementia and strokes, the patients were in geriatric wards (G-beds) in a proportion of 78.1% (25/32) and 52.9% (9/17).

Patients suffering from cancer and hepatic failure were younger, the proportions of patients ≤75 years old were respectively 59.4% (76/128) and 61.5% (8/13). In case of heart failure, stroke, respiratory failure and dementia, the proportion of patients older than 75 years was higher.

The frequencies were 81.3% (13/16) for heart failure, 94.1% (16/17) for stroke, 56.3% (9/16) for respiratory failure and 84.4% (27/32) for dementia (see figure below).

Figure 4: Distribution of age of palliative patients by group of pathologies

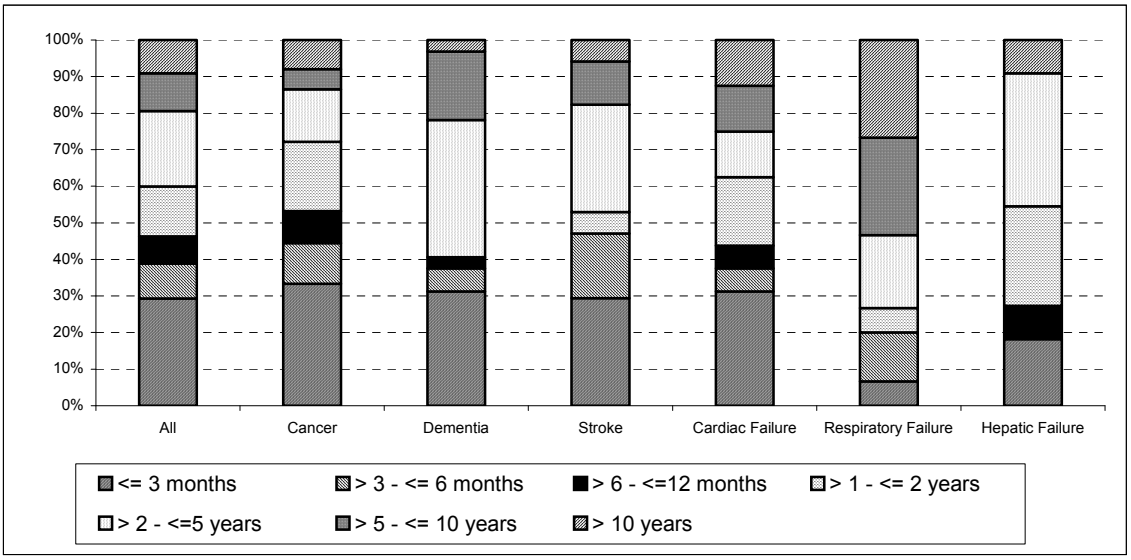


9.3.4.2 *Time since diagnosis*

For almost one third of palliative patients (71/242), the diagnosis was established 3 months before and for half of them (112/242) it was established during the current year.

The diagnosis was established at least 2 years ago for 73.2% (11/15) of patients with respiratory failure and for 59.4% (19/32) of the patients with dementia. For one third of patients the diagnosis was established 3 months ago in case of diseases like cancer, heart failure, stroke and dementia (next figure).

Figure 5: Time since diagnosis by pathologies



9.3.4.3 *Survival prognosis*

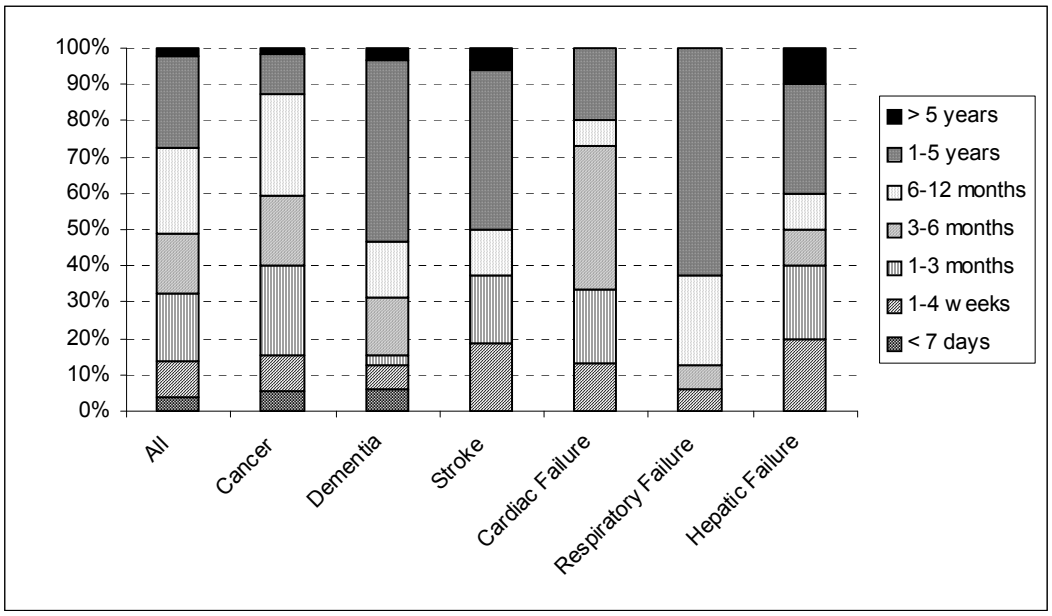
In this survey, the survival prognosis delay widely varied from less than 7 days to more than 5 years (next table). Caregivers thought that 32.5% of patients (79/243) had a life expectancy of three months or less. They also estimated that 27% of patients (67/243, 27.6%) would be alive after one year. Data on survival prognosis were missing for 6 patients (6/249, 2.4%).

Table 24: Survival prognosis

Survival prognosis	Nb Patients	Distribution (%)	
< 7 days	10	4.1	32,5
> 1 and ≤ 4 weeks	24	9.9	
> 1 and ≤ 3 months	45	18.5	
> 3 and ≤ 6 months	40	16.5	39,9
> 6 and ≤ 12 months	57	23.5	
> 1 and ≤ 5 years	62	25.5	27,6
> 5 years	5	2.1	
Total	243	100	100

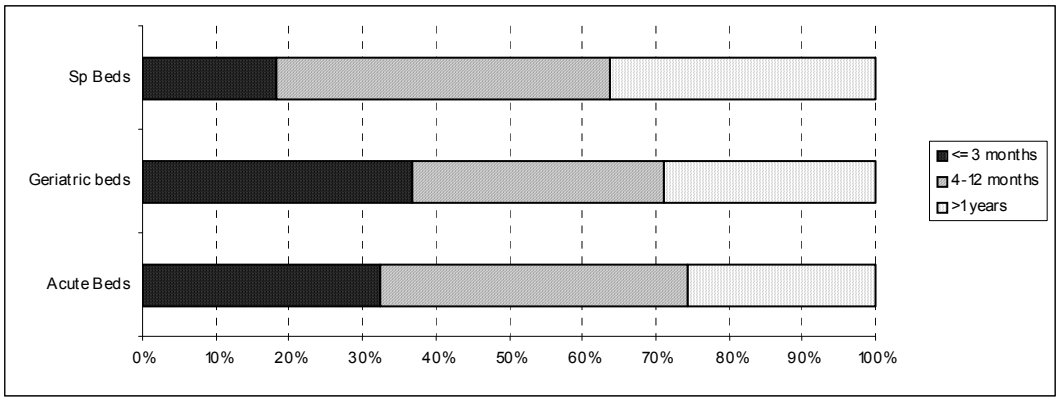
Medical and nursing staff expected that palliative patients with cancer or cardiac failure would have a shorter survival time than patients with dementia or respiratory failure (figure below).

Figure 6: Survival prognosis by pathology of palliative inpatients



As shown in the next figure, the estimation of survival time by caregivers varied according to the type of beds. Longer survival time was predicted for patients in special treatment beds but 22 patients only were hospitalized in this type of beds. The highest proportion of shorter survival time was observed in geriatric beds (28/76), followed by acute beds (47/145).

Figure 7: Survival in function of the beds' type



9.3.4.4 *Summary of medical characteristics of hospitalized patients*

The table below summarize the characteristics of hospitalized patients who were considered as "palliative" by the physician and the nurse:

Table 25: Characteristics of hospitalized patients: summary

	Cancer	Other pathologies	p
N	128	121	
Age			< 0.0001
< 75 years	76 (59%)	35 (29%)	
>= 75 years	52 (41%)	86 (71%)	
Time since diagnosis			0.0913
< 1 years	67 (53%)	55 (47%)	
1 – 5 years	42 (33%)	41 (35%)	
>= 5 years	17 (14%)	30 (26%)	
Prognosis			
<= 3 months	51 (40%)	28 (24%)	0.0100
> 3 months	77 (60%)	87 (76%)	
<= 1 year	112 (88%)	64 (56%)	< 0.0001
> 1 year	16 (12%)	51 (44%)	
Type of beds			< 0.0001
C	14 (11%)	2 (2%)	
D	81 (63%)	53 (44%)	
G	21 (16%)	56 (46%)	
Sp	12 (9%)	10 (8%)	

In summary:

- **Half of palliative patients suffered from cancer.**
- **Palliative patients suffering from cancer were younger.**
- **The estimated survival prognosis was shorter than 1 year for 88% of cancer patients.**
- **Three quarters of cancer patients were hospitalized in acute beds.**
- **Palliative patients suffering from other pathologies were older.**
- **The estimated survival prognosis was at least 1 year for 44% of them.**
- **They were mainly hospitalized in geriatric or specific treatment beds.**

9.3.5 Treatment plan

In this section, all information concerning patients and families were collected by interviews with the caregivers and not by direct interviews of the patients or their families.

9.3.5.1 *Expectations from the treatment plan*

Physicians and nurses paid more attention to patients' comfort (71.9% and 73.5%, respectively) than to life prolongation (26.1% and 24.9%, respectively). Nevertheless, physicians and nurses didn't know the wishes of the patients or families in 28.5% of cases (see next table).

Table 26: Expectations from the treatment plan

	Patients N (%)	Families N (%)	Physicians N (%)	Nurses N (%)
To prolong life	81 (32.5%)	70 (28.1%)	65 (26.1%)	62 (24.9%)
To improve comfort	66 (26.5%)	105 (42.2%)	179 (71.9%)	183 (73.5%)
No specific wishes	31 (12.5%)	5 (2.0%)	1 (0.4%)	1 (0.4%)
No information available	21 (8.5%)	44 (17.7%)	4 (1.6%)	3 (1.2%)
Not able to speak or absent	50 (20.0%)	25 (10.0%)	-	-
Total	249	249	249	249

The most important patients' expectations from the current treatment was a life prolongation (81/249, 32.5%) and secondly a comfort's improvement (66/249, 26.5%). Among the families, the expectations about comfort were more frequent (105/249, 42.2%) (table above). When the patients expected a life prolongation, the families expressed the same expectations in 60.5% of cases (49/81), the physicians (nurses) in 51.9% (50.6%) of cases (42/81, 41/81). Conversely when the physicians considered only a symptomatic treatment, the families agreed in 57.5% of cases (103/179) and the patients in 35.2% of cases (63/179).

When analysing the physician's point of view, the proportions of life prolongation expectations were similar for patients suffering from cancer (32/128. 25.0%) and for patients suffering from other pathologies (33/121, 27.3%). Among non cancer patients, these proportions varied with the pathologies. The lowest one was recorded in case of dementia (1/32, 3.1%). Higher frequencies were recorded in case of heart failure (5/16, 31.3%), stroke (6/17, 35.3%), respiratory failure (6/16, 37.5%) and hepatic failure (8/13, 61.5%).

The proportion of life prolongation's expectations decreased with patients' age: from 38.1% for 55-64 years old patients to 19.2% for patients older than 85 years. The contrary was observed in case of comfort improvement's expectations: 62.5% for 55-64 years old patients to 80.7% for patients older than 85 years.

The proportion of life prolongation's expectations increased with patients' prognosis: 6.3% for a prognosis equal or lower than 3 months (5/79), 22.5% for a prognosis of 4-6 months (9/40), 33.3% for a prognosis of 7-12 months (19/57) and 41.8% for a prognosis of at least 1 year (28/67).

The frequency of life prolongation's expectations was the lowest in the geriatric beds (11/77, 14.3%), intermediate in acute beds (43/149, 28.9%) and the highest in the special treatment beds (11/23, 47.8%).

From the physician's point of view, the proportion of life prolongation's expectations little changed between day 1 (26.1%) and day 14 (42) (28.9%). Nevertheless, this slight increase partly resulted from shifts in the treatment's expectations. Indeed 27.7% (18/65) of patients treated with a life prolongation's intention at day 1 were shifted at day 14 (42) to a treatment aiming to control symptoms. Contrarily, at day 14 (42) the treatment's objective became a life prolongation for 12.8% of patients (23/179) treated at day 1 to control the symptoms. The first shift, life's prolongation to symptom's control, was higher among nurses (25/62, 40.3%).

9.3.5.2 *Therapeutic strategies*

The type of treatment was generally clearly expressed and well defined by the caregivers (see next table). For a large proportion of patients, they excluded a cardiac resuscitation (177/249, 71.1%) and a transfer to intensive care unit (155/249, 62.2%) (next table).

When an admission in intensive care unit was considered (81/249, 32.6%), the main objective was to prolong life (41/81, 50.6%) and the second was to improve the symptoms (20/81, 24.7%). Other motivations were mentioned for 2 patients (2/81, 2.5%) (table 28).

Antibiotics were considered planned or ongoing for 90.0% of patients (224/249), transfusion for 78.3% of patients (195/249), a specific treatment of the pathology (like chemotherapy or radiotherapy for cancer patients) for 57.0% of patients (142/249) and parenteral or enteral infusions for 49.8% of patients (124/249) (table 27). Specific treatment of the pathology, antibiotics and transfusion were given in order to control symptoms respectively in 56.3%, 66.5% and 73.8%. The objectives of treatment like parenteral or enteral infusion were almost equally distributed among life's prolongation and symptom's control (table 28).

Table 27: Therapeutic strategies at day 1

	Excluded N (%)	Considered/planned N (%)	Ongoing N (%)	Not defined N (%)
Cardiac resuscitation	177 (71.1%)	64 (25.7%)	-	8 (3.2%)
Admission in intensive care unit	155 (62.2%)	81 (32.6%)	-	13 (5.2%)
Specific treatment of the pathology	94 (37.7%)	24 (10.9%)	118 (47.4%)	13 (5.2%)
Parenteral and/or enteral infusion	110 (44.2%)	82 (32.9%)	42 (16.9%)	15 (6.0%)
Antibiotics	20 (8.0%)	157 (63.1%)	67 (26.9%)	5 (2.0%)
Transfusion	43 (17.3%)	178 (71.5%)	17 (6.8%)	11 (4.4%)

Table 28: Treatment's objectives at day 1

	To prolong life N (%)	Only to control symptoms N (%)	Only as psychological support N (%)	Other objective N (%)	Not précised N (%)	Total
Admission in intensive care unit	41 (50.6%)	20 (24.7%)	-	2 (2.5%)	18 (22.2%)	81
Specific treatment of the pathology	52 (36.6%)	80 (56.3%)	3 (2.1%)	6 (4.2%)	1 (0.7%)	142
Parenteral and/or enteral infusion	59 (47.6%)	56 (45.2%)	4 (3.2%)	4 (3.2%)	1 (0.8%)	124
Antibiotics	72 (32.1%)	149 (66.5%)	1 (0.4%)	2 (0.9%)	0 (0.0%)	224
Transfusion	49 (25.3%)	144 (73.8%)	1 (0.5%)	-	1 (0.5%)	195

At day 14 (42), the number of patients for whom a treatment was excluded increased whatever the treatment analysed (next table). This frequency was the highest for the specific treatment of the pathology and for admission in intensive care unit. For few patients, the treatment was excluded at day 1 and was considered, planned or ongoing at day 14 (42) (see table 30).

Table 29: Therapeutic stategies at day 14 or 42

	Excluded N (%)	Considered/planned N (%)	Ongoing N (%)	Not defined N (%)
Cardiac resuscitation	191 (76.7%)	51 (20.5%)	-	7 (2.8%)
Admission in intensive care unit	183 (73.5%)	54 (21.7%)	2 (0.8%)	10 (4.0%)
Parenteral and/or enteral infusion	118 (47.4%)	77 (30.9%)	42 (16.9%)	12 (4.8%)
Specific treatment of the pathology	126 (50.6%)	14 (5.6%)	103 (41.4%)	6 (2.4%)
Antibiotics	40 (16.1%)	158 (63.4%)	46 (18.5%)	5 (2.0%)
Transfusion	58 (23.3%)	162 (65.1%)	12 (4.8%)	17 (6.8%)

Table 30: Evolution of therapeutic strategy between day 1 and day 14 (42)

	Excluded at Day 1 N (%)	Excluded at Day 14(42) N (%)
Cardiac Resuscitation	177 (71%)	191 (77%)
Admission in ICU	153 (61%)	180 (72%)
Parenteral and/or enteral infusion	94 (38%)	123 (49%)
Specific treatment of the pathology	108 (43%)	114 (46%)
Antibiotics	20 (8%)	40 (16%)
Transfusion	38 (15%)	57 (23%)

At day 14 (42), we observed an increase of the intention to prolong life for treatment like admission in intensive care unit or specific treatment of the pathology. These frequencies decreased for treatment such as parenteral or enteral infusion, antibiotics and transfusion (next table).

Table 31: Treatment's aims at day 14 (42)

	To prolong life N (%)	Only to control symptoms N (%)	Only as psychological support N (%)	Other objective N (%)	Not précised N (%)	Total
Admission in intensive care unit	46 (82.1%)	7 (12.5%)	-	-	3 (5.4%)	56
Specific treatment of the pathology	55 (47.0%)	56 (47.9%)	1 (0.01%)	2 (1.7%)	3 (2.5%)	117
Parenteral and/or enteral infusion	49 (41.2%)	56 (47.1%)	6 (5.0%)	4 (3.4%)	4 (3.4%)	119
Antibiotics	54 (26.5%)	147 (72.1%)	1 (0.5%)	2 (1.0%)	-	204
Transfusion	43 (24.7%)	129 (74.1%)	1 (0.6%)	-	1 (0.6%)	174

9.3.5.3 Discussion and transmission of treatment plan

At day 1, the treatment plan was discussed between the team of physicians and nurses for 191 patients and only between physicians for 27 patients. There was no discussion about the treatment plan for 29 patients.

The proportion of treatment plan's discussion was almost equally distributed among cancer patients and patients suffering from another pathology. But for patients presenting another pathology, this frequency was higher in case of stroke (100%, 17/17), hepatic failure (92.3%, 12/13) and dementia (90.6%, 29/32).

When the survival prognosis was lower than 3 months, the proportion of treatment plan's discussion was slightly higher: 89.9% versus 87.0% (71/79 versus 141/162). The contrary was observed when the cut-off point chosen for survival prognosis was 1 year. Indeed when the survival prognosis was lower than 1 year, the proportion of treatment plan's discussion was lower: 75.4% versus 80.3% (132/175 versus 53/66).

The global objective of the treatment had some influence on the discussion of the treatment's plan. Indeed when the objective was to prolong life, the treatment plan was discussed for 85.7% of patients (54/63). In case of comfort improvement, this proportion was 89.9% (161/179).

When patients were hospitalized in geriatric beds, the treatment's plan was discussed for most patients (75/77, 97.4%). This proportion was lower for patients in Sp beds 19/23, 82.6%) and for patients in acute beds (124/147, 84.3%).

At day 14 (42), the number of patients for whom the treatment's plan was discussed increased. This was actually discussed between the team of physicians and nurses for 215 patients and between physicians only for 18 patients. There was no discussion about the treatment plan for 15 patients.

The treatment plan when discussed was written in patients' record (179 patients). For 36 patients, it was only verbally transmitted. At day 14 (42), the frequency of written information increased (204 patients) and the frequency of oral transmission diminished (24 patients).

9.3.5.4 *Treatment plan: univariate analysis*

The table below compares the proportion of life prolongation and improvement comfort in function of the pathology, age, prognosis, type of beds and the treatment's discussion. In this univariate analysis, the most significant difference was observed for the prognosis.

