

# Culture and End of Life Care: A Scoping Exercise in Seven European Countries

Marjolein Gysels<sup>1,2,4\*</sup>, Natalie Evans<sup>1,5</sup>, Arantza Meñaca<sup>1</sup>, Erin Andrew<sup>1</sup>, Franco Toscani<sup>3</sup>, Sylvia Finetti<sup>3</sup>, H. Roeline Pasman<sup>5</sup>, Irene Higginson<sup>2</sup>, Richard Harding<sup>2</sup>, Robert Pool<sup>1,4</sup>, on behalf of Project PRISMA

**1** Barcelona Centre for International Health Research, Universitat de Barcelona, Barcelona, Spain, **2** Department of Palliative Care, Policy and Rehabilitation, King's College London, London, United Kingdom, **3** Fondazione "Lino Maestroni", Istituto di Ricerca in Medicina Palliativa, Cremona, Italy, **4** Centre for Social Science and Global Health, University of Amsterdam, Amsterdam, The Netherlands, **5** Department of Public and Occupational Health, Emgo Institute for Health and Care Research, Expertise Center for Palliative Care, VU University Medical Center, Amsterdam, The Netherlands

## Abstract

**Aim:** Culture is becoming increasingly important in relation to end of life (EoL) care in a context of globalization, migration and European integration. We explore and compare socio-cultural issues that shape EoL care in seven European countries and critically appraise the existing research evidence on cultural issues in EoL care generated in the different countries.

**Methods:** We scoped the literature for Germany, Norway, Belgium, the Netherlands, Spain, Italy and Portugal, carrying out electronic searches in 16 international and country-specific databases and handsearches in 17 journals, bibliographies of relevant papers and webpages. We analysed the literature which was unearthed, in its entirety and by type (reviews, original studies, opinion pieces) and conducted quantitative analyses for each country and across countries. Qualitative techniques generated themes and sub-themes.

**Results:** A total of 868 papers were reviewed. The following themes facilitated cross-country comparison: setting, caregivers, communication, medical EoL decisions, minority ethnic groups, and knowledge, attitudes and values of death and care. The frequencies of themes varied considerably between countries. Sub-themes reflected issues characteristic for specific countries (e.g. culture-specific disclosure in the southern European countries). The work from the seven European countries concentrates on cultural traditions and identities, and there was almost no evidence on ethnic minorities.

**Conclusion:** This scoping review is the first comparative exploration of the cultural differences in the understanding of EoL care in these countries. The diverse body of evidence that was identified on socio-cultural issues in EoL care, reflects clearly distinguishable national cultures of EoL care, with differences in meaning, priorities, and expertise in each country. The diverse ways that EoL care is understood and practised forms a necessary part of what constitutes best evidence for the improvement of EoL care in the future.

**Citation:** Gysels M, Evans N, Meñaca A, Andrew E, Toscani F, et al. (2012) Culture and End of Life Care: A Scoping Exercise in Seven European Countries. PLoS ONE 7(4): e34188. doi:10.1371/journal.pone.0034188

**Editor:** Alejandro Lucia, Universidad Europea de Madrid, Spain

**Received:** November 17, 2011; **Accepted:** February 28, 2012; **Published:** April 3, 2012

**Copyright:** © 2012 Gysels et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

**Funding:** PRISMA is funded by the European Commission's Seventh Framework Programme (contract number: Health-F2-2008-201655). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

**Competing Interests:** The authors have declared that no competing interests exist.

\* E-mail: [mhgyels@gmail.com](mailto:mhgyels@gmail.com)

## Introduction

Given the ageing of European populations, there will be a growing demand for end of life (EoL) care in the coming years [1,2]. In a context of globalization, migration and European integration, culture is becoming increasingly important in relation to health care. It affects patients' and professionals' perceptions of health conditions and appropriate treatments, and it influences responses to illness, health care services and death [3,4]. When patients, their families and health professionals face chronic or terminal illness, with limitations to cure and difficult decisions, differences in cultural norms and values become especially salient.

In order to improve care [5,6], and ensure that palliative care can secure its share from national budgets and allocate these resources in a just way [7] there is a need for relevant evidence. The urgent calls for an evidence-base have already led to

increasing research activity in clinical practice and service provision [7,8,9,10]. The history of the hospice movement, originally developed in the UK, has been well described [11,12] and the adoption of the hospice model in the rest of the Anglo-Saxon world is equally well documented [13]. More recently, initiatives have started to map developments in EoL care in Europe and the rest of the world with a focus on service-provision [14,15]. Less is known about the socio-cultural context in which EoL care is developing. By including a section on culture and EoL care the Economist Intelligence Unit's comparative report recognised its importance for EoL care [1]. However, no attempt to explore this area more systematically in an international context has been made so far. This paper addresses evidence on the role of culture in EoL care in Europe.

European countries are in different stages of developing palliative care provisions and services take various organisational forms within health systems [1]. This is a consequence of different cultural traditions and attitudes towards the EoL and related care [16]. The differences in services can lead to further diversification in the understanding of EoL care across Europe, which presents challenges for research and international collaborations to improve EoL care on a wider scale.

This paper reports on a scoping exercise of cultural issues in EoL care of seven European countries: Germany, Norway, Belgium, the Netherlands, Spain, Italy and Portugal. These are seven of the eight participating countries in the PRISMA project, in the context of which this work was undertaken [17]. The evidence of the eighth country, the UK, was published separately [18,19], because it is so different from the other European countries and therefore not comparable with the same criteria. The focus of this scoping exercise of the European countries was two-fold. First, we aimed to explore and compare socio-cultural issues that shape EoL care in each of the countries. Second, we aimed to critically appraise the research evidence on cultural issues in EoL care produced in the different countries to throw light on its adequacy as a basis for the further development of EoL care.

## Methods

### Approach

A scoping exercise with the purpose of aggregating and interpreting the evidence on culture and EoL care in the seven targeted European countries. This type of review is suitable to map evidence in a broad topic area which has not been reviewed before. The review was exploratory and applied an iterative and inductive approach. Therefore it did not specify concepts in advance of the synthesis, but let the delineation of the phenomenon of culture in relation to EoL care emerge in the analysis of the literature. We started with an open and broad review question, which was refined by the search results and the findings in the studies retrieved.

### Search Strategy

A team of researchers undertook some pilot searches, separately for each country, to get an idea of the scope of the literature that informed about culture and EoL care for each country, and the suitability of the search terms. The following search terms were used for the pilot searches:

*Country name(s):*

(Germany OR German\*)

(Norway OR Norwegian\*)

(Belgium OR Belg\*)

(Netherlands\* OR Dutch OR Holland)

(Spain OR Spanish\*)

(Italy OR Italian\*)

(Portugal OR Portug\*)

**AND**

(palliative OR terminal OR “end of life” OR end-of-life OR death OR dying OR “continu\* care” OR “advance directive\*” OR hospice\* OR “supportive care”)

**AND**

(cultur\* OR intercultural OR cross-cultural OR transcultural OR qualitative OR ethnography OR anthropology OR interview\* OR “focus group”)

These were chosen with the aim of retrieving articles concerning EoL care where cultural and social factors were sufficiently relevant to be referred to in the title, abstract, topic or key words.