Table 32: Summary (univariate analysis)

	Life prolongation	Improvement of comfort	p
N	65	179	
Pathology			0.6501
Cancer	32 (49%)	94 (53%)	
No cancer	33 (51%)	85 (47%)	
Age			
< 75 years	37 (57%)	72 (40%)	0.0204
>= 75 years	28 (43%)	107 (60%)	
Prognosis			
<= 3 months	5 (8%)	73 (41%)	< 0.0001
> 3 months	56 (86%)	104 (58%)	
<= 1 year	33 (51%)	141 (79%)	0.0019
> 1 year	28 (43%)	36 (20%)	
Type of beds			0.0024
C/D	43 (66%)	101 (56%)	
G	11 (17%)	66 (37%)	
Sp	11 (17%)	12 (7%)	
Discussion of the treatment			0.3591
Yes	54 (83%)	161 (90%)	
No	9 (14%)	18 (10%)	
Outcomes at day 14 (42)			0.0016
Deceased	3 (5%)	38 (21%)	
Discharged	32 (49%)	92 (51%)	
Hospitalized	30 (46%)	49 (27%)	

9.3.5.5 *Treatment plan: multivariate analysis*

After adjustment for age, sex, status, pathology, type of beds and outcome, the prognosis remained the most important factor influencing life's prolongation (next table) (logistic regression). A longer prognosis was associated with more frequent intention to prolong life, as shown in the univariate analyses. The intention to prolong life has been less frequent for patients who deceased during their hospitalization or who were discharged alive.

Table 33: Multivariate analysis: factors influencing the intention to prolong life

	OR	LCL	UCL	p
Prognosis	1.760	1.360	2.279	<0.0001
Deceased	0.225	0.060	0.848	0.0275
Discharge alive	0.498	0.259	0.959	0.0370

OR= Odd Ratio, LCL = lower confidence limit, UCL = upper confidence limit

Key points

Physicians and nurses paid more attention to patient's comfort than to life prolongation.

Life prolongation expectations:

- **were not more frequent among cancer patients than among non cancer patients,**
- **decreased with patient's age,**
- **increased with patient's prognosis,**
- **had the lowest frequency in geriatric beds.**

The multivariate analysis shows that the prognosis is the most important factor influencing life's prolongation.

The type of treatment was generally clearly expressed and well defined by the caregivers.

For a rather large proportion of patients:

- **cardiac resuscitation and transfer in ICU were excluded,**
- **antibiotics and transfusion were considered, planned or ongoing.**

Specific treatment of the pathology and parenteral (or enteral) infusions were considered, planned or ongoing for half of patients.

The treatment plan:

- **was discussed for most patients,**
- **was discussed for all but two patients hospitalized in geriatric beds,**
- **was discussed when the survival prognosis was shorter (<= 3 months) or longer (>1 year).**

9.3.6 Hospital palliative care team's referral

9.3.6.1 Prevalence

The frequency of hospital palliative care team's referrals is presented in the next table: One hundred and ten patients (110, 44.2%) were or might be referred to the hospital palliative care team. Assistance of the team had been requested for 78 patients (31.4%) and planned or considered for 32 others patients (12.8%). Caregivers did not judge this type of assistance necessary in 44.2% of cases (110/249).

Table 34: Hospital palliative care team's referral

Completed	33 (13.3%)	110 (44.2%)
Ongoing	45 (18.1%)	
Planned	4 (1.6%)	
Considered	28 (11.2%)	
Excluded	110 (44.1%)	110 (44.2%)
Not discussed	28 (11.2%)	29 (11.6%)
No information available	1 (0.4%)	
Total	249	

9.3.6.2 Patient's profile

Caregivers referred younger patients to the hospital palliative care team. 55% of patients for whom the palliative team was requested were younger than 75 years. When the referral to the palliative care team was excluded, patients were older (64.5% above 75 years). This proportion was almost identical when the referral to the hospital palliative team was not discussed (see next figure).

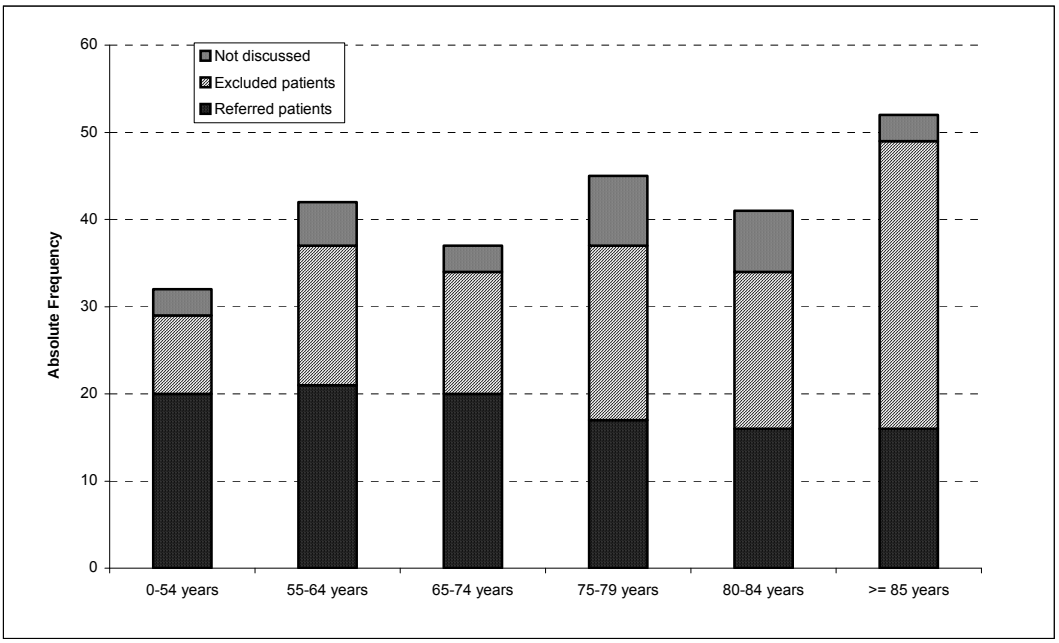
In case of intervention of the hospital palliative care team, the proportions of men and women were identical. When the intervention of the hospital palliative care team was excluded, women counted for two thirds of the patients concerned.

In other words, 49.6% of men and 39.7% of women had been referred to the hospital palliative care team.

Half of the patients (55/107) for whom the hospital palliative care team was requested is married. The highest proportion of exclusion of the hospital palliative care team was observed for widowed persons (47/79).

The hospital palliative care team intervened for 51.1% of patients coming from their home (89/174). The highest proportion of exclusions was observed for patients coming from nursing homes (16/26. 61.5%).

Figure 8: Referral to the hospital palliative care team and patients' age



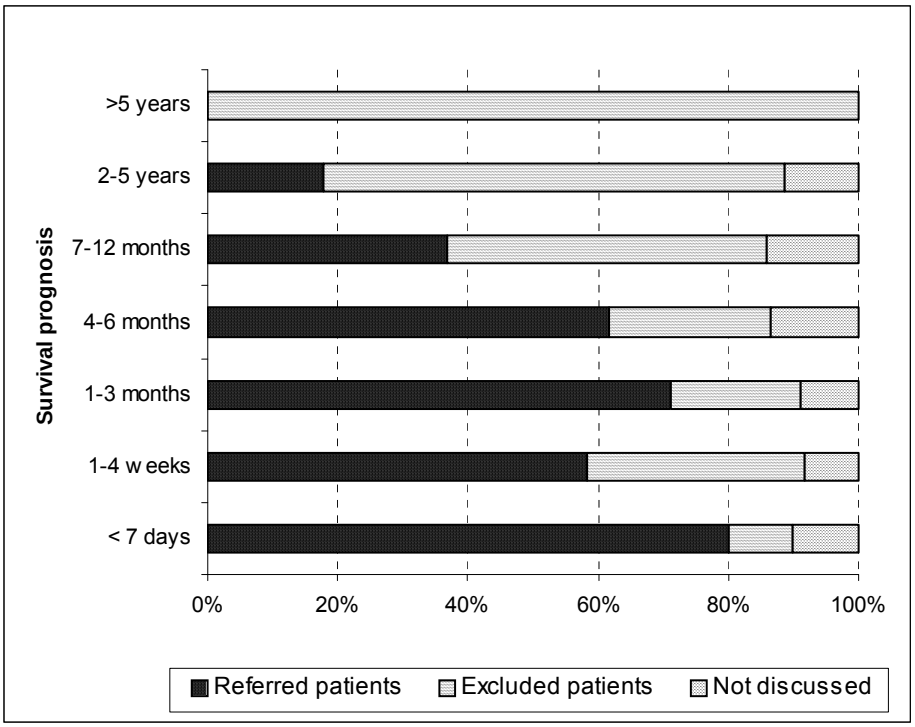
Two thirds of patients (73/110) for whom the hospital palliative care team was requested suffered from cancer. Nevertheless the referral to the hospital palliative care team was excluded for one third of cancer patients (41/110) and two thirds of non cancer patients (69/110).

The relative frequency of hospital palliative care team's referral increased with shorter survival prognosis (next figure). Indeed the hospital palliative care team was requested for 80.0% of patients with a survival of 7 days. When the survival prognosis was estimated between 1-5 years, the hospital palliative care team was requested for 17.7% of patients.

When the caregivers intended to prolong life, the hospital palliative care team was requested for 26.2% of patients (17/65). This proportion doubled when the treatment's objective was to improve patients' comfort (50.8%, 91/179).

When patients were hospitalized in an acute bed, the hospital palliative care team was requested for half of patients (75/149. 50.3%). In Geriatric and Sp beds, these proportions were lower, respectively 37.7% (29/77) and 26.1% (6/23).

Figure 9: Intervention of the hospital palliative care team and patients' prognosis



When patients were known by the caregivers, the hospital palliative care team was slightly more frequently requested i.e. for 45.4% of the patients (49/108) (excluded for 40.7%, 44/108). When it was not the case, these proportions were 42.9% (60/140) and 47.1% (66/140) respectively.

9.3.6.3 *Reasons of intervention*

Only one reason justified the intervention of the hospital palliative care team for few patients (22/101, 22.0%). For other patients, more than one reason justified this intervention. The 3 most frequent reasons invoked were psychological support of the patient (69 times), psychological support of patient's family (67 times) and control of symptoms (63 times). Among the other reasons, to prepare a transfer to a palliative unit was mentioned 25 times and a return to home 23 times.

9.3.6.4 *Patients' outcome*

In case of hospital palliative care team's intervention, 21.8% (24/110) of patients deceased, 36.4% (40/110) were always hospitalized and 41.8% (46/110) were discharged. When the hospital palliative care team's intervention was excluded, these proportions were respectively 15.5% for death (17/110), 27.3% for hospitalization (30/110) and 57.3% discharged patients (63/110).

9.3.6.5 *Univariate analyses: referral to hospital palliative team*

Next table compares the proportion of patients who were (or could be) referred to the hospital palliative care team in function of the pathology, age, prognosis, treatment's objective, type of beds, known by the caregivers and the outcome.

This univariate analysis shows that the most significant difference was observed for the prognosis and the pathology.

Table 35: Summary: Profile of patients referred to hospital palliative care team (univariate analysis)

	(Potentially) referred patients	Excluded patients	p
N	110	110	
Pathology			< 0.0001
Cancer	73 (66%)	41 (37%)	
No Cancer	37 (34%)	69 (63%)	
Age			0.0029
< 75 years	61 (55%)	39 (35%)	
>= 75 years	49 (45%)	71 (65%)	
Survival prognosis			
≤ 3 months	54 (51%)	18 (17%)	< 0.0001
> 3 months	52 (49%)	90 (83%)	
<= 1 year	95 (90%)	57 (55%)	< 0.0001
> 1 year	11 (10%)	49 (45%)	
Treatment's objectives at day 1 (for doctor)			0.0017
Life prolongation	17 (15%)	37 (34%)	
Symptom's improvement	91 (83%)	71 (65%)	
Type of beds			
Acute	75 (68%)	56 (51%)	0.0176
Geriatric	29 (26%)	39 (35%)	
Special treatment	6 (5%)	15 (14%)	
Known by the caregivers			0.4583
Yes	49 (45%)	44 (40%)	
No	60 (55%)	66 (60%)	
Outcomes at day 14 (42)			0.0715
Deceased	24 (22%)	17 (15%)	
Discharged	46 (42%)	63 (57%)	
Always hospitalized	40 (36%)	30 (27%)	

9.3.6.6 Multivariate analysis: referral to hospital palliative care team

The next table summarizes the effect of different factors on the referral to hospital palliative care team measured by a logistic multivariate regression. The prognosis remained the most important factor influencing patients' referral to the hospital palliative care team after adjustment for age, sex, status, pathology, treatment's objective, type of beds and outcome. Nevertheless, age, intention to prolong life and the presence of cancer were also significant. The referral to the hospital palliative team increased in case of shorter survival prognosis, younger patients, attention to comfort's improvement and presence of cancer.

Table 36: Multivariate analysis: factors influencing the referral to the hospital palliative team

	OR	LCL	UCL	p
Age	0.964	0.941	0.987	0.0026
Cancer	1.888	1.008	3.536	0.0471
Prognosis	0.596	0.478	0.743	<0.0001
Intention to prolong life	0.449	0.213	0.948	0.0356

OR= Odd Ratio, LCL = lower confidence limit, UCL = upper confidence limit

Key Points

The frequency of hospital palliative care team's intervention increased when:

- **patients were younger,**
- **patients suffered from cancer,**
- **patients had a shorter survival prognosis,**
- **the objective of the treatment was to improve patient's comfort,**
- **patients were hospitalized in acute beds.**

The frequency of hospital palliative care team's intervention decreased for

- **women,**
- **widowed persons.**

The reasons for intervention were multiple and mainly focused on psychological support of patients and their family and on symptoms' control.

9.3.7 Follow-up and discharges

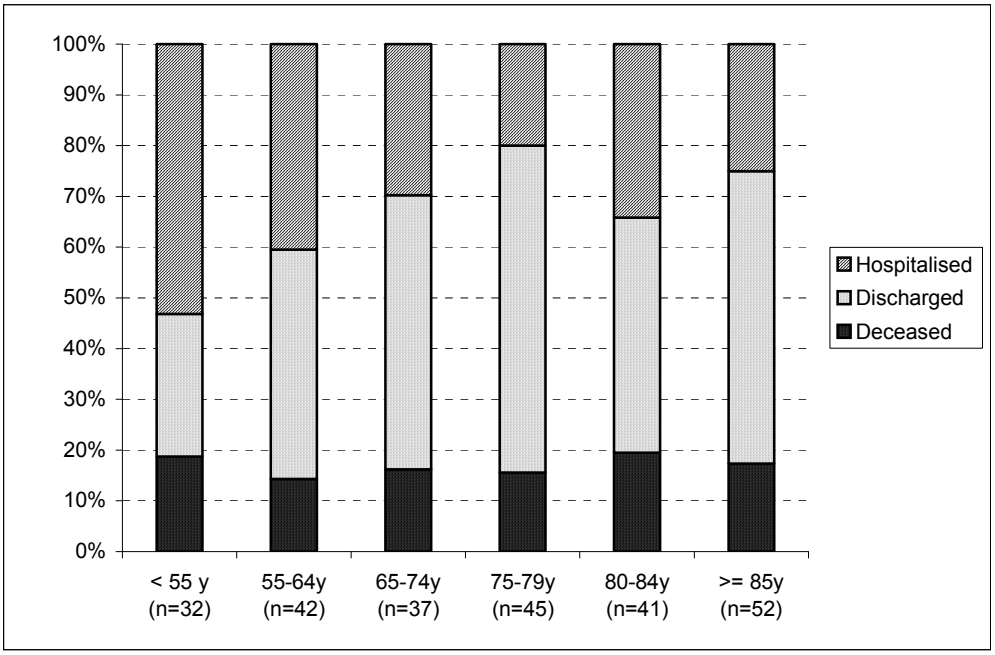
After 14 days of hospitalization in an acute care wards (42 days in non acute care wards), 42 patients (16.9%) had died in the hospital, 126 patients (50.6%) were discharged alive and 81 patients (32.5%) were always hospitalized in the same wards.

9.3.7.1 Patients' profile

The proportion of in-hospital deaths was higher, but not significant, among extreme age categories, younger or older patients. This proportion was 18.8% for patients younger than 55 years and 18.3% for patients older than 80 years. The proportion of still hospitalized was higher among patients younger than 65 years. The 75-79 years old patients showed the highest proportion of discharges (figure below).

The women counted for almost two third of deceased patients (26/42). Among discharged patients, 55.6% of patients were woman (70/126). In case of continued hospitalization, the proportion of men and women were equal (respectively 41/81 and 40/81).

Figure 10: Discharge status in function of age (years)



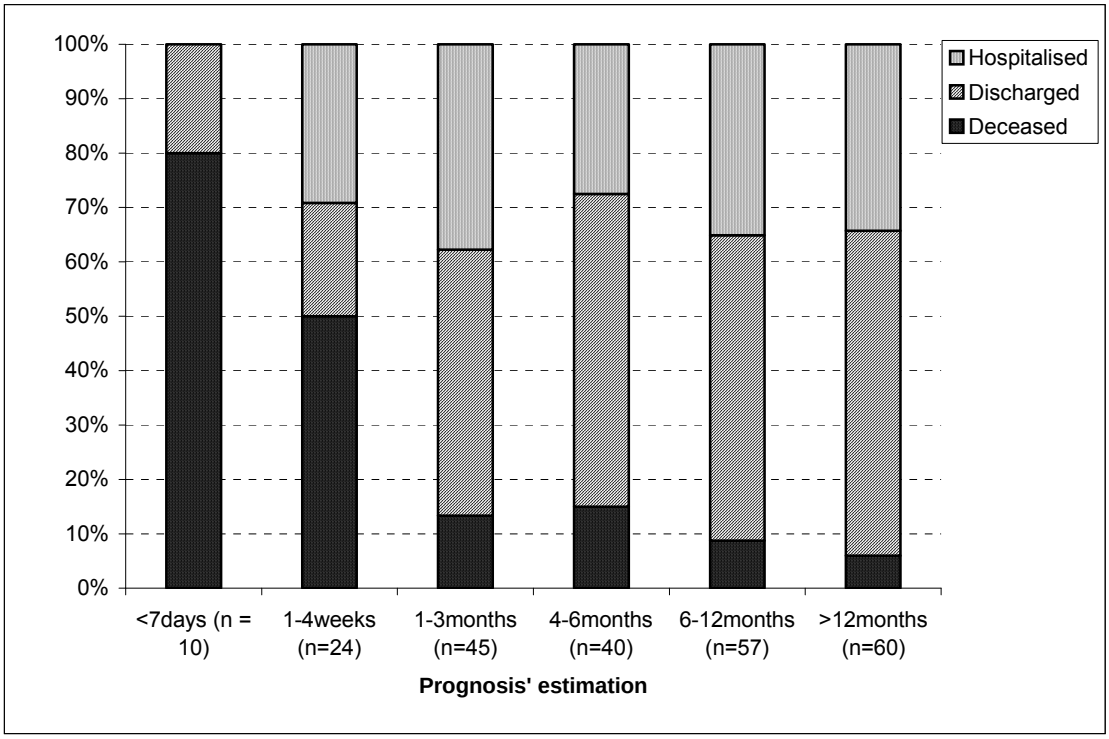
The proportion of deaths was higher among married (12.8%. 21/112) and widowed patients (19.0%, 15/79). The proportion of discharged patients was higher among divorced (57.1%, 8/14) and the proportion of continued hospitalizations higher among single patients (41.2%, 14/34).

Patients transferred from nursing homes presented the highest proportion of deaths (23.1%, 6/26) and the highest proportion of discharges (53.9%, 14/26). The highest proportion of continued hospitalizations was observed among patients coming from their residence (33.3%, 58/174).

The proportion of deaths and discharges were higher among cancer patients (18.8% and 53.1% respectively). Non cancer patients deceased less frequently (18/121, 14.9%) but the proportion of deaths varied with the pathology: 23.1% in case of hepatic failure (3/13), 21.9% in case of dementia (7/32) and 6.3% in case of heart failure (1/16). The proportion of continued hospitalizations was higher among non cancer patients (37.2%).

The proportion of deaths decreased with the survival prognosis quasi on an exponential way as shown in next figure.

Figure 11: Prognosis' estimation and discharge status



9.3.7.2 *Patients' management*

The physicians paid attention to comfort improvement for 90.5% of patients who deceased during the study (38/42). These proportions were respectively 73.0% for discharged patients (92/126) and 60.5% in case of continued hospitalizations (49/81).

The highest proportion of deaths was observed among patients hospitalized in geriatric beds (19.5%, 15/77). This proportion was 16.1% in acute beds (24/149) and 13.0% in special treatment beds (3/23).

The highest proportion of discharged patients was also observed in geriatric beds (55.8%, 43/77). In acute beds and in special treatment beds, these proportions were respectively 50.3% (75/149) and 34.8% (8/23).

9.3.7.3 *Outcomes and discharge management*

In this section, the outcome and discharge reality at day 14 (or 42) are compared to discharge wishes expressed by the physician at day 1 and also to the discharge management at day 1. "Discharge wishes" means the solution that would be the best for the patient. "Discharge management" means the discharge prepared for the patient. "Discharge reality" means what actually happened.

In case of hospitalization until death, the wishes corresponded to the reality for 15 patients (15/42, 35.7%) and the discharge management for 17 patients (17/42, 40.5%). For 12 patients (12/42, 28.6%), in-hospital death seemed unexpected (see table below). Data were missing for 2 patients.

Table 37: Deceased Patients (n=42)

	Discharge project reality at moment of death	
Discharge's wishes expressed by the physicians	No existence, death expected in the wards	Existing
Hospitalized until death	15	3
Other discharge	10	12
Discharge's management prepared by the physicians		
Hospitalized until death	17	5
Other discharge	12	6

When analysing data of discharged patients, caregivers tried to answer to patients' wishes but the proportion of agreed answers diminished progressively as the place of life was more different than the usual place. Indeed among patients going back home, the proportion of same wishes was 85.4% (41/48). These proportions were 76.3% for patients transferred into nursing homes (29/38), 56.3% for patients transferred into palliative care units (9/16), and 20% for patients transferred into medium care units (2/10) (Table below).

From the point of view of the wishes expressed, 50% to 76% of the wishes were fulfilled: 69.5% of 'back home' demands (41/59), 76.3% of 'nursing home' demands (29/38), 52.9% of 'palliative care' demands (9/17) and 50% of 'medium care' demands (2/4) (Table below).

The same trends were observed for discharge's management prepared by the physicians (Table below).

Same results are shown in table 39 in case of continued hospitalization.

Table 38: Discharged Patients (n=126)

	Discharge project reality at moment of discharge					
Discharge's wishes expressed by the physicians	Back home	Transfer to nursing home	Transfer to palliative care	Transfer to medium care	Transfer to acute care	Transfer to another place
Hospitalized until death			2			
Back home	**41**	7	4	2	3	2
Transfer to nursing home	3	**29**	1	4	1	
Transfer to palliative care	3	2	**9**	2	1	
Transfer to medium care	1			**2**	1	1
Transfer to acute care						1
Transfer to other place						
Discharge's management prepared by the physicians						
Hospitalized until death			2		1	
Back home	**42**	6	2	2		1
Transfer to nursing home	2	**27**	1	2		
Transfer to palliative care	1	2	**9**		1	
Transfer to medium care	1	1		**5**	1	1
Transfer to acute care						
Transfer to other place						**1**

Table 39: Hospitalized Patients (n = 81)

	Discharge project reality for continued hospitalization					
Discharge's wishes expressed by the physicians	Hospitalized until death	Back home	Transfer to nursing home	Transfer to palliative care	Transfer to medium care	Transfer to another place
Hospitalized until death	**2**	1		1		
Back home	3	**16**	1	1		
Transfer to nursing home	1	2	**21**	3	1	1
Transfer to palliative care	1	3	2		1	
Transfer to medium care	1	1		1	**2**	
Transfer to acute care						
Transfer to other place		1				
Discharge's management prepared by the physicians						
Hospitalized until death	**3**	2		1		
Back home	3	**17**	1	2		1
Transfer to nursing home		1	**17**	2	2	1
Transfer to palliative care		1			1	
Transfer to medium care	1	1			**1**	
Transfer to acute care						
Transfer to other place				1		

9.3.7.4 *Outcome at day 14 (42): univariate analysis*

Table below compares the proportion of patients deceased, discharged and hospitalized in function of the pathology, age, prognosis, treatment's objective and type of beds. In this univariate analysis, the most significant difference was observed for the prognosis and the treatment's objective.

Table 40: Summary (univariate analysis)

	Deceased	Discharged	Hospitalized	p
N	42	126	81	
Pathology				0.2929
Cancer	24 (57%)	68 (54%)	36 (44%)	
No cancer	18 (43%)	58 (46%)	45 (56%)	
Age				0.0463
< 75 years	18 (43%)	48 (38%)	45 (56%)	
>= 75 years	24 (57%)	78 (62%)	36 (44%)	
Prognosis				
<= 3 months	26 (63%)	29 (23%)	24 (31%)	<0.0001
> 3 months	15 (37%)	95 (77%)	54 (69%)	
<= 1 year	37 (90%)	84 (68%)	55 (71%)	0.0181
> 1 year	4 (10%)	40 (32%)	23 (29%)	
Type of beds				0.1740
C/D	24 (57%)	75 (60%)	50 (62%)	
G	15 (36%)	43 (34%)	19 (23%)	
Sp	3 (7%)	8 (6%)	12 (15%)	
Treatment's objective at day 1 (for doctor)				0.0016
Life prolongation	3 (7%)	32 (25%)	30 (37%)	
Symptom's improvement	38 (90%)	92 (73%)	49 (60%)	

9.3.7.5 *Outcome at day 14 (42): multivariate analysis*

The results show that the prognosis remained the only significant factor associated with patients' death after adjustment for age, sex, status, pathology, treatment's objective, type of beds (next table). The proportion of death increased when the survival prognosis decreased.

Table 41: Multivariate analysis: factors influencing discharge status (death).

	OR	LCL	UCL	p
Prognosis	0.500	0.387	0.647	<0.0001

OR= Odd Ratio, LCL = lower confidence limit, UCL = upper confidence limit

Key points

Among palliative patients, 17% had died, 32% were always hospitalized and 51% were discharged alive.

The proportion of deaths decreased with the prognosis survival time.

Deaths concerned:

- **Younger patients suffering from cancer (38%),**
- **Old women hospitalized in geriatric beds (26%).**

Continuing hospitalizations concerned:

- **younger patients whatever the pathology (56%),**
- **older patients coming from their home (33%).**

Discharges concerned:

- **cancer patients whatever their age (54%),**
- **old patients without cancer (34%).**

9.4 DISCUSSION: PALLIATIVE CARE IN HOSPITALS

9.4.1 Prevalence of palliative inpatients in Belgium

The first objective of this study was to estimate the prevalence of in-hospital palliative patients in Belgium. Slightly less than one out of ten inpatients was identified as a palliative patient. As far as we know, no Belgian study about prevalence of in-hospital palliative patients exists so that our results could not be confirmed by any other Belgian data. Similar percentages are reported from France[41, 43, 45, 47, 312, 314], United[46, 48, 315], Australia[316] and the United States[49], especially if we take into account different inclusion criteria's using to select the palliative patients' population[40]. Our results show the same trend as two recent studies concluding that one-half of all Flemish deaths take place in hospital[317] and that sixty percent of Belgian patients are hospitalized at least once in the last three months before death[27].

9.4.1.1 Patient identification

No major divergence was noted between the nurses' and the physicians' views when defining a patient as "palliative". This finding is in accordance with a French study[42] but contrasts with an English survey[48] mentioning that the nurses identifies a higher number of palliative patients than the doctors. Nevertheless, the purpose of this study differs from the English one. This study assessed the level of agreement between the nurses and the physicians when identifying "*palliative patients*" whereas the English investigators were interested especially in identification of "*patients having palliative care needs*".

9.4.1.2 Survival prognosis of palliative patients

An interesting result concerns the survival prognosis of the identified palliative patients' population. Two-thirds had a life expectancy longer than three months and half of the patients longer than six months. Probably, this finding could reflect the intuitive recognition that for some patients palliative care needs to be extended over a period longer than 3 months as it is now defined in our country. The section on definition also underlined that palliative care should not only be associated with terminal care but also be integrated as soon as possible in the course of any chronic ultimately fatal disease[38]. The results of the survey in hospital confirm this concept and indicate the importance of an appropriate interaction between curative and palliative approaches in the treatment of incurable and life-threatening diseases.

9.4.1.3 Diagnosis and subsequent end-of-life course

Another relevant result concerns the primary diagnosis. Cancer was the most frequent diagnosis but nearly half of patients had a non-malignant disease, such as dementia, cerebrovascular disease (stroke), congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD) or end-stage liver disease. These figures agree with the hospital death certificate data reported by Cohen[317] and certainly with data reported in other hospital settings by health care staff[41, 45, 48, 49, 312] or following case note review[46].

This result deserves attention because the literature shows that the trajectory of dying is influenced by the primary diagnosis[318], as described in the part about needs for specific diseases. Three different types of end-of-life periods have been described according to the nature of the underlying pathology:

1. People with terminal cancer generally follow an expected and relatively short course of obvious decline.
2. In contrast, people with chronic disease such as CHF or COPD go through periods of slowly declining health marked by sudden episodes of illness requiring hospitalization from which the patient recovers. This pattern may recur a few times whilst the patient's health steadily declines until the patient dies. There is considerable uncertainty about the time when death is likely to occur.
3. Patients who suffer chronic conditions such as stroke or dementia go through a third trajectory of end-of life marked by a steadily decline in mental and physical ability that finally results in death.

In conclusion, prognosis estimate is more difficult for non cancer patient[61] and this study shows that clinicians document more frequently cancer patients as dying patients than non cancer patients.

9.4.2 Treatment strategy

Several authors[319, 320] reported that palliative inpatients may receive inadequate care and aggressive life-prolonging interventions. They highlighted the difficulties of shifting from curative to palliative approach[321], with invasive treatments even when physicians were aware of the imminence of death.

9.4.2.1 Care planning

The objective of our study was not to assess the appropriateness of care, however, the results show that the caregivers from this study established an advanced care planning in the majority of cases, as previously reported in a Dutch study[321].

9.4.2.2 Patient/family preferences and information

An interesting finding is that the patient's and family's preference were unknown by the interviewed caregivers in one third of cases, including patients not able to speak, despite patients' right to determine their future care[322]. Previous researches[323] confirmed this lack of knowledge while others reported an essential difference of point of view between the patients and the caregivers[324]. The design of this study with caregivers' interviews does not allow any comparison with the views of the patients.

In contrast with Toscani[325], we did not note that life-prolonging treatments were regularly continued for the patients incapable of decision. Indeed, the physicians wanted a comfort's improvement for 86% (43/50) of patients who could not express and a life's prolongation for 14% (7/50) of them. All these findings should question about the wish of palliative patients to be informed and participate in medical decision making but also about the desire and the ability of health care providers to communicate with end-of-life patients.

Another observation concerns the treatment's goal and content. Comfort care plan were implemented by the caregivers for seventy percent of palliative patients in particular when recognized as terminally ill by the caregivers (< 3 months prognosis). Potentially life-prolonging interventions were considered in one quarter of the palliative patients. This percentage seems to be similar or slightly higher in the other surveys[326] but the comparison is hampered by variations between study designs and estimation methods.

9.4.2.3 Difficult border between the treatment's intentions

One however must take this conclusion with a lot of caution. Antibiotics, blood transfusions, specific treatments for primary disease and artificial food were considered or given to roughly 90%, 80%, 60% and 50% of the patients, respectively. Comparable figures were already reported before[325-327]. Some of these therapeutic procedures might be futile, a hallmark of over-treatment or simply used for improving life. Unfortunately, our study does not clarify the border between the goals of the treatments: even a chemotherapy[39] can be given to patient with intention to prolong the life or only to improve the quality of life. Clarifying the treatment's goal is of crucial importance for the treatment decision-making process[38] but some physicians nevertheless pointed out a large grey area between curative and palliative care.

The international literature throws light on explanations for the frequent use of treatments described in this study. First, according to the new WHO definition[328], "*palliative care is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life*" and European physicians[39] believe that a long-term survival prognosis should recommend a mixed management strategy involving both life prolonging and comfort measures. In this sample, a majority of palliative inpatients considered to have live-prolonging treatment had a survival prognosis superior to three months.

Moreover, the treatments under consideration (e.g. antibiotics, transfusion) may be directed to preserve quality of life and to contribute to a better management of the symptoms, as indicated by our respondents and confirmed by other researchers[38]. The last hypothesis would be that a life-prolonging treatment could be implemented at patient's or family's express request, as reported in some American[329] and European[321, 325, 330] studies. This could happen even if patient's preference differs from caregivers' wish. This study indeed shows a significant gap between the patient and the caregiver's preference. Among the 147 patients who had expressed a wish, more than one-half had requested life-prolonging treatment while only one-third of caregivers had the same intention. An explanation of this divergence between patients and caregivers could be[324, 331, 332] an inadequate information of the patients and their families. Information on treatment options includes the length and invasiveness of treatment, chance of success, overall prognosis, quality of life during and after the treatment. On another hand, according studies as that of Balmer[333], a lot of patients would accept potentially life-prolonging treatments with a much lower chance and smaller duration of benefit than would healthy controls or health care professionals.

9.4.2.4 Influence of the patient's characteristics on the treatment's strategy

A last issue concerning the treatment's strategy relates to the influence of patients' characteristics on the purpose of treatment. In contrast to Van den Block[334], this study did not note any difference between Flanders and Wallonia. On the other hand, the decision to institute a life-prolonging therapy was affected by survival prognosis and primary diagnosis. The patients with a short term survival did received life-sustaining treatments less often than the others. A considerable difference was also recorded according to the pathology: patients with a non-malignant disease received care that was more consistent with prolongation of life than palliation of symptoms when compared to cancer patients. Other authors described this finding between patients[334, 335] and this differential treatment was not a inevitably sign of over-treatment[336, 337]. Patient's age was also a consistent determinant. As reported in other studies[338], life-prolonging treatments were given more to younger patient compared with older patients. This finding suggests that the caregivers would like to prolong at all costs the life of younger patients and would decide to stop quicker treatments for older patients. This also could suggest that the caregivers had adapted their care planning to the fragility of the older patients.

9.4.3 Health care structure, referrals and requests for support from palliative care services

The study gives a number of information about the use of health care structure.

Most patients who had expressed a specific wish would like to go back home (90%). This was also the preference of a half of the families and 40% of health care providers. These results agree with many studies who concluded that on one hand, seriously-ill patients prefer to stay at home as long as possible and on the other hand, the families dread the physical and emotional load caused by a return at home. At the end of the survey, only forty percent of discharges for living patients were really discharged at home. As reported by others[20, 49], even if many patients choose to be cared for at home, a substantial number (30%) of living patients are discharged to nursing homes and some other ones (15%) are referred to acute-care or medium-care wards. The question of appropriateness of these institutions for the management of palliative patients should be explored in further researches.

Another interesting finding is the profile of patients who died in hospital (nearly one fifth of the sample). One-third of them had a survival prognosis of less than three months, what is consistent with Van den Block study[27] who demonstrated that if a patient is hospitalized during the final 3 months of life, the chance of dying in a hospital is very high.

9.4.3.1 *Palliative care: a reality in all hospital wards*

Patients for whom the treatment only aimed at symptom's improvement, were mostly hospitalized in medical and geriatric wards. Some of them also stayed in a surgical bed or a revalidation bed. These data combined with the requirements of the Belgian law[339] infer that all caregivers working in these wards need to be trained and supported in provision of palliative care. They should be able to offer palliative care to their patients and decide when to refer them to specialized palliative care services.

9.4.3.2 *Who should benefit from palliative care services?*

This observation leads to a key question: how to identify patients who will benefit from specialized services? In Belgium, law makes palliative care a basic right for all patients near death[339] and the provision of palliative care services has become an important public health issue during recent decades[340]. So, among the fourteen visited hospitals, all but one two included a hospital support team, six of them had a palliative care unit and all of them had an agreement with a home palliative care team. Despite the existence of these structures, a very small number of patients were referred to the palliative care services. More specifically, the hospital palliative care teams were involved for 18% of cases. The caregivers had formally excluded their assistance for 44% of cases because they did not judge it necessary. Only ten percent of the discharged patients (17/168) were referred to palliative care units and fifteen percent of patients going back at home or in nursing home (13/87) were referred to home palliative care teams. These proportions are lower than those reported in the United Kingdom[48, 315, 341, 342], in Australia[343] or in the United States[49, 344] but they are more similar to those reported in Italy[287] and in another Belgian survey[334]. This difference might be explained by variation in health care system and cultures.

9.4.3.3 *Low referral to specialized services: source of interrogation*

The low percentage of referral to specialized palliative care raises a number of questions. What is the precise role of specialized palliative care services? Do they have to take care of all patients or only of those whose symptoms are difficult to relieve? Are there barriers to referral? Who and which factors determine which patients will be referred? Experts' reports generally recommend the provision of palliative care services to all patients who need them but the literature[286, 345] shows that access to specialized services is unequally distributed among patients.

Several factors influence differences in access. First, cancer patients more frequently benefit from specialized palliative care than non cancer patients even if several authors[176, 346] support that needs of non-cancer patients also warrant the attention of palliative care providers. This differential referral is confirmed by other authors[48, 334, 347] and by data directly resulting from palliative care services. Indeed 65% of patients cared by hospital palliative care team were cancer patients. In specialized palliative wards, this proportion was 90%. Many reasons can explain the difference associated with the type of pathology. It may be linked to a controversial[335, 336, 348] perception that non-cancer symptoms are less frequent and more easily controlled than cancer symptoms. It may reflect a general perception that the palliative care services are dedicated to cancer patients. The difference can also explain by the greater difficulty to establish a survival prognosis for non-cancer patients[61].

Another key finding is the role of patient's age. Despite decreasing of life-prolonging treatments with age, older people have less access to palliative care services compared with younger people. This finding is consistent with a multitude of researches[48, 286, 343, 345, 349, 350] and several reasons have been reported. Some controversial studies[350-353] suggested that older patients might experience less symptoms and less psychological distress than younger patients. Moreover, the needs of older patients would be met elsewhere e.g. the nursing homes would offer an equivalent standard of palliative care services.

9.4.3.4 *Late referral to specialized services*

One last finding refers to the very late referral to specialized services. This study showed that a short survival prognosis and a desire to withdraw life-sustaining treatments facilitated a specialized team's intervention. These data agree with two recent studies[39, 354] who concluded that palliative care is primarily perceived as a mean to limit life-sustaining treatment or allow death. They are also consistent with surveys[355] that explored why patients were referred too late to palliative care services. According to these researches and to the web-based survey most of the clinicians desire to protect their patients from the exposure to the truth of incurability of illness. Therefore they delay the referral to specialized services until all possible "disease oriented" treatments have been tried.

9.4.4 Study limitations

Several limitations of this study should be mentioned when interpreting these results. The first one is the bias due to the patient's recruitment. The initial sample size calculations gave an estimate of 300 patients i.e. at least 3700 beds to recruit 300 palliative patients. The final sample size was smaller, 249 patients, for three reasons:

- the mean bed rate occupation was lower than the expected 80%;
- the study excluded patients with a length of stay shorter than 48 hours (25% of patients in some acute hospitals);
- several physicians refused to participate.

The main reasons for non participation were a lack of time, a lack of interest, no or few palliative patients. One possible denial of palliative situations by this group of clinicians might introduce some bias in our findings.

Nevertheless, the sample seems representative of the palliative patients because our results are comparable to those reported in other studies. This survey gives a valuable contribution to the understanding of the population and profile of palliative inpatients especially because it is the first Belgian survey performed at a national level.

A second limitation is that collected data were limited to the views of the health care providers and these may inaccurately reflect the patients' and families' perceptions.

Third, the validity of results must take into account that the nurses could have been influenced by the doctors' opinion during their interview.