These initial pilot searches retrieved bodies of literature of varying sizes from each country and this was compared and discussed in a team meeting. For Belgium, Spain, Italy and Portugal, so few articles were retrieved that it was necessary to make additional, more general searches. The definitive searches were conducted in the following electronic databases:

Web of Knowledge all databases (Web of Science with conference Proceedings (1899–2012), BIOSIS Previews (1969–2012), Inspec (1969–2012), MEDLINE (1950–2012), Journal Citation Reports (2000–2012)); OVID (AMED (1985–2012); PsycINFO (1806 to 2012); and EMBASE (1980 to 2012)); Cancerlit (1975–2012); ASSIA (1987–2012); and, CINAHL (1982 to 2012).

**Electronic search for Belgium, Spain, Italy and Portugal.** Due to the small size of the body of literature retrieved by the database search of Belgian, Spanish, Italian, and Portuguese literature, more general searches unrestricted by the terms relating to culture, were carried out using the search terms:

(Belgium OR Belg\*)

(Spain OR Spanish\*)

(Italy OR Italian\*)

(Portugal OR Portug\*)

**AND**

(palliative OR terminal OR “end of life” OR end-of-life OR death OR dying OR “continu\* care” OR “advance directive\*” OR hospice\* OR “supportive care”)

In addition, a number of country-specific databases were used when available, (see Table 1). The searches were updated to February 2012.

**Other searches.** Hand searches were carried out in reference lists of retrieved articles and cited reference searches were conducted. Archives of key journals were searched, in order to find relevant articles that had been missed in the initial database search. Journals were selected for hand searches if they contained a high frequency of relevant articles, identified in the electronic, hand and cited references searches (see Table 2).

Publications written by authors of the articles deemed relevant were searched via authors’ web pages (if available) and the Web of Knowledge ‘author search’ facility.

Searches were also conducted in a number of Spanish and Portuguese web pages dedicated to palliative and cancer care and these were categorised as ‘hand searches’ as the web pages had no search facility and the literature available via the web pages was explored manually. For Spain, the full medical anthropology bibliography [20], and medical anthropology conferences were also hand-searched.

Grey literature –documents that are disseminated outside standard publication channels such as scientific journals but which have a definite influence on scientific output (for example policy reports or conference proceedings)– was obtained from experts identified from the expert network on culture and EoL care that was created concurrently to the scoping as part of the PRISMA project.

### Screening and Data Extraction

All documents were considered for relevance based on titles and abstracts. When the information was not sufficient to decide on inclusion or exclusion, the full text was evaluated. Because of the dearth of evidence in this area and the exploratory nature of the scoping of this literature, the team first became familiar with the literature from each country and then discussed inclusion and exclusion criteria in a team meeting. This was then used as a guide for deciding about their relevance to the review question. We included reviews and original research studies that informed about

**Table 1.** Journals hand searched.

Country	Journals, conference indices, or websites subjected to hand searches
Germany	Omega Volume 1 Number 1 (1970) to Volume 58 Number 1 (2008); Mortality Volume 1 Issue 1 (1996) to Volume 13 Issue 4 (2008); Medical Anthropology Volume 21 (2002) to Volume 28 (2009).
Norway	Omega Volume 1 Number 1 (1970) to Volume 58 Number 1 (2008); Mortality Volume 1 Issue 1 (1996) to Volume 13 Issue 4 (2008); Scandinavian Journal of Caring Sciences Volume 15 Issue 1 (2001) to Volume 23 Issue 4 (2009); Medical Anthropology Volume 21 (2002) to Volume 28 (2009).
Belgium	Revue Médicale de Bruxelles, Ethical Perspectives: Issue 2–3/2002; Tijdschrift voor Geneeskunde; and Acta Hospitalia.
Netherlands	Non accessible (due to language limitations).
Spain	Spanish medical anthropology bibliography (available in Perdiguero and Comelles (2000)); Spanish National Conferences of Anthropology; The REDAM conferences; and The Medical Anthropology at Home Conferences; Spanish Society of Palliative Care website (SECPAL); Basque Society of Palliative Care website (SOVPAL); Spanish Association Against Cancer website (AECC)
Italy	Not included.
Portugal	Associação Portuguesa de Cuidados Paliativos website; História dos Cuidados Paliativos em Portugal website; ONCO.news (Associação de Enfermagem Oncológica Portuguesa - AEOP).

doi:10.1371/journal.pone.0034188.t001

socio-cultural issues in EoL care. We excluded studies on clinical tools, pain and symptom management, pharmaceuticals, donation and transplants, neonatal EoL issues, legal issues and psychology. However if any of these studies contained relevant elements they were read fully and included. The electronic searches were restricted to the English language. Handsearches in the national languages were conducted for Spain, Portugal, Italy, Germany, Belgium and the Netherlands. To optimise comparability between countries we restricted the review to papers that were produced after the arrival of the ideas of the palliative care movement.

Data extraction was conducted for all studies, which inventorised study details, participants, methodology, and main findings.

### Synthesis

The initial stage was mainly oriented towards examining the extent, range and nature of research activity, although this already implies interpretation and formed a part of the synthesis of the findings. A mapping of reported practices and concepts was carried out regarding cultural issues in EoL care for each country through techniques of identification, listing, tabulating and counting individual studies. The overviews and opinion pieces were from this point not systematically analysed, although they were read as background literature and informed the further stages of synthesis. Themes across multiple studies were developed inductively through constant comparison of findings. Each team member developed a country-specific narrative synthesis.

Second, the country-specific syntheses were exchanged among the members of the team and read. Each developed a framework of themes that was capable of integrating all the themes used in the syntheses of the other countries, retaining the capacity to still compare findings across countries in a meaningful way. These frameworks were then discussed in team meetings and a common framework was agreed upon, consisting of five themes: setting, caregivers, communication, medical EoL decisions, minority ethnic groups, and knowledge, attitudes and values of death and care. The narrative syntheses for each country were then rewritten according to these cross-cutting themes. This assisted the comparison of practices, and ideas related to developments in EoL care across the countries and the identification of similarities or differences in approaches.

A third step focused on the body of literature itself, as a source of information on how the evidence approaches and thereby constructs the issues it addresses. Then, by examining the number and type of studies, insight was gained into the evidence itself, and how cultural knowledge featured among other types of knowledge generated in research on EoL care (for example relating to clinical practice or service development). This showed the areas of expertise in different countries and revealed gaps in knowledge.