Finally, we noted a limitation linked to the selected methodology. The sample included patients who were identified as "palliative patient" on one given day by the caregivers but some patients might have been missed in the census. Similarly some patients identified as "palliative" may have been cured or survived much longer than anticipated.

9.4.5 Conclusion

In conclusion, this analysis attempts to understand the importance and the characteristics of the hospital palliative patients' population. Approximately, one out of ten inpatients was identified by the caregivers as a palliative patient. Results demonstrated the profile's diversity of this population in terms of pathology and survival prognosis: half of patients had a non-cancer disease and two thirds had a life expectancy of more than three months. These figures agree with an evolution of the palliative care model where palliative care is oriented to all incurable patients who need it, regardless their pathology or survival prognosis.

Comfort improvement was the main goal for a majority of patients. However, treatments such as antibiotics or blood transfusions were also frequently administered or considered: further researches should be conducted to study their appropriateness for end-of-life patients.

Other ways for further research should be to explore how the Belgian health care professionals help their palliative patient with care planning and assess patient's preferences for care at the end of life. This study only interviewed health care givers and patients' views might have strongly diverged from that of the caregivers.

Several key messages also emerge from the survey about use of health care services. Most palliative patients wished to go back home. Many of them were hospitalized until death; some of them were discharged in nursing homes or in other institutions. Moreover, the referral rates to palliative care services were low and occurred late as described by previous studies. Those referrals were furthermore influenced by the patient's age, medical diagnosis and prognosis estimations rather than on needs for symptom control and psycho-social support. This situation entails a risk of inequity in provision and access to palliative care service.

10 SURVEYS: GENERAL DISCUSSION

The objective of this section is to compare the results from the three surveys. In these surveys, six hundred fifty six palliative patients were enrolled. The patients' characteristics are presented in the table below. Results are not pooled because the methods differed between the three settings.

Table 42: Distribution of patients' characteristics in function of the three settings

	Home-based study	Nursing home-based study	Hospital-based study
Visited institutions	342 GPs	50 institutions	14 hospitals
Palliative patients	239 patients	168 patients	249 patients
Age (mean)	71.4 years	83.6 years	72 years
Gender	48% of female	61% of female	53% of female
Marital status	63% with a partner	20% with a partner	47% with a partner
Cancer diagnosis	79% of patients	17% of patients	51% of patients
Dementia	4% of patients	39% of patients	13% of patients
Survival prognosis	57% > 3 months	82% > 3 months	67% > 3 months

Nevertheless, the comparison is interesting because it gives an overview of the palliative patients' population in our country. It allows identifying and discussing common points, differences and specificities of each subpopulation.

10.1 LACK OF COMMUNICATION BETWEEN THE CAREGIVERS AND THE PALLIATIVE PATIENT?

10.1.1 Options for further treatment

The first common point is the fact that despite the legal obligation[322], the hospital physicians and the GPs did not always know patients' wishes concerning the treatment options in about one quarter of cases. This percentage was higher in nursing homes where most patients were affected by cognitive failure. A similar observation was made about the place to care and/or to die. On this matter, the web questionnaire indicated that many doctors did not discuss the patients' choices: speaking about death was a taboo for the patient and/or her/his family. These findings are probably associated with the difficulty experienced by the health care professionals on how to inform patients about their inevitable death[356].

This lack of communication is of concern because it might alter the patient's decision making. Some patients could experience an over-treatment[357, 358]. Other ones could lack of the needed palliative care[359]. Two thirds of the GPs interviewed in the web-based survey found difficult to start palliative care when the patient was not aware of his/her condition.

As shown by the 3 surveys, palliative patients experienced different places of care: home, nursing home and hospitals. This justifies an improvement of communication between all caregivers implied in palliative care.

10.1.2 Home: the preferred place for palliative care and for death

The place-of-death preferences expressed in our surveys were similar to those reported in other population-based studies and in Belgium[360, 361]. A majority of patients would prefer to be cared and to die at home: sixty percent of the hospitalized patients wished to go back home and about seventy percent of the home-based patients wished to stay at the same place. Most of those will see their wish coming true but a small number must be hospitalized. This must be weighted by the fact that in our survey patients' preferences were investigated only once whereas they may change in the course of the disease. Equally, social characteristics were not taken into account to explain patients' preferences.

Several published studies[362] were interested in factors influencing death at home. The patients' preference but also an agreement between the preferences of the patient and the preferences of the family seemed to have a powerful influence on achieving home death. In our hospital- and home- based studies, we recorded a significant gap between the patients' and the relatives' wishes.

In spite of legislative measures and social support set up in our country[363], many families preferred a terminal stay in hospital. Our quantitative design did not allow to explore the reasons of this choice but authors[364] reported that caring for a loved one at home was a great physical, emotional and financial burden.

Use and use's intensity of home care were other important factors to stay at home. In Belgium, GPs play a crucial role in the context of palliative care at home. The literature describes that most GPs feel that it is a central part of their work[349, 365] and they are currently providing palliative care to their patients[215, 366, 367]. In this study, about one half of the interviewees had at least one palliative patient at a given time and most of them valued their coordination role. However, they often felt uncomfortable when they were confronted with dying patients. Searchers[366, 368] associated this feeling with a lack of training. That might explain that the interviewed GPs identified more easily cancer patient as palliative and that they formally excluded resuscitation for one half of the patients only: the estimation of survival prognosis for non cancer patients and talking about resuscitation orders require indeed a specific competencies[56, 369].

10.2 FREQUENT HOSPITALIZATIONS

In this study, less than one out of ten patients expressed a preference to be cared and/or to die in hospital. However, hospital seems to be unavoidable for many palliative patients. One third (30%) of the home-based patients were hospitalized during the study (12 weeks). Seventy percent (70%) of the hospital-based patients came from their home: a quarter of them died at hospital and the other ones were discharged in the primary healthcare sector. These figures are not surprising. Hospital transfers are known to be necessary due to medical needs and/or to social reasons (80% and 5% in this study respectively).

The type of treatment was generally well defined for the palliative inpatients. Contrary to the home-based patients, cardiac resuscitation was clearly excluded for a large proportion of them. Treatments like antibiotic or transfusion were more often considered, maybe due to the larger number of patients who wished life prolonging treatments.

One unexpected fact was the great number of patients who were admitted through the emergency department. Authors[370, 371] showed that ending life in the emergency department is a reality for some patients (25-65%). As others[34, 372], they emphasized the contribution of written in advance directive's transmission and/or of a direct contact between the domiciliary and the hospital caregivers to fulfil the wishes of the patient when possible.

10.3 DYING IN A NURSING HOME

This setting requires a separated chapter for two reasons. First, the palliative population in this setting is specific and second, at least a quarter of Belgian people die there[373]. According to our results, publications of the public authorities[374] and another KCE report[375], at least 4% of the residents were palliative patients. As previously reported[376], the population was very old, more often female and isolated. The nature of diagnosis also differed: more than 80% of the patients suffered from a non-cancer disease and 40% presented a dementia as main pathology. The life expectancy appeared generally longer and the treatment's options aimed mostly at the comfort.

Most patients wished to stay in the residency and as confirmed by others[374], they died there. The caregivers asserted that they were able to take care of patients without external support. They excluded a hospital admission for the majority of them. Our study did not aim at care's quality assessment in the nursing home.

There is no doubt that caregivers are trained to provide a high standard of care to patients and that their interest in palliative care is growing[377]. But nevertheless, a lot of studies[16, 378, 379] and the part about "needs in miscellanous settings" reported that some of dying residents have unmet needs.

10.4 LIMITED RELATIONSHIP WITH SPECIALIZED PALLIATIVE CARE SERVICES

The last and notable point which we would like to discuss is the relationship between the health care professionals and the specialized palliative care services. In most cases, the caregivers leaved out the possibility to call in the specialized structures. According to the Web-based survey, the GPs knew well all the palliative care services but they resorted to it rarely. Less than 10% of GPs used a palliative home care team and they considered referral to a palliative care unit in only 5% of home-based patients. In nursing homes, the caregivers' opinion was even more cut. A transfer to a palliative care unit was definitively excluded for three quarter of residents and no data were registered about the use of a palliative care team. Such services seemed more often considered by the hospital caregivers. Finally, during the studies' time, a relatively low proportion of patients received a support from the specialized palliative care services. Five percent (31/627) of the total patients were transferred to a palliative care unit and a palliative care support team was intervened with one third of the inpatients.

It's difficult to compare our results with the international literature[380], mainly because the role of the specialized services significantly differs between countries. However, it seems that palliative care services were less often used in Belgium. Not all patients require a specialized palliative care's intervention[82] but there is an assumption that some people could miss out these services and others would be referred too late[176, 366, 381, 382]. It could be the case in our country, especially since we noted that palliative care team's interventions were significantly related with cancer, younger people and shorter survival prognosis.

Key points

- **The physicians ignored patients' wishes concerning the treatment options in around one quarter of cases.**
- **A majority of patients preferred to be cared at home whilst many families preferred a terminal stay in hospital and GPs sometimes felt uncomfortable when caring for dying people.**
- **Hospital was unavoidable for many patients, particularly in medicine and geriatric wards. More than a half of hospital patients had to be admitted in emergency department.**
- **Palliative care in nursing home concerned older patients with non-cancer disease : it was mostly provided by the local staff without any external support.**
- **A relatively low proportion of patients received support from palliative care services. Specialized intervention seem to be late and particularly target young and cancer patients.**

Part four: Economic surveys

11 COSTS OF TREATING TERMINAL PATIENTS IN DIFFERENT HEALTH CARE SETTINGS

11.1 INTRODUCTION

Terminal patients are treated in a variety of health care settings in Belgium: inpatient ward or palliative care unit of an acute care hospital or university hospital, nursing home, home care with or without a mobile palliative support team. Costs are an important aspect of treating terminal patients. For instance, a retrospective analysis of the Belgian Sentinel Network of General Practitioners – an epidemiological surveillance system of a representative sample of Belgian general practitioners – identified determinants of hospitalization during the three final months of life[27]. This study found that hospitalization was less likely if, amongst other things, the general practitioner provided palliative care and if treatment had a palliative rather than a curative focus. To date, little is known about costs of treating terminal patients in Belgian health care settings.

In a context of spiralling health care costs and limited resources, public policy makers and health care payers are concerned about the costs of treating terminal patients. Although there are some methodological concerns about the study, the Independent Sickness Funds claimed that expenditure on palliative care increased from 42 million € in 2003 to 77 million € in Belgium in 2007, an annual average increase of 16%[383]. Palliative care accounted for 0.4% of Belgian health expenditure in 2007. Expenditure on palliative care mainly related to nursing care (65% of expenditure), palliative support teams (13%), and the allowance for palliative home care (12%). An analysis by the RIZIV/INAMI, the Belgian third-party payer, found that public expenditure on ambulatory palliative care amounted to 59 million € in 2003, consisting of 7.6 million € for mobile palliative support teams; 7.1 million € for the allowance for palliative home care: 36.2 million € for home nursing; 6.2 million € for nursing homes; and 1.9 million € for the abolition of patient co-payment for consultation by the general practitioner[384].

There is a need to quantify the costs of treating terminal patients in hospital, nursing home or at home. Furthermore, a cost study may allow the identification of the cost drivers of treating terminal patients. Finally, cost data can be fed into future economic evaluations of various approaches to care for terminal patients.

The aim of this chapter is to measure the costs of treating terminal patients. To this effect, a review of the international literature on the costs of treating terminal patients is undertaken. Also, a comparative analysis is carried out of the costs of terminal patients who receive palliative care, and terminal patients who receive classical care in different settings in Belgium. Finally, data from the Christian Sickness Funds serve to calculate health expenditure for patients who have received the allowance for palliative home care.

11.2 METHODS

11.2.1 Literature review

11.2.1.1 Search strategy

Studies were identified by searching PubMed, Centre for Reviews and Dissemination databases (Database of Abstracts of Reviews of Effects, NHS Economic Evaluation Database, and Health Technology Assessments Database), Cochrane Database of Systematic Reviews, and EconLit up to September 2008. Additionally, the bibliography of included studies was checked for other relevant studies. Search terms included 'palliative care', 'end of life', 'terminal patients', 'health economics', 'costs', 'economic burden', 'cost analysis' alone and in combination with each other.

The review was limited to studies published between 2000 and 2008. Earlier articles were considered of limited relevance because changes in the organisation and financing of palliative care over time are likely to influence cost estimates. There was no limitation on the language of the article.

11.2.1.2 Inclusion/exclusion criteria

The literature review targeted studies on the costs of palliative care. Inclusion was limited to studies that contrasted palliative care delivered in different healthcare settings, and to studies that compared palliative care with alternative therapeutic approaches. Studies that analysed costs at end of life, but did not focus on the specific costs of palliative care were excluded. Our review did not incorporate economic evaluations investigating the efficiency of palliative therapies. Another exclusion criterion was studies that failed to convert health care resource utilization into costs.

Inclusion was restricted to articles published in peer-reviewed journals. Congress abstracts were not considered because they do not provide sufficient details of methodology and results.

11.2.1.3 Data analysis

To compare costs between studies, costs were actualized to 2007 values using a rate of inflation based on the evolution of the Consumer Price Index. Costs were converted using purchasing power parities for Belgium, i.e. market exchange rates adjusted for differences in purchasing power between countries and Belgium.

11.2.1.4 Assessment of methodological quality

A qualitative appraisal was carried out of the methodological quality of cost studies by investigating study population, data sources, methods of data collection, scope of included costs and time horizon[385].

11.2.2 Costs of treating terminal patients in Belgian health care settings

A cohort study was set up comparing the costs of terminal patients who receive palliative care with the costs of terminal patients who receive classical care in different settings in Belgium. Costs were calculated in hospitals, nursing homes and home care.

In hospitals and nursing homes, a retrospective analysis was undertaken relying on routinely collected information. Within the timeframe of the study (data collection of 6 months), a prospective data collection was not feasible as it included the selection of palliative patients in hospitals and nursing homes, their follow-up until death and a waiting time (3 to 4 months) before final bill data, prior to their analysis.

On the opposite, a prospective data collection has been set up for patients staying at home: this was the only solution to collect all health care related bills since all these bills are never saved in the home care setting. The palliative home cared patients were invited to collaborate by the palliative home care support team PANAL (Leuven) and Delta (Liege). Within the timeframe of this study, it was not possible to collaborate with GPs to collect prospectively the bills of "classical home cared" patients since a GP has normally only 2 to 5 palliative patients per year. The palliative home cared patients were asked to sign an informed consent form. This study was approved by the Ethical Committee of University Hospitals Leuven.

11.2.2.1 Selection of patients

This study selected terminal patients in hospitals, nursing homes and home care. Hospital patients deceased between 1st January 2007 and 30th June 2007 were enrolled in the study. It was not possible to include patients deceased between 1st July 2007 and 31st December 2007 (i.e. the inclusion period for nursing homes, cf. infra) because invoice data for such patients were not available at the time that the cost analysis was carried out. In each hospital, patients were recruited from the oncology wards, geriatric wards, cardiology wards and palliative care units.

The analysis did not enrol patients in intensive care units as this population fell outside the scope of the study: their situation does not allow deciding on their palliative versus

curative status. However, their exclusion may have led to an under-estimation of costs. With respect to haematological cancers, patients suffering from Hodgkin's or non-Hodgkin's lymphoma were included. However, patients suffering from leukaemia were excluded because leukaemia is considered to be an acute disease that is unlikely to result in an admission to a palliative care unit. Patients from different wards were pooled for the purpose of the cost analysis. Patients who had a hospital stay exceeding six days were enrolled.

Nursing home residents who died between 1st July 2007 and 31st December 2007 were included. The starting date of 1st July 2007 was intentionally chosen because invoicing procedures became legally more transparent from that date onwards. Patients who moved to another nursing home or were admitted to the nursing home during the 30 days preceding death were excluded.

Home care patients deceased between 1st July 2008 and 1st November 2008 were enrolled.

Since the type of pathology influences costs, the study included patients who suffer a chronic disease. This means that acute illness, sudden death and death following therapeutic complications were excluded. Information about the diagnosis of patients was requested to ensure that patients in the three settings (i.e. hospitals, nursing homes and home care) are comparable.

A physician (Prof. Menten) and a nurse (Betty Kutten) assessed the real care provided to terminal patients during the last 30 days of their life with a view to determining whether the patient received palliative care or classical care. This assessment was carried out in collaboration with the treating physician and/or nurse. An exclusion criterion was incomplete medical/nursing records.

The following decision algorithm was used by the two researchers to label the terminal patients as "palliative" or "classical care" patients in hospitals and in nursing homes. First there in all hospitals and nursing homes a meeting between the researchers and the chief nurse and/or the treating physician(s) or the palliative nurse clarified the institutional attitudes concerning the transition from cure to care. The following points were discussed e.g., availability of written palliative guidelines, use of 'do not reanimate codes', practice of advanced care planning in palliative care, management of terminal patients

In hospitals, all patient files from the geriatric, cardiology and oncology wards who died between 1st January 2007 and 30th June 2007, were analysed one by one by the two researchers to look for the decision making process in the last 30 days of life. In nursing homes, all files of the patients who died between 1st July and 31st December 2007 were included. Medical and nursing notes were analysed. Based on these notes the patients were classified in two groups i.e. "classical care" and palliative patients. Then the researchers analysed the administration of drugs, of artificial food and fluid, the diagnostic and therapeutic interventions, the transfers to others wards… to check if the patients effectively received what was planned. If a "classical care" patient received finally just pain and symptom control, he was included in the palliative group although the caregivers did not state they intended to treat the patient as a palliative patient. On the opposite, some patient called "palliative patients" got intensive diagnostic or therapeutic interventions, sometimes started by the physician in charge, sometimes on request of the family: in this case, the patient originally called "palliative patient" was included in the "classical care" group based on what was done really instead of what was intended to do.

11.2.2.2 Selection of settings

The study purported to compare costs between palliative care and classical care in three different settings, i.e. hospitals, nursing homes and at home. Therefore, costs were calculated for:

- Hospital patients with palliative care;
- Hospital patients with classical care;
- Hospital patients in palliative care units;

- Nursing home patients with palliative care;
- Nursing home patients with classical care;
- Home care patients receiving advice from a mobile palliative support team (only patients with palliative care).

Home care patients without a mobile palliative support team (i.e. patients with classical care) were excluded due to the small number of such patients in our data collection during this short inclusion period. However, such patients are included in the analysis of health expenditure on palliative home care (cf. infra).

11.2.2.3 Selection of institutions

The goal was to include a representative sample of institutions within the settings of hospitals, nursing homes and home care.

Choice of hospitals

The study included a university hospital, a public hospital and a catholic hospital; one of each type in Dutch-speaking Belgium and one of each type in French-speaking Belgium. Specific hospitals were selected for pragmatic reasons i.e. the Catholic university hospital of Leuven and the public university hospital of Sart Tilman in Liège. Moreover, many hospitals are part of merged institutions with a mixed public-private character: the researchers' choice was restricted to the few public and catholic hospitals that have a unique character. Finally, it should be noted that "CHR du Val de Sambre" does not have any palliative care unit.

Choice of nursing homes

The study included public and Catholic (Caritas) nursing homes in Dutch-speaking and French-speaking Belgium. Nursing homes satisfying these criteria were selected for pragmatic reasons.

Originally, a distinction was planned between small nursing homes (< 60 beds) and large nursing homes (> 200 beds). Contacts with nursing homes revealed that few (large) institutions that satisfied these criteria were willing to participate in the study. Moreover, small nursing homes had a limited number of eligible patients as such institutions have few deaths over the course of a year. Therefore, the limits were changed to less than 110 beds for small nursing homes and more than 150 beds for large nursing homes. However, the experts consulted in September 2008 argued that the size of the institution was not a relevant factor influencing costs. They also felt that the difference between 110 and 150 beds was too small to allow for a meaningful comparison. Therefore, it was decided that size of institutions had no longer to be taken into account when including institutions in the sample.

Choice of home care

Networks providing mobile palliative support teams in palliative home care were selected for pragmatic reasons. To this effect, the Delta network (Chênée, Liège) in French-speaking Belgium and the "Palliatief Netwerk Arrondissement Leuven" (PANAL) in Dutch-speaking Belgium were included in the study. Both networks were responsible for a city (Leuven and Liège) and a large rural area so that patients from cities and rural areas could be included. For this reason networks in Brussels and Antwerp were not considered.

11.2.2.4 Sample size

To the best of the authors' knowledge, this is the first study of the costs of palliative care in Belgian hospitals, nursing homes and home care. In the absence of data on the prevalence of terminal patients and on the variance of costs at the time of the study, it was not possible to use statistical formulae to calculate sample sizes or to explore specific hypotheses using statistical tests.

Instead, this cost analysis aims to carry out a descriptive study, quantifying costs of palliative care in Belgium. The results of our cost analysis may serve to inform sample size calculations of future studies.

The selection of hospital and nursing home patients was carried out as follows. Patients were stratified on the basis of whether they had receive palliative care or classical care based on the decision making process described in 11.2.2.1. Patients within each group were ordered by date of death: every patient or every other or every third patient was included for final cost analysis to result in the preconceived number of patients to be analysed. The study intended to enrol 25 patients at random from each of six types of hospitals (i.e. university/public/catholic hospital in Dutch-speaking and French-speaking Belgium). Also, the intention was to include 50 patients at random from each type of nursing home (public/Caritas nursing homes in Dutch-speaking and French-speaking Belgium). In total, our target was set at 150 hospital patients and 200 nursing home patients.

With regard to home care, the study purported to include 30 terminal patients in Dutch-speaking Belgium and 30 terminal patients in French-speaking Belgium. All consecutive patients who answered to the inclusion criteria were enrolled in the analysis but unfortunately the number of 30 patients was not attained.

11.2.2.5 Perspective

The analysis took a societal perspective, wherever possible, by measuring direct health care costs (e.g. hotel services, medicines, medical fees) as well as indirect costs (e.g. productivity loss of informal caregivers in home care setting).

For hospitals, costs were broken down into fixed hospital costs, charges incurred by patients, and charges incurred by the RIZIV/INAMI.

For nursing homes, the analysis considered costs incurred by patients. These comprised costs invoiced by nursing homes to patients and fixed nursing home costs (that are paid by patients in the form of a daily tariff). Eventual hospitalization costs were included as well since they are for individual patients a substantial cost.

In consultation with the Belgian Health Care Knowledge Centre, it was decided that the costs of training hospital and nursing home staff and the costs of paramedics (e.g. physiotherapists) fell outside the scope of this study.

For home care, the analysis elicited private expenditure incurred by patients. Given that invoices reported private expenditure only and patients did not always collect all invoices, it was not possible to calculate total (private and public) expenditure. The only exception was medical fees, for which data on total expenditure were gathered based on official nomenclature codes. Hospitalization costs were present in this group of patients who all died at home.

Based on the advice of the Ethical Committee, costs of shroud, mortuary, and transportation of the deceased patient by the undertaker were not included. Costs made in the context of the future evolution of the infrastructure fell outside the scope of this study.

11.2.2.6 Time horizon

The time horizon of the cost analysis was 30 days preceding death: this study focused on costs of terminal patients and the research team decided to gather data on health care costs and indirect costs during the last month of life.

11.2.2.7 Data sources

This study quantified real costs based on actual resource use wherever possible. In general, actual resource use with respect to fixed costs of hospitals and nursing homes were computed. This means that a detailed exercise extracted relevant cost information from accounting data in each participating hospital and nursing home, instead of using charges for hotel services. The measurement of costs provides a major added value of this analysis.

Moreover, charge data were used for some items for practical reasons. Data sources are, therefore, based on a mixture of cost and charge data. The scope of cost and charge data is specified in the following sections.

Data sources for hospitals

Data sources for hospitals consisted of accountancy data and invoice data.

Fixed costs originated from the FINHOSTA accounting system[386] for consistency and data comparability between hospitals. These accounting data served to calculate costs based on actual resource use, including costs of hospital staff (excluding medical fees), energy (i.e. heating, water and electricity), infrastructure, and nourishment.

Invoice data reflected charges: they related to medical fees (fees for physician consultations, laboratory tests, clinical biology), pharmacy (medicines and medical devices), and other charges (i.e. telephone costs and additional costs for a single room).

Data sources for nursing homes

Nursing home data were derived from the accounting system of each participating nursing home and from patient invoices.

Fixed costs of nursing homes were based on actual resource use and were derived from the accounting system. These fixed costs related to nursing staff; energy (i.e. heating, water and electricity), pharmacy (i.e. medicines and medical devices), technical devices (e.g. toilet chair, crutches) and nourishment.

Invoices provided data on charges related to medical fees (fees for outpatient physician consultations), pharmacy (i.e. medicines and medical devices), and other charges (i.e. additional nourishment, costs of telephone, hairdresser, transportation for ambulatory care, costs of ambulatory care). Costs of washing bed linen were not included as it was not possible to extract data on the additional washing costs attributable to the care of a terminal patient.

Data sources for home care

Data were collected for home care using a questionnaire provided in appendix. No validated questionnaires were available in the international literature and this questionnaire was developed ad hoc for the purposes of this study. The questionnaire was validated by the nurse teams of two networks providing mobile palliative support teams and by a patient panel. The data collection exercise was supervised by the mobile palliative support team.

The family was asked to register all illness-related expenses in ambulatory care onto the questionnaire and to collect relevant invoices in a box. On a weekly basis, data were registered with respect to nourishment; energy (i.e. heating, water and electricity), additional infrastructure (e.g. staircase lift), pharmacy (i.e. medicines and medical devices), technical devices (e.g. toilet chair, hospital bed, crutches), diagnostic and therapeutic interventions, medical fees, visits to Accident & Emergency (A&E) department, support from social services (e.g. nursing support, household support, home and family support), informal care, other costs (e.g. extra telephone costs) and ambulatory care in hospital. At the end of the data collection exercise, all invoices were returned to the family of deceased patients.

With respect to indirect costs, the duration of productivity loss of family and friends was derived from questionnaire data for patients in the home care setting. The unit cost of productivity loss reflected the average wage of a nurse with ten years of experience following the advice of the expert group in September 2008. In Belgium, family and friends who take leave to care for palliative patients at home have less days of leave during the following year. However, this effect was not taken into account in this analysis.

Support or counselling provided by a social worker, psychologist, pastor or moral consultant was not taken into account in any health care setting due to the negligible cost. However, this does not mean that the impact of this support is of negligible importance for the patient and his/her family.

11.2.2.8 Data analysis

Infrastructure

The data analysis calculated health care costs and indirect costs that can be attributed to the care of terminal patients. However, the causal link between costs and care of terminal patients may differ between settings. This is the case for costs of infrastructure. As a hospital is built specifically for the purpose of treating patients (including terminal patients), costs of hospital infrastructure can be attributed to care of terminal patients and, consequently, were included in the analysis. As nursing homes provide a living environment for senior citizens that is not specifically set up to care for terminal patients, the costs of nursing home infrastructure were not considered. In the home setting, costs of additional infrastructure linked to the care for a terminal patient (e.g. staircase lift, special refurbishment of bedroom) were included, but standard home costs were not taken into account.

Productivity loss of caregivers

Care was exercised when including indirect costs of productivity loss of informal caregivers. In the home care setting, the costs were calculated based on the productivity loss of family and friends who care for terminal patients. In the hospital setting, productivity loss was not considered because the continuity of care is assured by hospital staff. In a similar way, the experts argued that indirect costs in the nursing home setting should not be taken into account because few people take up leave to care for a terminal patient in nursing homes.

Fixed costs

Estimates of fixed costs in hospitals and nursing homes related to the full year of 2007. In order to attain a fixed cost per day per patient, we divided annual fixed costs by the number of lay days (i.e. days that patients occupy a bed). For the allocation of fixed costs in nursing homes, the number of lay days includes the time that a patient spent in hospital because the nursing home continues to incur fixed costs during that time period.

Time horizon

Costs were calculated over the period of 30 days preceding the death of the patient. However, it was not always possible to attribute costs to the final month of life when invoices did not state the date on which the health care cost was incurred. This is, for example, the case for specific incontinence materials and medication in nursing homes. Such costs were proportionally allocated to correspond to the time horizon of 30 days preceding the death of the patient.

Lump sum charges

Hospitals may charge a lump sum for medicines, radiology and clinical biology once during a hospital stay. These charges were included for patients who stayed in hospital for less than 30 days. Charges per hospital stay were added to 'pharmacy' when they related to medicines and were included in 'medical fees' when they reflected radiology and clinical biology. Lump sum charges were excluded for patients who stayed for more than 30 days because their proportional allocation to our time horizon of 30 days would result in a negligible cost.

Fixed costs in nursing homes

No uniform accounting system exists for nursing homes. Therefore, the analysis of fixed costs would rely on accounting data that differ between participating nursing homes. This may be a source for variability in estimates of total patient costs between nursing homes. To minimise this effect, mean fixed costs per patient per day were calculated across all participating nursing homes and this mean cost was then applied to compute costs for each individual terminal patient staying in a nursing home, i.e. mean fixed costs per patient per day were multiplied by the number of days that a patient stayed in a nursing home.

Mixed trajects

Patients can follow a mixed traject e.g. patients in nursing homes may be hospitalized for a few days during the 30 days preceding death. An intent-to-treat analysis was performed, implying that those patients remained in the nursing home group to which they were originally assigned. As the retrospective analysis of nursing home patients did not provide any data on hospitalization costs, the analysis calculated the length of hospital stay of nursing home patients and multiplied this by the average hospitalization cost per patient per day as derived from the analysis of terminal patients staying in hospital. During the expert meeting, it was decided not to include hospitalization costs for patients who stay at home as this would artificially increase costs of terminal patients staying at home. In reality, a complementary analysis showed that this cost was negligible for these patients who died all at home.

Patients can also follow a mixed care programme: patients may originally be classified as receiving classical care and then switch to palliative care. In this case, patients were assigned to the classical care group or the palliative care group based on the real treatment / care that was given (cfr criteria in 11.2.2.1).

Total cost calculations

Total costs were calculated as follows.

Costs of the last hospital stay preceding death consisted of fixed costs (average fixed costs per day per patient multiplied by the length of hospital stay) and medical fee, pharmacy and other charges during hospitalization. With respect to medical fees, pharmacy and other charges, a distinction was made between charges incurred by the patient and charges incurred by RIZIV/INAMI.

Nursing home costs during the 30 days preceding death were made up of fixed costs of nursing homes (average fixed costs per day per patient multiplied by the number of days in nursing homes); medical fee, pharmacy and other charges during stay in nursing homes; and hospital costs (average hospitalization cost per patient per day multiplied by the length of hospital stay) during the final month of life.

In the home care setting, all relevant costs were summed to attain a cost per patient during the 30 days preceding death.

The analysis also generated cost estimates per patient per day in each health care setting.

Costs were calculated at 2007/2008 prices.

Costs of patients receiving palliative care were compared with costs of patients receiving classical care using the independent samples t-test for variables having a normal distribution or using the Mann-Whitney U-test for variables not having a normal distribution.

11.2.3 Health expenditure for palliative home care based on data from the Christian Sickness Funds

The analysis of costs of palliative care in Belgian health care settings included a prospective study of home care for terminal patients. As the number of patients enrolled in this study was small, the results are completed by data from a retrospective study conducted by the Christian Sickness Funds[303]. This retrospective study had a more focused scope on a large sample of patients: it computed health expenditure on palliative home care. Non-reimbursed health and other expenses (e.g. social services) were not taken into account.

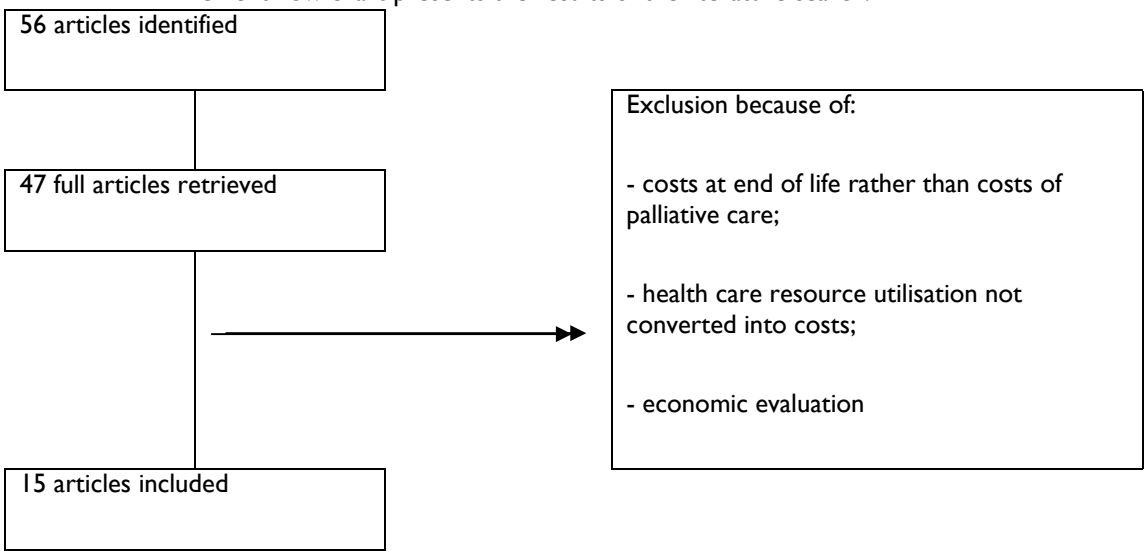
Data related to patients who received the palliative statute with an explicit engagement of first-line caregivers to provide palliative home care during the last six months preceding death. This introduces a possible bias because health expenditure may be higher for patients receiving a palliative statute for palliative home care. However, in our opinion, this bias is likely to be minor given that financial constraints may be less important in the context of end of life and because of the limited amount of the monthly allowance that such patients can apply for. Indeed, the monthly allowance is set at 491.22 € in 2008 and can be received for a maximum of two months[387]. The study enrolled patients aged over 40 years who died during the period July 2005 – July 2006.

Average daily expenditure was computed by dividing expenditure from the day that the palliative statute for palliative home care was received until the day of death by the number of days that the patient stayed at home. Expenditure of patients with a mobile palliative support team was compared with expenditure of patients without a mobile palliative support team. In order to have a meaningful comparison of health expenditure between both groups of patients, expenditure on a mobile palliative support team was not included as well as hospitalization costs.

11.3 RESULTS

11.3.1 Literature review

The next flow chart presents the results of the literature search.



Few studies have investigated the costs of treating terminal patients. Existing studies make up a disparate and varied body of evidence focusing on different aspects, including palliative care costs across health care settings, palliative care costs in different types of hospitals, costs in palliative care units and in other hospital units, costs of palliative care and of usual care in hospitals, and costs of different models of home palliative care. No study was identified that measured costs of treating terminal patients in nursing homes. The characteristics of existing studies have been summarised in the appendix about costs.

11.3.1.1 Costs of treating terminal patients across health care settings

As palliative care is delivered across hospital, outpatient and home care settings, a prospective, multi-centre study undertook a cost analysis of 80% of Spanish palliative care services[388]. Spanish palliative care services are diverse and include acute bed units in general hospitals, specialist cancer units, nursing homes, hospital support teams, and home care support teams. Cost data were gathered on 372 patients during the last six weeks of life by means of a weekly structured telephone interview. Hospital unit costs were derived from published sources, but unit costs for care other than hospital care were based on assumptions.

Total costs per patient amounted to 2,774 € and could be broken down into hospitalization costs of 2,390 € per patient and other costs (i.e. outpatient clinic and home care) of 384 € per patient. Cost estimates may have been influenced by the cultural context and the health care system in Spain. For instance, the high number of home care visits reflects the high emphasis placed on home care teams and the active support by family members in Spain.

A British study calculated palliative care costs for different types of advanced cancer patients from the time that they started strong opioid treatment until death[389]. The study enrolled 547 patients and was conducted from the perspective of the National Health Service. The authors considered costs of drugs, general practitioner visits, palliative care physician visits, and hospital admissions, but did not include costs of specialist nursing and hospital-based prescribing. Mean costs of palliative care amounted to 3,418 € for colon cancer; 4,672 € for breast cancer; 4,936 € for lung cancer; 5,069 € for uterus cancer; 6,577 € for stomach/oesophagus cancer; 7,086 € for prostate cancer; and 9,014 € for ovarian cancer. However, this study did not control for confounding factors (e.g. patient age, survival time, time to start of palliative care, duration of palliative care) which differed between cancer types. Hospitalization was the key driver of costs, accounting for 35%-77% of palliative care costs. The authors concluded that palliative care costs vary between different types of advanced cancer patients.

11.3.1.2 Costs of treating terminal patients in hospital

A case series measured and identified the determinants of palliative care costs of hepatocellular carcinoma in Hong Kong[390]. Two hundred and four patients were enrolled. The analysis was undertaken from a societal perspective, including costs of formal and informal services incurred by payers, caregivers and patients. The mean cost for formal health services per patient amounted to 3,546 € from first hospitalization until death. A regression analysis showed that severity and chemotherapy increased formal service costs per day, but patient age, number of days of observation and survivorship decreased formal service costs per day. This study did not include a control group of patients and results were specific to patients suffering from inoperable hepatocellular carcinoma.

A prospective cohort study calculated costs of palliative care in two hospitals providing internal medicine, surgical and obstetric care and in two hospitals offering extended care and rehabilitation in France[391]. Predictive factors of palliative care costs were identified. The analysis enrolled 119 patients. Total costs per day amounted to 493 € for all patients, 547 € for patients admitted to hospitals providing general medicine, and 440 € for patients admitted to hospitals providing extended care. The cost difference between the two types of hospital was explained by the fact that palliative care units in hospitals providing general medicine employed more staff. Total costs consisted of staff salaries (62% of costs), logistical expenses (23%), overheads (5%), medicines (5%), depreciation of heavy equipment (3%), disposable devices (1%), and diagnostic tests (1%). The following variables were predictive of higher costs: degree of anxiety of patients and their family; proximity of death; extreme dependence; ear, nose and throat cancer; young patient age; and the provision of certain procedures. Although this study was carried out in a limited number of palliative care units and enrolled a small number of patients, the authors concluded that the population of patients in palliative care units is not homogeneous from an economic point of view. In other words, palliative care unit costs depend on patient characteristics.

A US case-control study included 38 patients admitted to a hospital palliative care unit and 38 patients who died outside the palliative care unit and who were cared for by other medical or surgical teams[392]. The palliative care unit was a dedicated 11-bed inpatient unit staffed by a high-volume specialist team using standardised care. The analysis collected data on charges (based on official list prices) and on costs (based on actual resource use). The palliative care unit generated lower daily charges (-59%) and lower daily costs (-57%). Some of these savings originated from discontinuing costly interventions once patients were clearly identified as dying. It was not clear to what extent the high volume of the palliative care unit produced economies of scale and lowered costs.

A cohort study calculated costs of patients admitted to a hospital palliative care unit as compared to patients admitted to an intensive care unit or any unit other than palliative care in the United States[393]. In addition to this, approaches to controlling costs of a palliative care unit were identified. The cost per day for hospitalized patients during the last 20 days leading to their death was significantly lower on the palliative care unit than on intensive care units and non-palliative care units. Furthermore, the authors emphasised the importance of admitting patients to the palliative care unit at the right time with a view to containing costs. Approaches to controlling costs included a) appropriate admissions to the palliative care unit; b) direct admissions from the emergency department to the palliative care unit; and c) transfer of patients from more costly sites of care (e.g. intensive care unit) to the palliative care unit. Finally, palliative care unit costs diminished as a result of better coordination of care and elimination of unnecessary tests.

A retrospective, observational study of 314 veterans in the United States compared costs of palliative care with those of usual care during a terminal hospitalization[394]. Inpatient costs were broken down into ancillary (laboratory and radiology) costs and pharmacy costs. Hospital palliative care was associated with lower inpatient costs per day (-245 €) and lower ancillary costs per day (-100 €). There was no difference in pharmacy costs between palliative care and usual care. It should be noted that the specific organisation and financing of health care for veterans in the United States might hinder the transferability of those results to other health care settings.