## Results

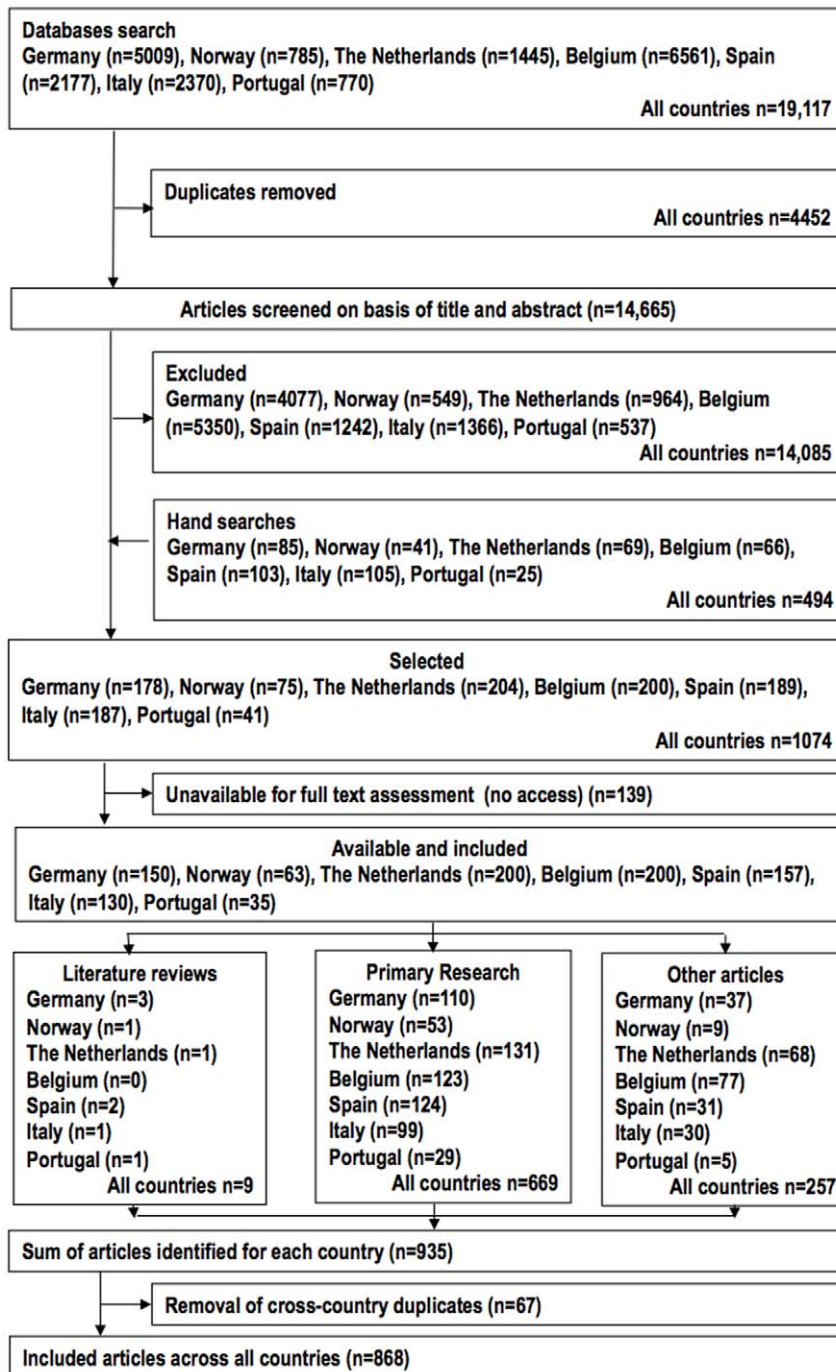
### Literature Flow

See Figure 1 for the flow chart of included countries.

**Table 2.** Additional databases by country.

Country	Additional databases
Germany	Non accessible (due to language limitations).
Norway	Non accessible (due to language limitations).
Belgium	CSA Illumina
Netherlands	CSA Illumina
Spain	IME (medicine); ISOC (social sciences); CUIDEN (nursing) and ENFISPO (nursing); Pubmed and Current Contents.
Italy	Non accessible
Portugal	IME (medicine); ISOC (social sciences); CUIDEN (nursing).

doi:10.1371/journal.pone.0034188.t002



**Figure 1. Flow chart of included countries.**

doi:10.1371/journal.pone.0034188.g001

## Nature of the Evidence

A total of 868 papers were reviewed.

## Synthesis: the Netherlands

Identified papers were well distributed between 1992 and 2012. Articles published before 1992 were in Dutch and beyond the scope of this review. These were, however, well cited in the papers appearing in international journals. This already points towards the contested history of palliative care in the Netherlands: it is either seen as an underdeveloped area of expertise, when one

considers its start with the establishment of hospices in the early 1990s [21], or as a field which already started to develop through work in nursing homes back in the 1960s [22].

The literature on the Netherlands provided information about a variety of settings in which EoL care is provided and the experience and role of health professionals involved [23,24,25,26,27,28,29,30]. End of life care used to be part of the country's highly developed home care system, with general practitioners playing an important role, which was further encouraged by national healthcare policy [25,28]. Some studies

described how the differences in EoL care settings affected the type of care provided [27,29]. Despite the key role played by informal carers in home care, only two studies focused on their experiences [31,32].

The majority of studies focused on medical EoL decisions (MELDs), reflecting the country's unique situation, where euthanasia was legalised in 2002 (together with Belgium in 2002 and Luxemburg in 2008). Euthanasia and physician assisted suicide (PAS) were the most common topics of research in this area. A recent comparative study of the Netherlands and Belgium on the first five years of euthanasia legislation showed that there are differences in how the legislation is applied in each country [33]. Other MELDs such as non-treatment decisions [34] and palliative sedation [35,36] were also explored. Considerable attention was devoted to the definitions, differences between, and incidences of, MELDS [37,38,39,40]. A culture of tolerance towards euthanasia and PAS was described which had been embedded in Dutch society for over 100 years [41,42].

Other articles explored the importance of self-governance for terminally ill people in a Dutch context [32]. Several aspects were explored regarding euthanasia, its emotional impact on physicians [43], patients' reasons for requesting euthanasia [44], and the experiences of relatives and friends of patients who received euthanasia [45]. One study focused on the role of the euthanasia consultant who evaluates the criteria for careful practice and advises about palliative care [46]. An ethnography showed that a request for euthanasia often served a symbolic purpose and enabled open discussion about taboo subjects of death and suffering [47]. Similar findings came from subsequent studies [32,48].

A recent study described the phenomenon of "self-directed deaths," individually controlled methods to hasten death, and showed that frequencies were very close to physician assisted death in the same year [49].

Issues relating to communication revolved mainly around advance directives (ADs) [41,50,51,52,53], disclosure and information giving [26,54,55,56,57,58,59]. The issues relating to ADs were determined by the euthanasia situation. Public knowledge about ADs was found to be high. These are documents in which one can state the wish for euthanasia in certain circumstances. [60]

Only three studies addressed EoL care relating to ethnic minority groups in the Netherlands. One study found that euthanasia was not less common, while symptom alleviation occurred less among this group [61]. Another study examined Dutch professional home care and the barriers to the use of this care for terminally ill Turks and Morroccans and their families [62]. It was shown that the latter group have conflicting ideas about 'good care' compared to their Dutch care providers and they found 'palliative care' a contradiction in terms due to their focus on cure. [63]

## Belgium

The majority (114) of articles were published between 2000 and 2010. The first publications appeared when the euthanasia debate had just started, resulting in the enactment of the euthanasia law in 2002. Unlike in the Netherlands, this debate was brief and palliative care played an important role in it. Although palliative care had only started five years before, it was very successful. The two movements developed in parallel. Shared workers were dedicated to both causes and this resulted in the model of 'integral palliative care' [64]. This model is inclusive of euthanasia, and as such it responds to the pluralist make up of Belgian society.

Against this background, research aimed at developing an understanding of place of care and death. Studies provided insight

into different settings where people die in Belgium [65,66,67,68,69], the determinants of place of death [66,69,70,71,72,73,74,75], and how place of death compared internationally [70,74,76]. One study focused on transitions between settings [77].

One key aspect of the health system in Belgium was that GPs tended to work alone and often had a long-standing and trustful relationship with patients. There was an emphasis on individualized care and the ability to choose one's own doctors.

Place of death influenced medical EoL decisions (MELDs) [78].

MELDs was the most researched topic in the Belgian literature, mainly focusing on definition of concepts [79,80,81,82], incidence of MELDs [69,80,83,84], decision making [85,86], including communication [87], key actors [88,89,90], and the role of health professionals [91,92,93,94,95,96,97,98,99,100,101].

These studies present evidence for or against the legal developments in Belgium. The studies that assessed MELDs in practice showed that the slippery slope effect had not materialized [65]. Also, with the availability of palliative care, euthanasia requests were less likely [102,103,104,105,106]. These requests were however not preventable in all cases. A recent study reported that 90% of physicians support euthanasia for terminal patients with extreme uncontrollable symptoms [107]. A study comparing practices of euthanasia and assisted suicide with the Netherlands, showed that there were significantly fewer cases in Belgium (1917) than in the Netherlands (10319), mostly in patients suffering from diseases of the nervous system, and in hospital [33].

Other topics related to MELDs included application of laws and other regulations, institutional written ethics policies, and opinions and attitudes [65,83,86,101,105,108,109,110,111,112,113,114,115,116,117,118,119,120,121,122].

The articles on communication examined disclosure [123,124,125,126,127,128,129] communication with different actors [98,127,130], barriers to communication [124,125,131,132] and ADs [96,115,116,133,134,135,136].

One paper looked at the approach to EoL care by different ethnic groups in Belgium and called attention to non-Western perspectives [137].

## Germany

The majority of articles were published within the last decade, with the remaining studies having been published between 1989 and 1999.

Home was identified as most people's preferred place of death, even though the majority of deaths actually occurred in hospitals [138,139,140,141]. The growing importance of nursing homes as a place of care and death, and the need to incorporate palliative care into these institutions, was highlighted [142,143].

In cross-country comparisons German physicians were found to be more likely to exclude patients, patients' families and non-medical staff from the decision making process [144,145]. ADs was a well-covered theme. Studies explored awareness of ADs, use and compliance [138,144,145,146,147,148,149,150,151,152] and desired level of bindingness [150,153,154,155].

Medical end of life decisions was also a major theme in the literature. Active euthanasia is illegal in Germany and the National Board of Physicians rejects any liberalisation concerning active euthanasia [156]. PAS is not illegal in Germany. However, physicians have the responsibility to attempt to apply all medical measures to prevent death, making PAS unfeasible in practice [157]. The German Medical Association rejects PAS as against its ethos [157].

Cross-country comparisons found that Germans had relatively low acceptance of euthanasia given the secular and individualistic

characteristics of the society [111]. This was ascribed to the use of the term ‘euthanasia’ by the Nazi regime [111]. Its association with Nazi medicine has been avoided by using different terminology. The preferred term ‘Sterbehilfe’ (literally “help to die”), was found to be the same as that of active and passive euthanasia in the international literature [158,159].

There was confusion among physicians and medical students regarding the difference between active and passive ‘sterbehilfe’, and the legality of assisted suicide [146,160]. In contrast to the high levels of opposition encountered for PAS and euthanasia, there was a high level of acceptance of palliative/terminal sedation [157].

The German literature on EoL care reflects a lack of social consensus on all topics and by all stakeholders.

## Norway

One study was published in the early 1980s, ten were published in the 1990s and the vast majority (34) were published between 2000–2010. A topic frequently touched upon within the original studies was the proportion of deaths in institutional settings in Norway. Norway has the highest percentage of beds in nursing home facilities per capita in Europe, more than twice that of most European countries and the highest number of deaths in nursing homes and hospitals [161,162]. Therefore the importance of palliative care provision within the nursing home setting was emphasised [163,164]. In contrast to other international studies, EoL care in a Norwegian nursing home was perceived as professional and good by patients’ families [165]. Several studies also focused on different aspects of home care [162,166,167,168,169,170,171].

Studies of carers examined their characteristics [172], concerns [173], activities [174], effects of caring [162,168,171,175,176], and setting where the care was provided [168,173].

One of the sub-themes relating to communication was the uncertainties experienced by doctors and nurses regarding disclosure [177,178]. A general reluctance to talk about death was found [172,179], and a 20 year study in one hospital showed that open discussion of death with patients had not increased over time [179]. This was ascribed to the Norwegian respect for privacy [172], although it could also be attributed to a strong death taboo.

Another communication issue concerns the stakeholders included in decision-making. Norwegian physicians have the ultimate responsibility for treatment decisions, and whether or not the views of other professionals were taken into account depended upon the individual physician’s views and the culture of the healthcare setting. Family members were often included in decision-making, which led to greater agreement concerning treatment options which was also the case for the understanding of the patient’s wishes.

Only one form of advance directive is available in Norway (the ‘Life Testament’), which has no legal status and is rarely used [172,180]. Its incidence was studied with two studies on patients [172,179] and two on health professionals [180,181].

Treatment limitation was the most frequently studied topic amongst the original studies, including its incidence [179,180,182,183], criteria for limiting life [172,181,184,185], and ethical dilemmas surrounding decisions [180,181,182,183,185,186,187]. The role of nurses and physicians was examined and the effect of EoL decisions [185,188,189,190].

Euthanasia and PAS are illegal in Norway and the practices are condemned in the Norwegian Medical Association’s ethical guidelines [186]. Norway’s Lutheran heritage, and a puritan ‘moral minority’, were said to influence the debate on euthanasia [191]. Norwegian physicians have more conservative attitudes

than other Scandinavian and western countries in regard to treatment limitation, euthanasia and PAS [177,180,186]. The low level of ‘hastening death’ found in Norway was attributed to a cultural respect for the law, which prevented even physicians who held liberal ideas concerning euthanasia from carrying out euthanasia in practice [180]. In Norway palliative sedation and euthanasia were said to have only recently been differentiated, and guidelines for practice provided.

Frequent topics in the Norwegian literature were healthcare spending and accounting. Elderly people were repeatedly said not to receive a ‘just’ allocation of resources [172,184,189,192]. Also, ethical dilemmas caused by the use of ‘high technology’ were frequently highlighted [188,190,192,193].

## Spain

Only six of the 123 studies for Spain were conducted before 1990 and since then research on EoL care has increased. The main palliative care resource was home care teams, the second, inpatient units [14]. There were no general data on place of death: the identified studies presented a range of percentages of home deaths: from 22% for elderly people who died in Catalonia in 1998 to 50% for terminal cancer patients in Asturias in 1995 [194,195,196,197,198,199,200]. Percentages of healthy people who would like to die at home were generally higher than those who actually die at home [200,201,202,203,204,205] nevertheless a recent survey showed that half of the population has preferences for specific care settings or hospitals for terminal patients [202]. There was greater consensus among healthcare professionals than among the general public that the home is the ideal place of death [206,207,208,209].

More than 84% of the patients were cared for by family members, mainly daughters and wives [195,198,210,211,212]. A majority of the caregivers were found to be overloaded [212,213] and did not have any economic help or enough information of the resources available [213,214,215]. Two concepts with negative connotations relating to the patient’s family were identified: the ‘conspiracy of silence’ [216,217,218], the partial or non-disclosure which is frequently attributed to family members; and, ‘claudicación familiar’ (family surrender), when patients die in hospital and not at home (the ideal place of death according to health professionals) [219].

Disclosure of information regarding diagnosis, prognosis and treatments was found to be the most frequently discussed in the literature and this was also the topic of the identified review [220]. International comparisons described southern European countries as partial and non-disclosure countries [221,222,223] and Spanish awareness studies suggested that this trend persisted over time [194,204,218,224,225,226,227]. On the other hand, studies with healthy populations show that preferences are evolving towards open disclosure [201,202,203,204,207,228]. Intermediate positions were also found; the majority of doctors stated that they would inform the patient only in certain circumstances or if requested by the patient [206,207,208,209,228,229,230,231,232]. The two main obstacles to giving bad news were found to be acceptance of the wishes of the family, hence tolerating the ‘conspiracy of silence’ imposed by the relatives, and feeling uncomfortable to give bad news [217].