The author of a US study adopted a case-control design to compare charges of 164 patients who received an inpatient palliative care consultation with charges of 152 inpatients who did not[395]. As such, this study assessed a consultative palliative care programme rather than a programme providing overall care. The measurement of charges in lieu of costs is a limitation of this analysis because charges may not have a consistent relationship with costs. Mean daily charges amounted to 4,043 € for cases and 4,358 € for control patients. Daily charges for consultative palliative care related to supplies and equipment (29% of charges), pharmacy (28%), laboratory and imaging (22%), room and board (20%), and other therapy (2%). Patients who received a consultation because of non-physical symptoms (e.g. care planning, personal concerns, spiritual concerns) generated higher charges.

A similar US study investigated costs of patients who received an inpatient palliative care consultation with costs of inpatients who received usual care[396]. However, this study enrolled a larger sample of patients (4,908 palliative care patients and 20,551 usual care patients), matched control patients to cases, included patients from eight diverse hospitals, and measured costs rather than charges. Also, this study distinguished between patients who were discharged alive and patients who died. Hospital costs related to costs of the intensive care unit, pharmacy, laboratory, and diagnostic imaging tests. Palliative care patients discharged alive had net savings of 1,684 € in costs per admission and 277 € in costs per day. Cost savings originated from reductions in laboratory and intensive care unit costs as compared with usual care patients. Palliative care patients who died had net savings of 4,872 € in costs per admission and 371 € in costs per day as a result of reductions in pharmacy, laboratory, and intensive care unit costs as compared with usual care patients. The authors concluded that hospital palliative care consultation teams generate savings.

11.3.1.3 Costs of treating terminal patients at home

The costs of palliative care at home were computed in an Italian case series[397]. The home care service provided a telephone hotline to patients and the team consisted of oncologists and nurses with additional skills in cancer nursing. This service was restricted to patients with an estimated life span of two months or less as estimated by clinicians. Costs of the home care service amounted to 39.9 € per patient per day. This figure covered costs of the support and coordination team (8.3 €), medicines (14.4 €), general practice fees (5.7 €), medical examinations (5.0 €), nursing (4.2 €), supplies (1.6 €) and specialist consultations (0.5 €).

An Italian retrospective, observational study analysed the costs of a home care programme according to the disease status and life expectancy of patients with haematological malignancies[398]. One hundred and forty-four patients were assigned to one of the following groups: a) terminal phase requiring palliative care (89 patients); b) advanced phase requiring palliative care (31 patients); c) chronic phase requiring supportive therapy (9 patients); and d) curable phase requiring supportive therapy (15 patients). A multi-professional home care team provided for around the clock support and routine visits to patients by staff. The team consisted of haematologists, nurses, psychologists and social workers. The general practitioner was also involved. Mean monthly costs of health care providers, materials and medicines, transfusion support, laboratory and diagnostic procedures amounted to 4,533 € for the terminal phase; 2,468 € for the advanced phase; 1,594 € for the chronic phase; and 4,270 € for the curable phase. Higher costs of the terminal phase and of the curable phase could be attributed to the higher number of medical and nursing visits, and transfusions required by such patients. This study showed that home care costs depend on disease status of patients. However, other variables that may influence home care costs, such as age and diagnosis of patients, were not controlled for. Also, the number of patients included in some disease status groups was relatively small.

A retrospective, observational study enrolled all patients undergoing palliative care who died from cancer in a Spanish town in 1998[399]. Patients received either standard care management (111 patients) or home care support by a specialized team (44 patients). The perspective was that of the Catalan Health Service and the time horizon was one month. Mean costs per patient were lower for patients receiving home support than for patients receiving standard care management (-683 €). This cost advantage of home support originated from lower costs of hospitalization, outpatient care use, emergency department visits, and days of stay in palliative care units in nursing homes. However, the authors could not rule out selection bias as possible differences in characteristics between patient groups (e.g. illness severity) may influence cost estimates. Cost estimates also reflected the practices of one specialized home support team and may not be applicable to other teams.

An Israeli analysis compared health care costs of two models of delivering palliative care at home to terminally-ill patients during their last year of life[400]. Costs of 120 patients receiving home-specialized palliative care services were contrasted with those of 515 patients receiving home non-specialized palliative care services. No detailed description of home (non-)specialized palliative care services was provided by the authors. Health care costs of home-specialized services were 30% lower than those of non-specialized services during the last year of life. The cost difference increased nearer the time of death. Lower costs of home-specialized services could be attributed to lower costs of hospitalizations and of oncology treatments. The authors argued that this may be explained by the nature of the specialized palliative care approach which provides for around the clock support and routine visits to patients by staff.

The cost impact of two new services allowing patients to be cared for at home was explored by a retrospective before-and-after study in England[401]. The services consisted of a rapid response team and discharge community link nurses. The rapid response team is a community-based team that makes patient visits during out-of-hours periods and that provides support to patients over the telephone. The discharge nurses facilitate speedy discharge of patients with complex needs who are receiving palliative care. Cost data related to 40 cancer patients receiving palliative care prior to implementation of these services and 40 comparable patients who accessed programme services. The mean cost of acute and community services amounted to 8,888 € for patients who accessed programme services and 8,760 € for patients who did not. The authors did not exclude the possibility that programme services were accessed by patients who are able to and wish to die at home, thus introducing potential selection bias.

A British cohort study compared costs of 173 patients attending one of five palliative day care centres with those of 53 patients who received support from specialist palliative home care teams[402]. The authors did not provide a detailed description of palliative day care and did not report costs of palliative home care.

Data were collected by means of a questionnaire asking patients to report costs of health and social care use in the previous four weeks. No statistical analyses were undertaken due to the small sample size and sample attrition. Costs of palliative day care amounted to 106 € per person per day, increasing to 146 € if unpaid resources (e.g. volunteers) were included. The authors also found that patients who attend palliative day care access a different package of care than those who do not. This may reflect differences in characteristics of these two groups of patients and imply that palliative day care and palliative home care are not substitutes.

11.3.1.4 Key points and limitations

The body of evidence on the costs of treating terminal patients was small and varied. Although palliative care requires a multidimensional and interdisciplinary approach, few studies calculated palliative care costs across health care settings. These studies showed that hospitalization costs represent the principal component of palliative care costs. A number of studies focused on palliative care in hospitals. The results consistently indicated that palliative care is cheaper than usual care or care delivered in hospital units other than the palliative care unit. From a cost perspective, hospitals need to pay attention to admitting patients to the palliative care unit at the right time. There is some evidence pointing to cost advantages of palliative care at home as compared to alternative care models, although this needs to be corroborated by further research. If palliative care is viewed as a component of a broader care programme (e.g. a comprehensive oncology programme), no study has examined the cost impact of palliative care on the care programme.

The reader must be careful when comparing costs of palliative care between studies for a number of reasons. First, the organisation and financing of health care systems vary between countries, implying that palliative care services and associated costs differ. Second, the definition of a palliative patient and, thus, inclusion/exclusion criteria differ between studies. Third, the definition, nature and content of palliative care and classical care vary between studies.

Caution needs to be exercised when comparing the costs of different approaches to delivering palliative care to patients. This is because the literature indicates that palliative care costs depend on patient characteristics such as diagnosis, status of disease and age. The population of patients receiving palliative care is heterogeneous from a cost perspective. Also, different care models appear to target different patient groups and offer varied packages of services. This implies that different approaches to delivering palliative care are not substitutes of each other. The literature on the costs of palliative care suffers from a number of methodological shortcomings. In the absence of randomised controlled trials, selection bias where patients self-select into a specific care model is an issue that is likely to influence cost estimates. A number of studies drew on patient data (e.g. patient questionnaire, telephone interview) with a view to collecting cost information. Memory biases (patients' ability to recall health resource utilisation and costs) might influence the reliability of such data. Cost estimates were derived for specific patient samples and are unlikely to be applicable to the population of patients receiving palliative care. The scope of included costs was generally restricted to direct health care costs associated with palliative care. This refers to costs of medicines, contacts with health care professionals and hospitalization. No study has considered direct non-health care costs associated with transportation to the health care professional or indirect costs arising from lost productivity.

It is difficult to determine the economic impact of treating terminal patients. Therefore, next table identifies the major cost items that need to be considered when calculating the costs of treating terminal patients from a societal perspective. In addition to direct health care costs, studies need to focus on eliciting direct non-health care costs and indirect costs of productivity loss. With respect to the latter, attention needs to be paid to calculating the indirect costs of reduced ability to attend school, work or carry out usual daily activities.

Table 43: Items to consider when calculating costs of treating terminal patients

Direct health care costs			Direct non-health care costs	Indirect costs
Medication	Health care providers	Other		
…	**General practitioner**	**Diagnostic tests**	**Transportation to health care provider**	**Time lost from school**
	Specialist physician	**Social worker**	**Child care costs**	**Time lost from work**
	Psychologists	**Accident and Emergency visit**	**Home adaptations**	**Reduced ability to carry out usual daily activities**
	Nurse	**Alternative medicine**		

Key points:

- **Palliative care requires a multidimensional and interdisciplinary approach and should be offered in different settings: however, few studies calculated palliative care costs across different health care settings.**
- **Hospital palliative care is cheaper than usual care or care delivered in hospital units other than the palliative care unit.**
- **From a cost perspective, hospitals need to pay attention to admitting patients to the palliative care unit at the right time.**
- **There is some evidence pointing to cost advantages of palliative care at home as compared to alternative care models, although this needs to be corroborated by further research.**
- **The population of patients receiving palliative care is heterogeneous from a cost perspective. Also, different care models appear to target different patient groups and offer varied packages of services. This implies that different approaches to delivering palliative care are not substitutes of each other.**

11.3.2 Costs of treating terminal patients in Belgian health care settings

11.3.2.1 Sample of patients and institutions

Hospitals

Six hospitals participated in the study, generating a total of 146 patients. For one hospital, all 21 eligible patients were included. The sample of 146 patients consisted of 17 patients from cardiology wards, 42 patients from geriatric wards, 35 patients from oncology wards, and 52 patients from palliative care units.

Nursing homes

Patients were initially selected from one organization per type of nursing home (i.e. public / Caritas nursing homes in Dutch-speaking and French-speaking Belgium). However, due to the limited number of terminal patients receiving palliative care or classical care in each organization, multiple organizations had to be enrolled for some types of nursing homes. In total, 39 nursing homes were contacted: 19 consented to participate in this study.

The sample included 50 patients from Dutch-speaking public nursing homes, 49 patients from Dutch-speaking Caritas nursing homes, and 50 patients from French-speaking Caritas nursing homes. As the number of patients that could be enrolled from public nursing homes in Wallonia was limited, it was not possible to extract a random sample: all 32 eligible patients were included. A total of 181 patients were included in the sample.

Home care

In the home care setting, patients were enrolled from two networks providing mobile palliative support teams in palliative home care, i.e. the Palliatief Netwerk Arrondissement Leuven (PANAL) in Dutch-speaking Belgium and the Delta network (Chênée, Liège) in French-speaking Belgium. At one point in time during the study, the Delta network decided to opt out of the study. Therefore, all other networks providing mobile palliative support teams in palliative home care in Wallonia were contacted to participate in the study. At a later point in time, the Delta network rejoined the study and was the only network in Wallonia to provide data on terminal patients.

In Dutch-speaking Belgium, PANAL enrolled 11 patients, seven of whom died during the study period. One terminal patient who did not die but provided cost data over a period of 30 days was also added to the sample. The three last patients who were no longer considered to be terminal patients over the course of the study period were excluded from the analysis. The Delta network in Wallonia enrolled 8 patients, seven of whom died during the study period. One last patient who did not die but provided cost data over a period of 30 days was also added to the sample. The total sample consisted of 17 patients.

The sample was made up of 16 patients with a primary diagnosis of oncology and one patient suffering from a neurological disorder. All patients, except for one patient, had applied for a palliative home care allowance. For the Flemish patients, six out of eight patients had filed an application with the Flemish care insurance and four out of eight patients had applied for a Flemish encouragement premium. With respect to informal care, a career break within the context of palliative care was granted to family/friends of four out of 17 patients. No career break within the context of providing medical assistance had been obtained by family/friends of terminal patients.

11.3.2.2 Results

Hospitals

Next table gives an overview of mean costs per patient per day across hospitals and for each hospital separately. Mean costs per patient per day across hospitals amounted to 391 € (± 156 €). Mean costs per patient per day consisted of fixed costs of 254 € (65% of mean costs), patient charges of 14 € (4%) and RIZIV/INAMI charges of 122 € (31%). Total costs and their breakdown into fixed costs, patient charges and RIZIV/INAMI charges tended to be similar between hospitals.

Table 44: Mean costs of all terminal patients (n=146) included in the sample of 6 hospitals

Institution	Mean fixed costs per patient per day (€)	Mean patient charges per patient per day (€)	Mean RIZIV/INAMI charges per patient per day (€)	Mean total costs per patient per day (€)
HOS 1	262	9	123	394
HOS 2	266	22	99	387
HOS 3	249	11	105	365
HOS 4	202	8	110	319
HOS 5	397	9	129	535
HOS 6	142	23	167	332
Total	254	14	122	391

The patient sample of 146 patients consisted of 53 terminal patients receiving classical care and 88 terminal patients receiving palliative care. Five patients followed a mixed care program: they originally received classical care and then switched to palliative care. Based on the criteria proposed before, four patients were assigned to the classical care group and one patient was assigned to the palliative care group.

The tables here below compare hospital costs between different care programs. Table A shows that mean costs per patient per day of 423 € for patients receiving palliative care were significantly higher than costs of 340 € for patients receiving classical care ($p = 0.002$). Higher costs of palliative care originated from higher fixed costs ($p < 0.001$). However, RIZIV/INAMI charges were significantly higher for patients receiving classical care ($p < 0.001$). No difference was observed between palliative and classical care in terms of patient charges.

Focusing on terminal patients receiving palliative care, 37 patients were cared for in cardiology, geriatric and oncology wards; and 52 patients were hospitalized in palliative care units. The higher costs of patients receiving palliative care as compared with patients receiving classical care can be attributed to the higher costs of palliative care patients cared for in palliative care units. Table B shows that mean costs per patient per day of 522 € for patients in palliative care units were significantly higher than costs of 283 € for patients in cardiology, geriatric and oncology wards. Higher costs of patients in palliative care units originated from higher fixed costs ($p < 0.001$), resulting from high staffing levels in palliative care units as compared with acute hospital units.

Table C indicates that terminal patients receiving classical care generate higher hospital costs than terminal patients receiving palliative care in an acute hospital unit. Indeed, mean costs of patients receiving classical care amounted to 340 € as compared to 283 € for patients receiving palliative care in an acute hospital unit. This cost difference can be attributed to higher RIZIV/INAMI charges for patients receiving classical care. This is likely to reflect the fact that classical care programs involve more physician consultations, laboratory tests, and medications than palliative care programs.

Table 45: Comparison of mean hospital costs between care programmes

Table A. Mean hospital costs of all patients with palliative care versus all patients with classical care

Cost item	Mean costs per patient per day of palliative care (€) n = 89	Mean costs per patient per day of classical care (€) n = 57	P-value
Fixed costs	318 ± 157	155 ± 49	< 0.001[a]
Patient charges	14 ±17	14 ± 13	0.217[a]
RIZIV/INAMI charges	91 ± 71	171 ± 130	< 0.001[a]
Total costs	423 ± 157	340 ± 143	0.002[b]

Notes:
Results are presented as mean ± standard deviation.
[a] Mann-Whitney U-test; [b] Independent samples t-test.

Table B. Mean hospital costs per palliative patient in cardiology/geriatric/oncology wards versus patients in palliative care units

Cost item	Mean costs per day per patient with palliative care in cardiology, geriatric and oncology wards (€) n = 37	Mean costs per patient per day in palliative care units (€) n = 52	P-value
Fixed costs	153 ± 46	435 ± 84	< 0.001[a]
Patient charges	19 ± 25	10 ± 7	0.150[a]
RIZIV/INAMI charges	111 ± 86	77 ± 55	0.014[a]
Total costs	283 ± 109	522 ± 98	< 0.001[b]

Notes:
Results are presented as mean ± standard deviation.
[a] Mann-Whitney U-test; [b] Independent samples t-test.

Table C. Mean hospital costs per patient in cardiology/geriatric/oncology wards with palliative care versus patients with classical care in the same wards

Cost item	Mean costs per day per patient of classical care (€) n = 57	Mean costs per day per patient with palliative care in cardiology, geriatric and oncology wards (€) n = 37	P-value
Fixed costs	155 ± 49	153 ± 46	0.941[a]
Patient charges	14 ± 13	19 ± 25	0.892[a]
RIZIV/INAMI charges	171 ± 130	111 ± 86	0.002[a]
Total costs	340 ± 143	283 ± 109	0.025[a]

Notes:
Results are presented as mean ± standard deviation.
[a] Mann-Whitney U-test; [b] Independent samples t-test.

Nursing homes

To account for variability in cost estimates between nursing homes, mean fixed costs were calculated across all participating nursing homes. Mean fixed costs per patient per day amounted to 49.6 €. This cost consisted of nursing staff costs of 38.6 €, energy costs of 2.3 €, pharmacy costs of 1.0 €, technical device costs of 0.4 € and nourishment costs of 7.3 €. The mean fixed cost per patient per day was multiplied by the number of days that a patient stayed in the nursing home to calculate total fixed costs per patient.

During the 30 days preceding death, patients stayed on average 25 days in a nursing home and 5 days in hospital. The mean fixed costs per patient per day of 49.6 € were multiplied by the number of days in a nursing home to calculate fixed costs per patient in a nursing home. Fixed costs per patient were added to costs of medical fees, pharmacy and other charges to obtain a total cost per patient during a patient's stay in a nursing home. The mean costs per patient per day across hospitals of 391 € (cf. supra) were multiplied by the number of days that a patient stayed in hospital. Nursing home and hospital costs were added to attain a total cost per patient during the final month of life.

The next table shows that total mean nursing home costs amounted to 3,243 € per patient over the final month of life. This corresponds with 108 € per patient per day (± 90 €). There was substantial variation in total mean nursing home costs per patient per day between institutions. The major drivers of total mean nursing home costs of 3,243 € per patient were hospital costs (mean costs of 1,787 €; 55% of total mean nursing home costs per patient) and fixed nursing home costs (1,256 €; 39%). Costs of pharmacy, medical fees and other charges made up 6% of nursing home costs per patient over the final month of life.

Table 46: Nursing home costs of terminal patients (n = 181)

Inst.	Mean fixed costs of nursing homes (€)	Mean pharmacy costs in nursing homes (€)	Mean medical fees in nursing homes (€)	Mean other charges in nursing homes (€)	Mean hospital costs (€)	Total costs over 30 days (€)	Mean total costs per patient per day (€)
NH1	1,066	82	108	11	2,660	3,927	131
NH2	1,199	155	157	12	1,842	3,365	112
NH3	991	50	110	16	3,710	4,876	163
NH4	1,232	228	83	26	1,540	3,109	104
NH5	1,225	69	72	41	1,605	3,013	100
NH6	1,100	40	50	27	2,730	3,947	132
NH7	1,326	218	199	76	700	2,519	84
NH8	1,404	48	6	7	0	1,464	49
NH9	983	49	128	8	3,780	4,948	165
NH10	1,220	53	94	11	1,526	2,903	97
NH11	1,404	218	0	5	0	1,628	54
NH12	1,170	147	96	15	2,100	3,528	118
NH13	959	116	6	6	3,990	5,077	169
NH14	1,404	53	24	6	0	1,488	50
NH15	1,293	37	42	8	1,541	2,920	97
NH16	721	41	26	63	6,132	6,982	233
NH17	1,030	143	0	0	3,360	4,532	151
NH18	1,240	93	150	13	1,470	2,966	99
NH19	1,222	62	153	26	1,587	3,049	102
Total	1,256	87	92	21	1,787	3,243	108

When hospital costs were excluded, total mean nursing home costs amounted to 57 € per patient per day. Variation in nursing home costs per patient per day was limited as illustrated by the quartile values: Q0 of 0 €, Q1 of 53 €, Q2 of 56 €, Q3 of 60 €, and Q4 of 122 €.