In Spain, the legal and administrative development of ADs is one of the most advanced in Europe [233]. Most doctors found the policies relating to their implementation a positive development [233,234]. However the public’s knowledge and use of ADs was very limited [202,235,236,237,238].

In an international study Spain was shown to occupy an intermediate position in Europe regarding the acceptance of

euthanasia among the general public [239], and the acceptance had risen since 1995 among the general public. [202,240,241]

In international comparisons, Spain was among the countries with the lowest prevalence of Do Not Resuscitate (DNR) orders, and among those where these were discussed less with the patient. There were low rates of treatment withdrawal [212,242,243, 244,245]. In Spain the rates of all three practices were higher than in Portugal, Italy, Greece, and in the case of withdrawal of dialysis Spain was above Germany. National studies suggested even higher use of these MELDS [246,247].

Terminal sedation was considered consistent with the traditional Spanish perception that unconsciousness is the 'best way out' [248,249]. However, terminal sedation is still controversial in Spain. The legal proceedings against the Leganés Hospital Emergency Unit have demonstrated that the boundary between euthanasia and terminal sedation is not totally clear [250]. Part of the controversy concerns its use to manage existential and family distress, more common in Spain than in other countries [216].

Regarding feelings towards death and dying amongst both health professionals and the general public in Spain, fears related to pain were found to be the most important [203,204,251, 252,253]. However morphine consumption per capita was below the European and global average [254]. Fears about death were found to be a major barrier to good EoL care [255].

Four research studies examined EoL experiences of migrants from Morocco [256,257], Latinamerica [258] and UK [259] in Spain, and four overviews were found that covered EoL issues for migrants [260,261,262,263].

## Italy

In Italy, there has been a steadily growing number of research studies since 1979. EoL care is delivered mainly by home care teams [264] and the number of hospices rose from four in 1996 [265] to 90 in 2005 [14] mainly due to new palliative care policies since 1999 [266]. From the different factors related to place of death within Italy [70,267,268], region was found to be the most determining: in the south of Italy, the percentage of home deaths was 94% for cancer patients [267].

As in Spain, more than 85% of cancer patients' caregivers were relatives [269,270,271,272], and caring had an important impact in their quality of life [270,271,272,273,274]. Nevertheless they were frequently characterised in a negative way as barriers to full disclosure and limitation of non-useful treatment [275,276,277].

Also as in Spain, most studies from Italy focused on disclosure of information, with a review from 2004 on this topic [278]. Awareness studies published between 1994 and 2009 showed that a trend of partial and non disclosure persisted [279,280,281, 282,283,284,285,286]. The choice of partial or non-disclosure arises within families, independently of patients' requests [287]. Other sources however suggest that physicians preferences are moving towards full disclosure [277,288,289,290].

ADs are not legally recognised. Recently the parliament approved a non-binding law that the patient does not express his/her 'will', but 'wish', and this was after there had been intense debate, influenced by public opinion, concerning a number of high-profile cases [291,292,293,294].

Europe-wide surveys of the general public found that Italy was among the countries with the lowest acceptance of euthanasia [112], but the differences between Catholic believers and non-believers were higher than in other European countries. Death was less likely to be preceded by a MELD than in other European countries [295] whereas terminal sedation was more frequent. A recent paper showed that there is still low and often incorrect awareness of palliative care among the general public [296].

Many of the studies focused on pain management and showed low opioid consumption [254] and a significant proportion of patients not receiving appropriate treatment [297,298,299,300, 301,302]. However knowledge about pain and analgesics was found to have improved [303,304,305].

Four articles focused on Italians as minorities in other countries [306,307,308,309]. Only one original study gave specific information on immigrants [310] and one overview presented the islamic perspective in pediatric biomedical ethics including EoL [311].

## Portugal

More than half of the articles were published in the last five years (11), with the remaining studies having been published between 1987 and 2003. The development of services and research started relatively late in Portugal where the first palliative care unit only opened at the end of 1994 [312]. There were country-wide statistical data on place of death: with almost one-third of all deaths occurring at home [313].

As in Spain and Italy, caregivers needs included information, time to relax and economical support and care [314]. Following again the southern Europe trend, disclosure was one of the main themes explored in original studies. Two studies, both conducted in Porto, described greater patient awareness (60–69%) and desire for information than in Spain or Italy [315,316].

Portugal, like Italy, is among the countries with the lowest public acceptance of euthanasia [112]. A study from 2009 reported that up to 39% of oncologists favoured the legalisation of euthanasia [317]. The use of terminal sedation was lower than in other countries. Delirium was the most common grounds for initiating sedation while pain was an uncommon reason [315]. Portugal's opium consumption was found to be above the European and global average [254].

A recent publication calls for attention to informal caregiving for older people [318]. Another recent study focuses on palliative care physicians' views of ADs, and found them relevant to ethical decision making [319].

## Discussion

### Socio-Cultural Issues in EoL Care: What the Evidence Says

There is still little agreement about what constitutes EoL care in Europe. Researchers, practitioners and policy makers have different understandings of its scope, definitions, goals and approaches [320,321] and there are limited resources for its development. Identifying and analysing diversity in understandings and practices in EoL care in the different countries is essential for reaching consensus on EoL care, and for achieving workable standards.

In this scoping exercise we found a diverse body of evidence on socio-cultural issues in EoL care with differences in meanings and priorities in each of the countries (see Table 3 and Table S1).

This reflects a situation where EoL care has developed in different directions since the unique ideas of the hospice movement found resonance in Europe. The initial concept of palliative care has changed through its increasing contact with mainstream medicine in the different countries [322] and with the cultural traditions relating to health, illness, death, dying, bereavement, and ideas about care, the family, and the duties of medicine and society.

This scoping exercise revealed practices in EoL care that attest to cultural differences in ideas of best practices in EoL care. Disclosure practices in Mediterranean countries contradict the obligation to open information about diagnosis and are influenced

**Table 3.** Numbers and percentage of studies identified per theme across studies.

Country	Type of article	Total	Setting	Caregivers	Communication	Medical EoL Decisions	Minority Ethnic Groups*	Knowledge, Attitudes and Values	
Germany	Reviews	3	N	0	0	0	2	0	2
		%	0	0	0	67	0	67	
	Original studies	110	N	18	6	43	49	2	36
		%	16	6	39	45	2	33	
	Overviews etc.	37	N	2	3	11	22	2	12
		%	5	8	30	59	5	32	
Norway	Reviews	1	N	0	0	0	1	0	1
		%	0	0	0	100	0	100	
	Original studies	53	N	22	12	21	30	0	31
		%	42	23	40	58	0	60	
	Overviews etc.	9	N	3	0	2	6	0	2
		%	33	0	22	67	0	22	
Belgium	Reviews	0	N	0	0	0	0	0	0
		%	N/A	N/A	N/A	N/A	N/A	N/A	N/A
	Original studies	123	N	25	3	14	61	11	10
		%	20	3	11	50	9	9	
	Overviews etc.	77	N	0	1	6	50	4	13
		%	0	1	8	65	5	17	
Netherlands	Reviews	1	N	0	0	0	1	0	0
		%	0	0	0	100	0	0	
	Original studies	131	N	16	9	24	70	3	35
		%	13	7	18	54	2	27	
	Overviews etc.	68	N	0	1	4	59	0	24
		%	0	1	6	87	0	35	
Spain	Reviews	2	N	0	0	1	0	0	1
		%	0	0	50	0	0	50	
	Original studies	124	N	33	18	38	29	3	33
		%	27	15	31	24	2	27	
	Overviews etc.	31	N	0	0	5	5	2	25
		%	0	0	16	16	6	81	
Italy	Reviews	1	N	0	0	1	0	0	0
		%	0	0	100	0	0	0	
	Original studies	99	N	19	11	38	24	3	25
		%	20	11	38	25	3	25	
	Overviews etc.	30	N	1	1	21	7	2	3
		%	3	3	70	23	7	10	
Portugal	Reviews	1	N	0	0	1	0	0	0
		%	0	0	100	0	0	0	
	Original studies	29	N	0	6	11	9	0	5
		%	0	21	38	33	0	19	
	Overviews etc.	5	N	0	0	1	2	0	1
		%	0	0	20	40	0	20	