The patient sample of 181 patients consisted of 108 terminal patients receiving classical care and 56 terminal patients receiving palliative care. Seventeen patients followed a mixed care program because they switched of group as explained above: four patients were assigned to the classical care group and 13 patients were assigned to the palliative care group.

Are there any cost differences between nursing home patients receiving palliative care and those receiving classical care? The next table shows that total mean nursing home costs per patient during the final month of life of 3,822 € for patients receiving classical care tended to be higher than costs of 2,456 € for patients receiving palliative care ($p = 0.068$) (see table below). Higher costs of classical care were driven by higher hospitalization costs ($p < 0.001$). These calculations were based on the average hospitalization cost per patient per day (derived from the analysis of terminal patients staying in hospital): higher hospitalization costs can consequently be attributed to a longer length of stay in hospital of nursing home patients receiving classical care. However, fixed nursing home costs ($p = 0.009$), pharmacy costs ($p = 0.002$), medical fees ($p < 0.001$) were significantly lower for patients receiving classical care. No difference was observed between palliative and classical care in terms of other charges.

Table 47: Comparison of nursing home costs between palliative and classical care, including patients receiving mixed care

Cost item	Mean costs per patient receiving palliative care (€) n = 69	Mean costs per patient receiving classical care (€) n = 112	P-value[a]
Fixed costs of nursing homes	1,306 ± 270	1,122 ± 423	0.009
Pharmacy costs in nursing homes	113 ± 106	71 ± 66	0.002
Medical fees in nursing homes	124 ± 102	72 ± 85	< 0.001
Other charges in nursing homes	24 ± 74	20 ± 37	0.485
Hospital costs	889 ± 2,421	2,536 ± 3,685	< 0.001
Total costs over 30 days	2,456 ± 2,117	3,822 ± 3,232	0.068

Notes:
Results are presented as mean ± standard deviation.
[a] Mann-Whitney U-test.
indicates that the exclusion of the 17 patients receiving a mixed care program did not change results.

Table 48: Comparison of nursing home costs between palliative and classical care, excluding patients receiving mixed care

Cost item	Mean costs per patient receiving palliative care (€) n = 56	Mean costs per patient receiving classical care (€) n = 108	P-value[a]
Fixed costs of nursing homes	1,334 ± 243	1,126 ± 422	0.001
Pharmacy costs in nursing homes	108 ± 105	72 ± 66	0.018
Medical fees in nursing homes	116 ± 100	73 ± 85	0.004
Other charges in nursing homes	20 ± 78	20 ± 37	0.240
Hospital costs	645 ± 2,174	2,499 ± 3,685	< 0.001
Total costs over 30 days	2,223 ± 1,896	3,790 ± 3,231	0.015

Notes:
Results are presented as mean ± standard deviation.
a Mann-Whitney U-test.

Home care

Mean monthly costs of home care per patient amounted to 4,464 €, corresponding with a mean cost per patient per day of 148.8 €. Mean monthly costs per patient primarily originated from the indirect costs related to the productivity loss of informal caregivers (mean cost of 2,596 €, 58% of total costs). Other drivers of monthly costs per patient were: support from social services (632 €, 14%), technical devices (295 €, 7%), medical fees (235 €, 5%), nourishment (207 €, 5%), and pharmacy (195 €, 4%). Patients did not incur costs related to diagnostic and therapeutic interventions or costs related to visits to A&E departments. The next table presents a breakdown of cost estimates of home care for terminal patients into various items. Next table highlights the variability in cost estimates reported by different patients. Quartile 4 values (i.e. maximum values) represented outliers for some cost items (e.g. technical devices, support from social services).

Patients were visited on average once a month by the mobile palliative support team.

Table 49: Home care costs of terminal patients (n = 17)

Cost item	Monthly costs (€)				
	Quartile 0	Quartile 1	Quartile 2	Quartile 3	Quartile 4
Nourishment	7	154	224	270	381
Energy	6	44	89	121	122
Additional infrastructure	50	63	75	88	100
Pharmacy	44	103	164	232	520
Technical devices	13	59	124	338	1,834
Diagnostic and therapeutic interventions	-	-	-	-	-
Medical fees	33	57	130	410	586
Visits to A&E department	-	-	-	-	-
Support from social services	18	74	200	380	4,776
Informal care (family/friends)	69	190	534	4,826	7,721
Other costs	23	37	50	69	88
Ambulatory care in hospital	72	87	102	113	124

11.3.2.3 Strengths and limitations of this study

Limitations linked to the design of the study

This analysis compared costs of terminal patients receiving palliative care with the costs of terminal patients receiving classical care in Belgian hospitals, nursing homes and home care. The results do not allow for a comparison of costs between health care settings: the organization and financing of care programs and the characteristics of the enrolled patients vary between health care settings. As a result, different cost estimates are generated in the three health care settings. The literature study also highlighted that the disparity in care programs and patient characteristics inhibits the comparability of cost estimates between health care settings.

Moreover, this patient sample may not be representative of the Belgian population of terminal patients. The size of the sample of this pilot study was limited and moreover this study over-sampled patients receiving palliative care in order to compare costs of palliative care with costs of classical care, Furthermore, the costs measured in the participating institutions may not be valid for any institution with terminal patients or palliative care services.

Innovative features of this study in comparison with the literature are the prospective design in the home care setting and the detailed data collection of real costs in institutions based on actual resource use wherever possible. The consequence of these methodological choices is that the research team invested a considerable amount of time and effort in enrolling institutions and patients. The research team still succeeded in including six hospitals, 19 nursing homes, two networks providing mobile palliative support teams, and 344 patients (out of a total of 786 eligible patients) in the sample. This recruitment was delayed by the summer period. Delays were aggravated by the need for obtaining approvals of hospital and nursing home management and individual physicians caring for terminal patients.

The comparison of costs between palliative care and classical care in the hospital and nursing home settings needs to be interpreted with caution. The wards and institutions to which patients belonged differed between patients receiving palliative care and patients receiving classical care. This choice was made in order to be able to enrol a sufficient number of patients in the study. However, this entails that cost differences between palliative and classical care may not only reflect differences in care programmes, but also cost variation between institutions and wards.

This analysis purported to compute the cost difference between palliative care and classical care. However, this was not possible when calculating fixed costs in hospitals and nursing homes. Annual fixed costs reflected the mix of patients receiving palliative care and classical care in each institution. Annual costs were then converted into a fixed cost per day per patient, irrespective of whether a patient received palliative care or classical care.

Rough estimate linked to the variability of data sources

The researchers faced problems given the complexity of relevant resources in palliative care in Belgian health care settings. Therefore, during this investigation, particular attention was paid to all costs necessary to achieve a truthful and complete representation of the costs of palliative care. As few details on the costs of palliative care are publicly available, an extensive cost model was set up drawing on data from a variety of sources. This is an optimal approach in the absence of publicly available data, but the reader should note that the findings give an approximation of the costs, but do not represent exact cost data.

The added value of this analysis lies in the identification and calculation of costs of terminal patients according to the care programme (i.e. palliative or classical care) in different health care settings. Caution needs to be exercised when comparing costs of palliative and classical care. As a randomised controlled trial raises ethical concerns, our study adopted a cohort design. On the one hand, the cost comparison of care programmes may be subject to selection bias because patients (or the family on behalf of patients) self-selected their care programme, and may be subject to performance bias because care programmes are not substitutes of each other. On the other hand, our cost estimates possess external validity in that they reflect differences in patient profiles and care programmes as observed in real practice.

Annual fixed costs in the hospital and home care settings were converted into average fixed costs per patient per day. The use of an average value implies that fixed costs did not differ between patients and did not vary with the length of stay. This contrasts with the literature review which demonstrated that hospital costs depend on a number of factors, including patient demographic characteristics and length of stay. However, our top-down approach necessitated the use of average fixed costs in the absence of individual patient data.

Estimates of costs of home care varied between patients for several reasons. First, the data collection period differed between patients in Dutch-speaking and French-speaking Belgium. In Dutch-speaking Belgium, patients started to register resource use and finished the registration process after four weeks. However, as most patients continued to live for another month, this means that the data collection period relates to the second to last month of life. This contrasts with French-speaking Belgium where patients registered resource use during the final month of life. This difference in data collection period is unlikely to influence cost estimates because patients tended to incur similar resource use during the final months of life: when comparing resource use between weeks, a similar pattern of resource use emerged. Second, some patients did not report medical fees because these fees were reimbursed by the palliative home care allowance. Therefore, expenditure on medical fees is underestimated. Third, differences in resource use exist between Dutch-speaking and French-speaking Belgium: for instance, expenditure on support from social services was higher in French-speaking Belgium than in Dutch-speaking Belgium.

Productivity loss estimates

To the best of the authors' knowledge, this is the first analysis to consider the indirect costs of productivity loss of informal caregivers in the home setting. In Belgium, informal caregivers of palliative patients have the right to take work leave for one month, with a possible extension for a second month. Recent data indicate the number of Belgian people taking leave from work to care for a palliative family member amounted to 194 persons in 2006 and 205 persons in 2007[403]. Our analysis did not consider the impact of palliative home care leave on the number of days of leave during the following year as this aspect fell outside the scope of our analysis.

Costs in hospitals

The comparison between palliative care units and acute hospital units showed the impact of higher staffing levels on costs in palliative care units as compared with staffing costs in acute hospital units. Indeed, the legal staffing levels in Belgian hospitals is 1.5 full-time equivalent nurses per bed in a palliative care unit and 0.4-0.5 full-time equivalent nurses per bed in an acute hospital unit.

On the other hand, RIZIV/INAMI and patient charges were higher in acute hospital units than in palliative care units. This may reflect the fact that treatment of patients receiving palliative care in acute hospital units generates higher costs than in palliative care units. If this hypothesis is true, questions might be raised about the appropriateness of costly tests and treatments in palliative patients hospitalized in acute units.

Hospital costs of patients receiving palliative care in cardiology, geriatric and oncology wards are likely to be underestimated. Those patients require actually more intensive monitoring and follow-up by hospital staff than non palliative patients in the same wards. However, the calculations of fixed costs were based on annual hospital staff costs of these acute care wards. As a result, the analysis was not able to distinguish between staff costs for patients receiving palliative care (and perhaps more time) and for non palliative patients.

Costs in nursing homes

In the hospital and nursing home settings, the analysis derived estimates of fixed costs from accounting data. In Belgium, all hospitals are required to follow the FINHOSTA accounting system[386], thus guaranteeing consistency and comparability of data between hospitals. Such a uniform accounting system does not exist for nursing homes. Our analysis relied on accounting data that are specific to each participating nursing home, thus inhibiting the comparability of data between nursing homes. However, the authors felt that the collection of real cost data was preferable to the alternative of collecting charge data which may or may not reflect true health care resource use. Nevertheless, there is a need for developing a uniform accounting system for nursing homes.

Costs in nursing homes may be influenced by the size of the institution as measured, for instance, by the number of beds. This factor was not taken into account in our sample. This decision was taken because few large nursing homes were willing to participate in our study and because the number of patients that could be enrolled from small nursing homes was limited. Also, the expert meeting believed that the size of the institution was not a relevant factor.

Further research needs to be undertaken to refine and validate our estimated costs of palliative care in Belgian health care settings. Such an exercise may aid policy makers in developing reimbursement mechanisms that closer reflect real costs.

Costs of home care

This analysis estimated mean monthly costs of home care per patient of 4,464 €. A terminal patient can apply for a monthly allowance for palliative home care of 589.31€ in 2009[404]. This means that home care workers, including the general practitioner, take the engagement to deliver palliative home care as long as possible and that the patient receives a contribution to the costs for a maximum of two months. Care should be exercised when interpreting cost estimates derived from a limited sample of 17 patients. There was indeed considerable variability in cost estimates reported by the patients. This analysis needs to be replicated using a large patient sample.

Key points:

- **Mean hospital costs per patient per day amounted to 391 €. These costs were driven by fixed costs (65% of costs) and RIZIV/INAMI charges (31%).**
- **Hospital costs of patients receiving palliative care of 423 € per patient per day were significantly higher than costs of patients receiving classical care of 340 € per patient per day (p = 0.002). Higher costs of palliative care originated from higher fixed costs (p < 0.001).**
- **With respect to patients receiving palliative care, mean hospital costs per patient per day of 522 € for patients in palliative care units exceeded costs of 283 € for patients in cardiology, geriatric and oncology wards (p < 0.001). Higher costs of palliative care units resulted from higher fixed costs (p < 0.001).**
- **Hospital costs of patients receiving classical care of 340 € per patient per day were significantly higher than costs of patients receiving palliative care in an acute hospital unit of 283 € per patient per day (p = 0.025). This cost difference can be attributed to higher RIZIV/INAMI charges for patients receiving classical care (p = 0.002).**
- **Mean nursing home costs (including hospital costs) per patient per day amounted to 108 €. The major drivers of nursing home costs were hospital costs (55% of costs) and fixed nursing home costs (39%).**
- **Excluding hospital costs, there was little variation in costs between nursing homes.**
- **Nursing home costs for patients receiving classical care of 127 € per patient per day tended to be higher than costs for patients receiving palliative care of 82 € per patient per day (p = 0.068). Higher costs of classical care were driven by higher hospitalization costs (p < 0.001).**
- **Mean home care costs per patient per day amounted to 148.8 €. The major component of home care costs was the indirect costs related to the productivity loss of informal caregivers (58% of costs).**

11.3.3 Comparison with health expenditure for palliative home care based on data from the Christian Sickness Funds

11.3.3.1 Sample of patients

The retrospective study of reimbursed health expenditure on palliative home care conducted by the Christian Sickness Funds enrolled a total of 4,856 patients[303]. These patients were selected as they benefited from advantages linked to their palliative status in the home setting.

The characteristics of this sample are compared with those of the adult population covered by the Christian Sickness Funds. The two next tables indicate that the patient sample had similar characteristics to the Christian Sickness Funds population in terms of geographic location, gender and age. Moreover, the proportion of patients who benefited from increased reimbursement and/or the social maximum invoice amounted to 54.14% in the Christian Sickness Funds population and 46.54% in the sample. Finally, sample patients died at home (72.32% of patients), in hospital (17.79%), in a palliative care unit (8.98%) or in a nursing home (0.91%).

Table 50: Geographic location of patient sample and Christian Sickness Funds population

		Christian Sickness Funds population		Sample	
		N	%	N	%
Dutch-speaking Belgium	West-Vlaanderen	6.805	16,61	815	16,78
	Oost-Vlaanderen	6.965	17,00	869	17,90
	Antwerpen	7.805	19,05	1.008	20,76
	Vlaams-Brabant	4.230	10,33	513	10,56
	Limburg	3.668	8,95	684	14,09
	Total	29.473	71,95	3.889	80,09
Brussels		1.606	3,92	83	1,71
French-speaking Belgium	Henegouwen	3.600	8,79	257	5,29
	Waals-Brabant	856	2,09	83	1,71
	Namen	1.619	3,95	160	3,29
	Luik	2.701	6,59	245	5,05
	Luxemburg	1.086	2,65	137	2,82
	Total	9.862	24,07	882	18,16
Belgium		40.965	100	4.856	100

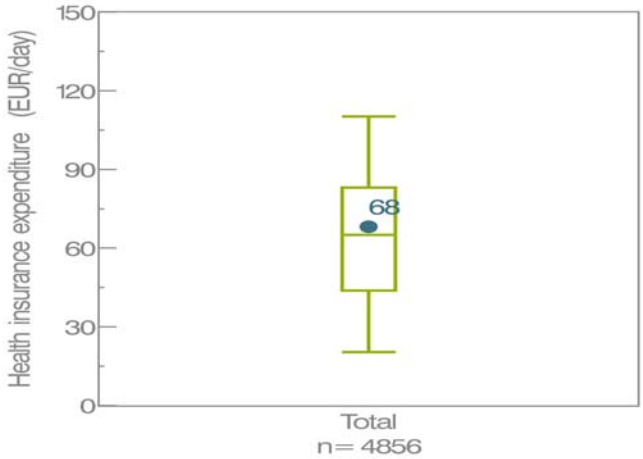
Table 51: Gender and age of patient sample and Christian Sickness Funds population

		CSF population		Sample	
		N	%	N	%
Gender	Male	19.958	48,72	2.779	57,23
	Female	21.007	51,28	2.077	42,77
Age	41-44	391	0,95	60	1,24
	45-49	722	1,76	115	2,37
	50-54	996	2,43	175	3,60
	55-59	1.530	3,73	280	5,77
	60-64	1.809	4,42	391	8,05
	65-69	2.579	6,30	507	10,44
	70-74	4.132	10,09	690	14,21
	75-79	6.231	15,21	888	18,29
	80-84	8.446	20,62	814	16,76
	85-89	6.590	16,09	487	10,03
	90-94	5.160	12,60	317	6,53
	≥ 95	2.379	5,81	132	2,72
Total		40.965	100	4.856	100

11.3.3.2 Results

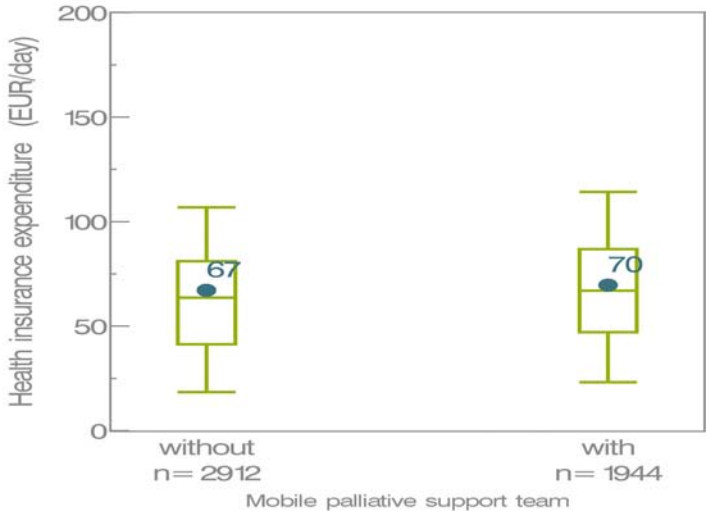
The next figure presents estimates of daily reimbursed public health expenditure. The figure below reports the 10th percentile, 25th percentile, median, mean, 75th percentile and 90th percentile. Mean daily public and private expenditure amounted to 68 € and 3 €, respectively.

Figure 12: Daily reimbursed public health expenditure on palliative home care



The sample of patients consisted of 1,944 patients with a mobile palliative support team and 2,912 patients without a mobile palliative support team. The next figure exhibits public expenditure for each patient group. Mean daily public expenditure amounted to 67 € for patients without a mobile palliative support team and 70 € for patients with a mobile palliative support team. Mean daily private expenditure amounted to 3 € for patients without a mobile palliative support team and 3 € for patients with a mobile palliative support team.

Figure 13: Daily reimbursed public health expenditure of patients with(out) mobile palliative support team



11.3.3.3 Discussion

The design and the scope of this study (public expenditure) do not allow any comparison with our prospective study. However, results are interesting as they reflect the reimbursed costs of a large sample (N=4900) of palliative patients who stayed at home before death.

The results indicate that daily expenditure of palliative patients staying at home is considerable. In addition, this expenditure hardly varies between patients with a mobile palliative support team and patients without any mobile palliative support team.

Further research is required to explore in depth health service utilization of palliative patients staying at home.

Key points:

- **Mean daily public and private health expenditure of palliative patients staying at home amounted to 68 € and 3 €, respectively.**
- **Expenditure did not vary between patients with a mobile palliative support team and patients without any mobile palliative support team.**

11.4 ACKNOWLEDGEMENTS

The authors would like to thank the institutions, patients and their family that have participated in this study. Their assistance in collecting the data has been invaluable. In particular, we are greatly indebted to patients and family in the home care setting who were willing to collect data during a challenging period of their lives. We would like to dedicate this study to the memory of all terminal patients who passed away over the course of this study.

The following hospitals participated in the study: AZ Middelheim, CHR du Val de Sambre, Saint Pierre Ottignies, Sint-Augustinus, UC Sart Tilman, UZ Leuven.