doi:10.1371/journal.pone.0034188.t003

by the continuous presence of the family in EoL care [323]. This can cause conflicts between the norms prevailing in the medical profession on the one hand and physicians' and families actual practices on the other [221,222,223]. Also, the focus on cultural identity may be due to self-reflection as a consequence of the

process in which palliative care is incorporated into national health systems. Aspects of the hospice movement's particular philosophy can be experienced as foreign, for example the emphasis on awareness as part of good death contradicts the traditional Spanish ideas about dying well [248]. In other instances its strong moral



values have come into contact with alternative conceptions of good care, which were based on professional experience of care for the dying developed over long periods of time. Here we think of the Dutch situation where euthanasia has developed as acceptable as a last resort and has long since been a topic that can be discussed openly [324]. The research generated in these seven countries on cultural issues at the EoL is directed towards the countries autochthonous cultural traditions and practices.

Although this scoping exercise approached the evidence by country, this does not mean we interpret 'culture' exclusively in terms of 'national culture' where cultural differences are aligned with the territorial borders of the nation state. However, for the scoping of this field we think this approach was justified. First, the scoping exercise was exploratory; no previous work has attempted to map cultural issues in EoL care across different European countries. Second, because we understand culture as an abstract notion, rather than a concrete set of values, beliefs, attitudes, opinions or other ethnic features we did not determine a priori any factors that could constitute culture. Third, regarding the topic of EoL care, we could follow national boundaries as there are distinct approaches between countries which are the result of different institutional forms of health care and a variety of ways of organising the professions that are in charge of care provision at the EoL. The reviews confirm that there are clearly distinguishable national cultures of EoL care.

This scoping study situated the identified literature in time, providing insight into a country's research activity vis-à-vis its development of services. This shows (with the exception of the Netherlands, which already had a research tradition in EoL care) the first studies appearing not much later than the establishment of services on the European continent, with a growing production towards more recent times.

### Contrast with the UK

The findings from this review on culture and EoL care from the seven European countries contrast with the UK research activity in this area, where EoL care has developed considerable expertise on ethnic minority groups. Recently a review of original studies and a review of reviews on this topic was published (also in the context of this project), which represents a body of research that was produced in response to the recognition of inequities in access to healthcare and the quality of services provided related to patients' ethnicity [18,19]. Thirteen reviews were identified in this area of which four reviews were commissioned to directly influence policy and this already shows the recent interest in these issues in the UK [18]. The 45 original studies focused for a great part on the need to develop 'cultural competence' in health care [19].

In contrast, very little attention has been paid to cultural issues of ethnic minorities in EoL care in the European countries included in this review. In the Netherlands we found that some pioneering work had started in this area, and in the other countries there were a few scattered exceptions.

This scoping of the literature informs about the gaps in the evidence on culture and EoL care and this points to future needs for research for the further development of the evidence-base. In the UK, apart from the research on ethnic minority groups, a vast literature exists on EoL care and this has not yet been reviewed with attention to socio-cultural issues. This was also not possible in this project due to time and resource constraints. Such a study could shed light on the culture-specific pre-occupations with EoL care in the UK. It could show the dominant concerns towards care at the end of life and the configurations of positions towards these concerns in a diversity of contexts and settings. It is important to

attend to culture and its uses in a broad sense so that it includes the majority culture as this will reveal that particular well-established practices are in fact culturally and historically situated. When these practices are then compared with those of other countries (as we did in this scoping exercise) it can show why certain practices become normalised while others remain unrecognised or become contested. Insights such as these lead to awareness of cultural differences and can enhance international collaborations.

### The Nature and Quality of Research in EoL Care and the Significance of Cultural Knowledge

The insights from this scoping exercise contribute to the debate about the quality and nature of research in palliative care. As a consequence of the evidence-based medicine movement, biomedical research has been favoured in palliative care. This is reflected in what is considered high quality research where criteria of strength are used according to the potential for eliminating bias [325]. Recently, these classification levels of evidence have been debated in areas of health research where these criteria are not representative of quality [326]. People at the end of their lives need care which is holistic and individual to address the patient and family's complex problems, and these can not be grasped by methodological approaches that exclude contextual factors. The challenges presented by people at the end of their lives to enrolment and participation in trials in terms of retainment and ethical considerations lead to the exclusion of the most vulnerable, which is the group that is of most relevance to palliative care. Clinical practice guidelines based on the effectiveness results of RCTs have the danger of increasing existing health inequities [327]. Socio-cultural knowledge is important in EoL care and we need research that generates understanding of the ways these affect illness experiences and caring and that enables the building of a discipline that is capable to respond to the needs of diverse and changing communities.

### Limitations

The literature from Norway was limited to publications in English. No electronic searches were carried out with other than English terms in the main databases. However, publications identified from Spain, Italy, Portugal, Belgium, the Netherlands and Germany in their respective national languages from the vernacular databases searched or those obtained by hand searches were included in the review.

### Recommendations

On the basis of the findings of this literature scoping on cultural issues in EoL care in seven European countries we make the following recommendations for future research:

- The mapping and investigation of the literature has generated insight into cultural differences in understanding, priorities and expertise relating to EoL care across Europe. The analysis of the number and the type of studies (see Figure 1 and Table 3) serve as a systematic basis for further more focused analysis.
- The gaps identified in the evidence point to areas that should be the focus of exploratory studies, and the better-represented themes (summarized in Table S1) can inform the research questions of other systematic reviews, or particular topics can be further interrogated or complemented with new studies.
- Given the current expansion of EoL care into new areas, this field of research should be given due attention beyond the countries included in this review, and beyond Europe, on a global level.

- Research on cultural issues in EoL care needs to start from a well-informed understanding of the notion of culture to avoid stereotyping, which was a consequence of some previous research.
- The lack of research on ethnic minorities' views, experiences, and practices is striking and deserves future study.
- Dominant cultural ideas equally need to be subjected to cultural investigation, which will uncover ideological interests and the way that some taken-for-granted practices are the product of wider forces.
- Robust multi-country studies in this review confirmed the existence of major cultural differences but sometimes did not explain the reasons for these differences. It is therefore advisable to explore these cultural issues more deeply through in-depth qualitative or mixed-methods studies.
- Future empirical evidence in this field is needed to serve as a basis from which to develop a more robust understanding of theoretical concepts related to culture (for example cultural competence) and EoL care (for example suffering, the experience of symptoms, and dignity).

## Conclusions

This scoping of the literature is a first comparative exploration of the cultural differences that exist in the understanding of EoL care in these countries. There was very little work in the evidence we unearthed specifically looking at cultural issues. With the exception of some pioneering work on EoL care for ethnic minority groups in a few countries, no expertise had developed in this area. European countries wrote about their 'own' cultural traditions and practices.

This scoping also critically appraised the research evidence on cultural issues in EoL care produced in the different countries to throw light on its adequacy as a basis for the further development of EoL care. The work on culture presented here provides an understanding of the evolution of the concept of palliative care across several European countries, shows the different cultural norms that influence care at the EoL and gives a view of the existing diversity in what is considered good care. This type of

## References

1. The quality of death: Ranking end-of-life care across the world. *A report from the Economist Intelligence Unit Commissioned by Lien Foundation*. Available: [http://viewswire.eiu.com/report\\_dl.asp?mode=fi&fi=1267294911.PDF&rf=0](http://viewswire.eiu.com/report_dl.asp?mode=fi&fi=1267294911.PDF&rf=0). Accessed on August 4, 2010.
2. Higginson IJ, Constantini M (2008) Dying with cancer, living well with advanced cancer. *European Journal of Cancer* 44: 1414–1424.
3. Kleinman A (1980) Patients and healers in the context of culture. Berkeley, CA: University of California Press. - p.
4. Morris D (1999) Culture and Pain. Berkeley, CA: University of California Press.
5. Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, et al. (1997) Perceptions by family members of the dying experience of older and seriously ill patients. *Annals of Internal Medicine* 126: 97–106.
6. Tolley DC, Payne R (2007) Hospice Partnerships with Academic Entities: Philosophical and Historical Background and Assessment of Future Needs. *Journal of Pain and Symptom Management* 1: 90–98.
7. Jubb AM (2002) Palliative care research: trading ethics for an evidence base. *Journal of Medical Ethics* 28: 342–346.
8. Kaasa S, Hjersted MJ, Loge JH (2006) Methodological and structural challenges in palliative care research: how have we fared in the last decades? *Palliative Medicine* 20: 727–734.
9. Richards MA, Corner J, Clark D (1998) Developing a research culture for palliative care. *Palliative Medicine* 12: 399–403.
10. Riley J, Ross JR (2005) Research into care at the end of life. *Lancet* 365: 735–737.
11. Clark D (1998) Originating a movement: Cicely Saunders and the development of St Christopher's Hospice 1957–1967. *Mortality* 3: 43–63.
12. Clark D (1999) Cradled to the grave? Terminal care in the United Kingdom, 1948–1967. *Mortality* 4: 225–247.
13. Saunders CM, Kastenbaum R (1997) Hospice care on the international scene. New York: Springer.
14. Centeno C, Clark D, Lynch T, Rocafort J, Prail D, et al. (2007) Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC task force. *Palliative Medicine* 21: 463–471.
15. Clark D, Ten Have H, Janssen R (2000) Common threads? Palliative care service developments in seven European countries. *Palliative Medicine* 14.
16. Gysels M, Evans N, Meñaca, Andrew E, Bausewein C, et al. (2011) Culture is a priority for research in end of life care in Europe: a research agenda. In press.
17. Harding R, Higginson I (2010) PRISMA: A pan-European co-ordinating action to advance the science in end-of-life cancer care. *European Journal of Cancer* 46: 1493–1501.
18. Evans N, Menaca A, Andrew EVW, Koffman J, Harding R, et al. (2011) Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life strategy. *BMC Health Services Research* 11: 141.
19. Evans N, Menaca A, Andrew EVW, Koffman J, Harding R, et al. (2011) Systematic review of the primary research on minority ethnic groups and end-of-life care from the UK. *Journal of Pain and Symptom Management* 34: 261–286.
20. Perdiguerro E, Comelles (2000) *Medicina y cultura. Estudios entre la antropología y la medicina*. Barcelona.
21. Zyliec Z (1993) Hospice in Holland: the story behind the blanc spot. *American Journal of Hospice and Palliative Care* 4: 30–34.
22. Janssens R (1999) Report of concepts of palliative care in the Netherlands. Nijmegen: Pallium Project.
23. Abma T (2001) Evaluating palliative care: Facilitating reflexive dialogues about an ambiguous concept. *Medicine, Health Care and Philosophy* 4: 261–276.

knowledge is a legitimate and necessary part of what constitutes best evidence for the improvement of EoL care in the future.

## Supporting Information

### Table S1 Sub-themes of culture and EoL care across countries.

(DOC)

## Acknowledgments

PRISMA had the overall aim to co-ordinate high-quality international research into end-of-life cancer care. This project aimed to provide evidence and guidance on best practice to ensure that research can measure and improve outcomes for patients and families. PRISMA activities aimed to reflect the preferences and cultural diversities of citizens, the clinical priorities of clinicians, and appropriately measure multidimensional outcomes across settings where end-of-life care is delivered. Principal Investigator: Richard Harding. Scientific Director: Irene J Higginson. In recognition of the collaborative nature of PRISMA, the authors thank the following PRISMA members: Gwenda Albers, Barbara Antunes, Ana Barros Pinto, Claudia Bausewein, Dorothee Bechinger-English, Hamid Benalia, Lucy Bradley, Lucas Ceulemans, Barbara A Daveson, Luc Deliens, Noël Derycke, Martine de Vlioger, Let Dillen, Julia Downing, Michael Ehteld, Natalie Evans, Dagny Faksvåg Haugen, Lindsay Flood, Nancy Gikaara, Barbara Gomes, Sue Hall, Stein Kaasa, Jonathan Koffman, Pedro Lopes Ferreira, Johan Menten, Natalia Monteiro Calanzani, Fliss Murtagh, Bregje Onwuteaka-Philipsen, Roeline Pasman, Francesca Pettenati, Tony Powell, Miel Ribbe, Katrin Sigurdardottir, Steffen Simon, Bart van den Eynden, Jenny van der Steen, Paul Vanden Berghe, Trudie van Iersel. We would also like to thank Marie Hoogstraten who assisted with the update of this scoping to 2012.

## Author Contributions

Conceived and designed the experiments: MG NE AM EA FT SF IJH RH RP. Performed the experiments: MG NE AM EA FT SF IJH RH RP. Analyzed the data: MG NE AM EA FT SF IJH RH RP. Contributed reagents/materials/analysis tools: MG NE AM EA FT SF IJH RH RP. Wrote the paper: MG NE AM EA FT SF IJH RH RP. Country specific scoping: NE AM EA SF HRP. Supervision: MG. Identification of need for review: MG Comparative analysis: MG.