The following nursing homes participated in the study: Bethlehem, Herent; Booghuys, Leuven; Dijlehof, Leuven; Home Louis Demeuse, Herstal; Home Notre Dame, Carnières; Institut Notre Dame de Banneux, Frasnes-lez-Gosselies; Kapucijnenhof, Leuven; Keienhof, Kumtich; La Closière, Wavre; Maison Marie Immaculée, Soignies; Meerlehof, Lummen; Remy, Leuven; Résidence Aurore, Gilly; Résidence Grandgagnage, Villers-le Bouillet; Seniorie du Vigneron, Ransart; St. Alexius, Tienen; St. Joseph du Beauregard, Liège; St. Jozef, Nieuwerkerken; Ter Vlierbeke, Kessel-Lo.

Part five: Round-up and lessons for Belgium

12 ROUND-UP AND LESSONS FOR BELGIUM

This report is in line with the recent report of the "Federale Evaluatiecel Palliatieve Zorg - Cellule Fédérale d'évaluation des soins palliatifs". The objective is to give policymakers background information to set priorities for the development of palliative care in Belgium. This project analyses palliative care with complementary approaches: systematic literature reviews, a web survey among GPs, prevalence studies in different settings, a pilot study to estimate costs in the same settings. The interpretation of the results needs to take account of some methodological limitations detailed at the end of this chapter.

12.1 DEFINITION OF A PALLIATIVE PATIENT: IMPORTANCE OF NEEDS

12.1.1 Importance of patients' needs and of disease's characteristics

There is no consensus in the literature about the definition of a palliative patient. However, most definitions (mainly based on the WHO's one) emphasize the patient's status and needs in the definition of palliative care. In the same way, Belgian GPs label a patient as "palliative" according to the extra care he/she needs and those needs might be present early in the course of the disease (e.g. in case of neurodegenerative pathology). Many health care systems rely on the expertise of health professionals to state if the patient has a palliative status.

Many definitions rely on common components that were included in the definition used in the surveys of this project: "a patient suffering from an incurable, progressive, life-threatening disease, with no possibility to obtain remission or stabilization or restraining of this illness". The use of this definition in this study led to an agreement between doctors and nurses for most patients.

12.1.2 Patient prognosis: major shortcomings

The results of this survey underline the limits of the use of the prognosis to define a palliative patient. More than half of the patients labelled as "palliative" in this study were alive after three months (in home (replacement) settings) or had an estimated survival time greater than 3 months (in hospitals). Statistics from the independent Sickness Funds also concluded in 2007 that one third of the patients lived longer than the three months life expectancy requested to benefit from the "palliative forfait".

12.2 POPULATION OF PALLIATIVE PATIENTS IN BELGIUM

Research papers usually define palliative patients as the population who benefit from palliative care. One original feature of this research is to assess the population of patients potentially candidates for palliative care in Belgium, independently of their prognosis and of the care they received.

Estimates of the size of palliative populations were calculated for each setting and extrapolated for Belgium. In home settings, GPs would care for 8000 to 13 000 palliative patients. In nursing homes, 5500 residents should be considered as palliative. In hospitals, doctors and nurses would consider that 3000 patients answer to the definition. These three figures can not be summed up given the transfer between settings. Nevertheless, this study gives a range of the prevalence of the population in Belgium who is considered as being palliative: between 10000 and 20000 patients would have this label according to their health care professionals. Less than 400 beds are available in palliative care units, making palliative care in other settings a priority for the Belgian health care system.

12.3 PALLIATIVE CARE: AN ANSWER TO PATIENTS' EXPECTATIONS

12.3.1 Correlation between patient wishes and place of death

One of the most important findings of this study is that most patients die where they wished, when the main caregiver knows about these wishes. This conclusion is similar to the one of a previous Belgian study[301]. Most palliative patients prefer to die at home and in home replacement settings.

The study of the Christian Sickness funds (40 965 persons deceased) found that 45% of the population died in hospital, a quarter at home (15% with palliative care),a quarter in nursing home and 5% in palliative care units[303]. Two thirds of the persons who benefited from a palliative "forfait" were not hospitalized after the request for this allowance, showing a potential link between the elucidation of expectations and their consequent fulfilment.

These figures are better than those recorded in England and Wales, where nearly 7 out of ten patients die in hospital[405]. In the Netherlands, more than half of deaths (54%) occur among patients with a chronic condition: one third of them (32%) die at home, a quarter die in a nursing home[406].

12.3.2 Correlation between initial plans and further treatment options

In home (replacement) settings, the treatment options expressed by the health professionals were mostly followed: only some persons did receive a treatment that was previously excluded. Possible treatment options were mainly hospitalizations and antibiotics.

In hospital, antibiotics, blood transfusions, treatments for primary disease and artificial food were considered or given to roughly 90%, 80%, 60% and 50% of the patients, respectively. These percentages seem high with regards to the health status of the population under study. However, this survey does not clarify the border between the treatment goals i.e. to prolong life versus to improve the quality of life. The clarification of the treatment's goal is of crucial importance for the treatment decision-making but the physicians point out the grey area between curative and palliative care as well as the potential evolution in the patient's wishes.

12.3.3 Need for clarifying the patient expectations and optimizing communication between care settings

The study underlines the need to explicit the patients' preferences in order to orient the care and place of care according to his/her wishes. Unfortunately, the hospital physicians and the GPs ignored patients' wishes concerning the treatment options in about one quarter of cases.

The absence of knowledge of patients' wishes is particularly problematic in case of hospitalization. Hospitalizations concerned indeed one third of the patients from the home setting in this study, 38% of the patients of the Senti-MELC study[301] (last month of life) and 3 out of 4 persons in the study from the Christian Sickness (last 6 months of life)[303]. In case of hospitalization, a prior clarification of the patient's preferences in relation with further treatment options and place of death are prerequisites to fulfil his/her expectations. As stated above, treatment options are mostly followed if the caregivers are aware about them. Knowing the patient's expectations requires an optimal communication between lines of care as described in transmural care models.

12.4 PALLIATIVE CARE: AN ANSWER TO THE PATIENT NEEDS

One element of the WHO international definition is that palliative care should be based on the patient's and family's needs. However, the epidemiological studies brought to light the discrepancies between patients' and families' preferences in relation with preferred place of care.

12.4.1 Identification of all patients with palliative needs

The identification of palliative patients is e.g. influenced by the underlying pathology. The surveys showed that GPs identified more easily cancer patients as palliative patients. In contrast, patients with chronic diseases as heart failure, COPD or dementia have a slow health decline making more difficult to identify their palliative needs. Their life expectancy might be a few years, implying the need for social support and continuing care during an extended period.

12.4.2 Common needs of palliative patients

The exhaustive literature search about needs of palliative patients identified multiple needs clustered in five groups. The first group covers biological needs, mainly the control of symptoms as for example pain, breathlessness, gastro-intestinal problems. The four other groups are psychological needs, social needs, health care related needs and spiritual needs.

Two domains of needs require attention. The first one covers the needs for stepwise delivered information: patients and their caregivers need sensitive communication and psychological support. However, the web based survey showed that many GPs, in particular without any training in palliative care, feel uncomfortable to communicate with patients. The situation might be even more difficult for specialists as communication and palliative care are less frequently included in their training.

The second domain where patients have important and frequently unmet needs is the social support, in particular for activities of daily living. The fulfilment of these needs would give to terminally ill patients an opportunity to live as long as possible within their familiar environment. Social support is important and frequently deficient in the group of chronic patients (e.g. pulmonary disease, heart failure).

Palliative care needs are similar between patients at the end stage of any disease. However, the surveys confirm the literature findings i.e., health professionals identify more easily cancer patients as palliative patients with needs[405]. In hospital, cancer patients were more often referred to the palliative team. In home settings, GPs identified a much higher proportion of cancer patients than expected. As a result, patients with chronic disease as heart failure or pulmonary disease might have less access to palliative care and therefore more unmet needs as stated above.

12.4.3 Needs of patients with dementia

Lack of symptom management, lack of forward care planning, limited access to specialist palliative care and difficulty in predicting the (long) survival time are frequent. Efforts are needed to improve the communication with those patients who cannot express themselves properly, especially in terminal phases of illness. Specific attention is also required to provide information to the family in order to take and to participate to decisions about the patient's end-of-life.

12.4.4 Unmet needs: informal caregivers

The literature reviews did notice the lack of attention to the informal caregivers. Nonetheless, all palliative care models either at home or in transmural settings heavily rely on their availability and competences. Interventions should therefore specifically target them to answer to their needs and to give them an appropriate support in order to prevent situations of exhaustion.

12.5 WHICH PALLIATIVE CARE MODEL?

Transmural care models ensure a continuity of care between settings, in particular in case of transfers during the last weeks of life.

12.5.1 Data from the literature: some avenues but no evidence

Most models under study were either home settings or transmural care models. The content of the care models was heterogeneous and no evidence could be found to demonstrate the superiority of any model in terms of better outcomes.

As a matter of fact, studies found an effect of some models on the control of symptoms, on the patient's comfort and on psycho-social outcomes (e.g., quality of life, communication, anxiety, spiritual well-being). Effects on other outcomes were more inconsistent between studies and some authors did not identify any effect of the care model on the outcomes under study.

12.5.2 Target populations of the models

Most papers described care models designed for a specific population, based on the pathology: half of them targeted cancer patients. The question is to know if this vision is the most appropriate one for palliative care, given the fact that most palliative patients have similar needs. Moreover, a splitting according to pathologies multiplies the structures and might leave behind groups of patients with unrecognized and unmet needs, as chronic patients for example.

12.5.3 Health professionals: is there a preference?

12.5.3.1 Who should coordinate the care?

The answer to this question is not clear. In the literature, a specialized nurse often plays a leading role in the care models. In the web survey in Belgium most Belgian GPs think they should have the coordination role of palliative care at home. A distinction is however necessary between the role of coordination (that implies time for professional contacts and case management) and a role of key person to ensure the continuity of care.

However, multidisciplinary teamwork is of utmost importance, independently of the persons who compose the team.

12.5.3.2 Importance of training

Having training in palliative care seems a more important element than the qualification of the leading caregiver. The web survey among GPs shows that having training in palliative care is the most important variable correlated with the perception of palliative care. GPs with training see palliative care as an essential task: they experience less difficulty and have a better knowledge of palliative care structures.

The literature study on needs indicates that training in palliative care has to encompass all medical and non medical domains in order to cover most patients' needs. Competence in palliative care is a must e.g. to identify all patients with palliative needs, to assess these needs in the five domains, to communicate with the patient and the family, to discuss advance care planning, to provide adequate care of quality, to decrease the personal emotional barriers, to refer to specialized professionals when specific needs call for it (e.g. social needs), to manage the coordination between settings if required.

12.5.4 Interventions in palliative care models

The type and number of interventions largely varied between the models described in the literature. The main groups of interventions were:

- Interventions in relation to the patient management: case management, liaison services, needs assessment;
- Interventions in relation with outreach services e.g., hospice, hospital, technical services at home;
- Systems to answer to unexpected events: after-hours support, phone line 24H a day;
- Information and psychological support for the patient and his/her family.

Belgium has structures that facilitate the care of the patient at home with mobile teams and continuity of care in the first line. However, missing aspects are i.e., needs assessment for non cancer patients, liaisons between health care settings and multidisciplinarity[407].

12.6 COSTS OF PALLIATIVE CARE

The literature review found that the costs of palliative care varied according to the pathology. However, few studies analysed the costs in different settings as in this survey. Costs of specialized care at home were usually lower than in hospitals but the designs of the studies did not exclude selection biases i.e. patients who stay at home have a functional status and social network that allow this situation. Furthermore, costs were usually limited to the medical costs. Indirect resource use linked to the presence of informal caregivers has been rarely taken into account, as it has been in this study.

This costs study has the unique feature to calculate costs within different settings and to compare the costs of care with and without palliative intervention within a setting. The methodology of the data collection does not allow comparisons between settings and the recruitment of patients does not either allow to generalize the results but this pilot study gives an insight into the situation in all Belgian settings.

In the home setting, the most salient point was the total costs paid by the patient and the high variability recorded within this small sample. Median monthly costs were higher than 1500 euros, three times as much as the lump sum paid by the National Health Insurance and Disability Institute. A part of this sum might be later reimbursed, although medical fees only represented a limited proportion of the budget. Informal care (loss of income), support from social services and nourishment were the most costly items.

Cost calculations in hospital acute wards showed that a patient with palliative care has lower costs than a patient who does not benefit from the intervention of the palliative care team. The costs difference is explained by higher INAMI/RIZIV charges in the absence of palliative intervention: this finding probably reflects more diagnostic/therapeutic interventions. The question is to know if those interventions administered within "classical care" trajects are appropriate for patients at the end of life whilst other terminal patients benefit from palliative interventions with less procedures. Costs were highest in palliative care units, probably resulting from higher staffing levels.

One lesson learned from the costs calculation in nursing homes is the definite role of hospitalizations. Half of the monthly costs in nursing homes were attributable to hospitalizations that occurred during the study period. This study in nursing homes further highlighted the role of palliative care to decrease hospitalization costs: patients without palliative care had higher costs than residents with palliative care, due to the higher hospitalization costs in the first group. This finding shows that well organized palliative care is of paramount importance in nursing homes: nearly all palliative patients prefer to stay and to die in their residence whilst this option entails less expense for the patient and for the health system.

12.7 CAUTION IN THE INTERPRETATION OF THE RESULTS

This study is the first one that gives an estimation of the situation of patients who need palliative care in Belgium i.e. the prevalence in different settings and an approximation of costs according to their situation. However, the interpretation of the results has to take account of several limitations. A first limitation is that the quality of care could not be included in the design of this project.

12.7.1 Limited transferability of results from the literature review

The literature study has inherent limitations linked to the recentness of the palliative care discipline. Good quality research only emerges, in particular in relation with the possible health care models.

Moreover, the organization of palliative care and the related models vary between countries and the interpretation has to take account of the national health care system. As an illustration, many studies on care models have been conducted in Anglo-Saxon countries where nurses play a much more predominant role in the first line of care than in Belgium.

12.7.2 Surveys limitations

The web based survey only targeted motivated GPs whilst half of patients in Belgium die in hospital wards. Moreover, the answers reflect the perception of the GPs that might differ from the patients' perceptions.

The surveys in different settings had also limitations linked to the selection of the sample and to the sample sizes. Several hospitals were recruited to keep a balance between all types of hospitals but the patient population might not be representative of the whole palliative patient population due to the selection procedure. The recruitment of palliative patients for the prospective survey about costs at home was also difficult and yielded a very small sample size.

Another limitation is the selection of the patients based on the caregivers' appraisal: other patients with palliative care needs could have been missed in all setting. This suspicion is supported by the low prevalence found in nursing homes and the high prevalence of cancer patients identified by the GPs.

Finally, in the epidemiological surveys, answers by proxy caregivers could have biased the results. In the study about costs, the variability of data sources only gave a rough estimate of the costs, with few possible comparisons between settings.

12.8 PERSPECTIVES FOR BELGIUM

12.8.1 The palliative patient: a question of needs rather than a question of prognosis

The current policy in Belgium relies on a definition based on the patient's prognosis. Patients with a defined life prognosis are entitled to benefit a lump sum and the abolition of personal contribution for (para)medical care at home. The literature and surveys clearly show that life prognosis does not identify patients with palliative care needs. First, prognosis is often inaccurate, especially when long and in case of diseases other than cancer. Secondly, many patients with chronic diseases (in particular dementia) have palliative care needs well before the end of life.

On the opposite, the definition of the palliative patient in this study obtained a large consensus between caregivers i.e." a patient suffering from an incurable, progressive, life-threatening disease, with no possibility to obtain remission or stabilization or restraining of this illness". One solution to define the patient with palliative care needs could therefore rely on this definition. This assessment implies a judgment by the usual main caregiver in cooperation with an experienced team, in order to enhance the accuracy of the assessment. This option requires furthermore the use of standardised instruments to assess the needs. Suggestions have been outlined in the chapter on needs. More specific proposals were also detailed for patients with dementia in the report from the Belgian Qualidem study[408]. The identification of a patient with palliative care needs is independent of his/her entitlement to the "forfait": it helps defining further care trajectory and need for medical/social support.

12.8.2 Palliative care services: often missing or too late

Palliative care structures exist in Belgium; the question is to know if professionals do call them for every patient who would benefit from their intervention. Less than one out of 10 GPs used these services at home in the past year. The study of the Christian Sickness Funds also found that less than half of the patients who die at home benefit from the "forfait" and one fifth of the demands occur during the last week of life.

In hospital, professionals considered a referral to the palliative care team for less than half of the patients, less often for patients who were older and/or with a non cancer disease.

Several hypotheses might explain the lack of call for palliative services. On one hand, the prognosis by the physician is far from being accurate. On the other hand, the physician might not identify the patient as a person with palliative needs due to a lack of competence or a refusal to tackle the situation with the patient, especially if the family does not agree.

12.8.3 Training of the caregivers: a must in all settings

The web survey and the literature emphasized the role of the team and the training of caregivers in order to provide good quality of palliative care. The literature makes a distinction between 'basic palliative care' and 'specialized palliative care'. Basic palliative care is the standard care that should be provided by all health care professionals within their normal duties to patients with life-limiting disease. Specialized palliative care is a higher standard of care provided at an expert level by a trained multi-professional team when difficult symptoms can not be controlled by the usual healthcare team.

This distinction between basic and professional specialization is important. All health professionals care for patients with palliative care needs and need basic training in palliative care. This must be integrated in educational trajects of all health professionals. Furthermore, continuing medical education is essential afterwards, in order to keep up with the last developments in palliative care.

12.8.4 Palliative care tailored to the patient needs

12.8.4.1 When the patient wishes to stay at home

Dying at home has several implications. The first one is an attention to social needs, including support for the activities of daily living. Interventions today mostly focus on medical needs whilst autonomy is also a major condition to stay at home. The second implication is the existence of transmural care models that allow easy transfer between settings with the possibility to come back home after the crisis. Furthermore, multidisciplinary care by a team allows the holistic care of the patients, in order to ensure the fulfilment of all needs in the five domains.

Many GPs who answered to the web survey expressed their interest for coordinating palliative care. However, the survey among those (motivated) GPs also shows that some of them do not feel comfortable with palliative care or do not want to be the main coordinator. In any case, the organisation of palliative care will benefit from the intervention of the multidisciplinary palliative team, whilst the GP remains the key contact person.

12.8.4.2 When the patient wish to die in his/her residency for elderly

Nearly a quarter of the population die in nursing homes, and most residents express this wish. The high prevalence of palliative patients in nursing homes coupled with their specific profile (high prevalence of dementia) has implications for the organization of care.

The first one is to ensure that human resources are sufficient to cover the needs of the patients. Nursing homes benefit from a part time palliative reference person. However, little is known about the quality and content of palliative services. It is therefore difficult to weigh up the need for further support either by additional training of caregivers or by an external specialized palliative team as in the home setting.

The second point is an attention to all five domains of needs in this elderly population. Communication with the family is also important e.g. to set up advance care directives and to provide an information up-to-date about the patient status. As stated above, all these tasks imply time and training of the personnel. The question is to know to what extent this training might be standardised across all nursing homes, for all caregivers and encompassing all domains of palliative care.

A remarkable point is that nursing homes have a pre-existing structure that allows implementing palliative care models. Those models can rely on a multidisciplinary team with training, under the responsibility of a specialized health professional. In parallel, the generalization of policies within all nursing homes could lead to an identification of all patients in need of palliative care, to protocols concerning end-of-life and to a systematic record of advance care plans.

12.8.4.3 When the patient stays in hospital

One out of ten patients in hospital (except short stays) is considered by the team as a palliative patient. The lack of knowledge of advance care directives for one third of the patients coupled with the high cost of medical care underlines the need for hospital policies, similar to those in nursing homes: systematic identification of patients with palliative care needs, protocols concerning end-of-life, systematic record of advance care plans.

A better identification of all palliative patients within the hospitals should be coupled with a decrease in medical interventions and with an enhanced palliative care support by specialized health professionals (in particular mobile palliative teams). Specialized palliative care offer in hospitals should focus on the strengthening of transmural models to facilitate the link and come back to the first line of care.

The shift of resources from therapeutic/diagnostic acts towards human resources has the best chances to answer to the patient needs and to decrease unnecessary procedures.

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