24. Borgsteede SD, Deliens L, Beentjes B, Schellevis F, Stallman WAB, et al. (2007a) Symptoms in patients receiving palliative care: a study on patient-physician encounters in general practice. *Palliative Medicine* 21: 417–423.
25. Borgsteede SD, Graafland-Riedstra C, Deliens L, Francke AL, van Eijk JT, et al. (2006) Good end-of-life care according to patients and their GPs. *British Journal of General Practice* 56: 20–26.
26. de Vogel-Voogt E, van der Heide A, van Leeuwen AF, Visser AP, van der Rijt CCD, et al. (2007) Patient evaluation of end-of-life care. *Palliative Medicine* 21: 243–248.
27. Georges JJ, Grypdonck M, Dierckx de Casterle B (2002) Being a palliative care nurse in an academic hospital: a qualitative study about nurses' perceptions of palliative care nursing. *Journal of Clinical Nursing* 11: 785–793.
28. Groot MM, Vernooij-Dassen M, Crul BJP, Grol R (2005) General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. *Palliative Medicine* 19: 111–118.
29. Hermens M, ten Have H (2003) Moral problems in palliative care practice: A qualitative study. *Medicine, Health Care and Philosophy* 6: 263–272.
30. van Staa AL, Visser A, van der Zouwe N (2000) Caring for caregivers: experiences and evaluation of interventions for a palliative care team. *Patient Education and Counseling* 41: 93–105.
31. Proot IM, Abu-Saad HH, Crebolder H, Goldsteen M, Luker KA, et al. (2003) Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scandinavian Journal of Caring Sciences* 17: 113–121.
32. Proot IM, Abu-Saad HH, Goldsteen M, Spreeuwenberg C, ter Meulen RHJ, et al. (2004) The needs of terminally ill patients at home: directing one's life, health and things related to beloved others. *Palliative Medicine* 18: 53–61.
33. Rurup ML, Smets T, Cohen J, Bilsen J, Onwuteaka-Philipsen BD, et al. (2012) The first five years of euthanasia legislation in Belgium and the Netherlands: description and comparison of cases. *Palliative medicine* 26: 43–49.
34. Huijter M, van Leeuwen E (2000) Personal values and cancer treatment refusal. *Journal of Medical Ethics* 26: 358–362.
35. Rietjens JAC, van Delden JJM, van der Heide A, Vrakking AM, Onwuteaka-Philipsen BD, et al. (2006) Terminal sedation and euthanasia - A comparison of clinical practices. *Archives of Internal Medicine* 166: 749–753.
36. Seymour JE, Janssens R, Broeckart B (2007) Relieving suffering at the end of life: Practitioners' perspectives on palliative sedation from three European countries. *Social Science & Medicine* 64: 1679–1691.
37. Gordijn B, Janssens R (2004) Euthanasia and palliative care in the Netherlands: an analysis of the latest developments. *Health Care Analysis* 12: 195–207.
38. Onwuteaka-Philipsen BD, van der Heide A, Koper D, Keij-Deerenberg I, Rietjens JAC, et al. (2003) Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. *Lancet* 362: 395–399.
39. Rietjens JAC, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G (2005) A comparison of attitudes towards end-of-life decisions: Survey among the Dutch general public and physicians. *Social Science & Medicine* 61: 1723–1732.
40. Sullivan M, Ormel J, Kempen G, Tymstra T (1998) Beliefs concerning death, dying, and hastening death among older, functionally impaired Dutch adults: A one-year longitudinal study. *Journal of the American Geriatrics Society* 46: 1251–1257.
41. De Haan J (2002) The new Dutch law on euthanasia. *Medical Law Review* 10: 57–75.
42. Van Nieuwenhuysse R (1990) Euthanasia in the Netherlands. *Issues in Law & Medicine* 6: 229–245.
43. Van Marwijk H, Haverkate I, Van Royen P, The AM (2007) Impact of euthanasia on primary care physicians in the Netherlands. *Palliative Medicine* 21: 609–614.
44. Van der Wal G, Van Eijk J, Leenen H, Spreeuwenberg C (1992) Euthanasia and assisted suicide. II. Do Dutch family doctors act prudently? *Family Practice* 9: 135–140.
45. Swarte N, van der Lee M, van der Bom J, van den Bout J, Heintz A (2003) Effects of euthanasia on the bereaved family and friends: a cross sectional study. *British Medical Journal* 327: 189.
46. Buiting HM, Willems DL, Pasman HR, Rurup ML, Onwuteaka-Philipsen BD (2011) Palliative treatment alternatives and euthanasia consultations: a qualitative interview study. *Journal of pain and symptom management* 42: 32–43.
47. Norwood F (2007) Nothing More To Do: Euthanasia, General Practice, and End-of-Life Discourse in the Netherlands. *Medical Anthropology* 26: 139–174.
48. Voorhees J, Drickamer M, Rietjens J, van der Heide A (2009) Discussing Physician-Assisted Dying: A Qualitative Study of Doctors' Experiences in the US & the Netherlands. *Journal of the American Geriatrics Society* 57: S76–S77.
49. Chabot BE, Goedhart A (2009) A survey of self-directed dying attended by proxies in the Dutch population. *Social Science and Medicine* 68: 1745–1751.
50. Klinkenberg M, Willems DL, Onwuteaka-Philipsen BD, Deeg DJH, van der Wal G (2004) Preferences in end-of-life care of older persons: after-death interviews with proxy respondents. *Social Science & Medicine* 59: 2467–2477.
51. Rurup M, Onwuteaka-Philipsen B, van der Heide A, van der Wal G, Deeg D (2006) Frequency and determinants of advance directives concerning end-of-life care in The Netherlands. *Social Science & Medicine* 62: 1552–1563.
52. Rurup ML, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G, van der Maas PJ (2005) Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands. *Journal of the American Geriatrics Society* 53: 1138–1144.
53. Van Delden J (2004) The unfeasibility of requests for euthanasia in advance directives. *Journal of Medical Ethics*. pp 447–451.
54. Abma TA, Widdershoven GAA (2005) Sharing stories - Narrative and dialogue in responsive nursing evaluation. *Evaluation & the Health Professions* 28: 90–109.
55. Francke AL, Willems DJ (2000) Palliatieve zorg vandaag en morgen, feiten, opvattingen en scenario's. Elsevier, Maarssen.
56. Goldsteen M, Houtepen R, Proot IM, Abu-Saad HH, Spreeuwenberg C, et al. (2006) What is a good death? Terminally ill patients dealing with normative expectations around death and dying. *Patient Education and Counseling* 64: 378–386.
57. Osse B, Vernooij-Dassen M, Schade E, de Vree B, van den Muijsenbergh M, et al. (2002) Problems to discuss with cancer patients in palliative care: a comprehensive approach. *Patient Education and Counseling* 47: 195.
58. Osse B, Vernooij-Dassen M, Schade E, Grol R (2005) The problems experienced by patients with cancer and their needs for palliative care. *Supportive Care in Cancer* 13: 722–732.
59. Puts MT, Versloot J, Muller MJ, van Dam FS (2004) [The opinion on care of patients with cancer undergoing palliative treatment in day care]. *Ned Tijdschr Geneesk* 148: 277–280.
60. van Wijmen MP, Rurup ML, Pasman HR, Kaspers PJ, Onwuteaka-Philipsen BD (2010) Advance directives in the Netherlands: an empirical contribution to the exploration of a cross-cultural perspective on advance directives. *Bioethics* 24 (3): 118–126.
61. Buiting H, Rietjens J, Onwuteaka-Philipsen B, van der Maas P, van Delden J, et al. (2008) A comparison of physicians' end-of-life decision making for non-western migrants and Dutch natives in the Netherlands. *The European Journal of Public Health* 18: 681–687.
62. de Graaff FM, Francke AL (2003) Home care for terminally ill Turks and Moroccans and their families in the Netherlands: carers' experiences and factors influencing ease of access and use of services. *International Journal of Nursing Studies* 40: 797–805.
63. de Graaff FM, Francke AL, van den Muijsenbergh ME, van der Geest S (2010) 'Palliative care': a contradiction in terms? A qualitative study of cancer patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliative Care* 9: 19.
64. Bernheim JL, Deschepper R, Distelmans W, Mullie A, Bilsen J, et al. (2008) Development of Palliative Care and Legalisation of Euthanasia: Antagonism or Synergy? *BMJ* 336: 864–867.
65. Bilsen J, Van der Stichele R, Broeckart B, Mortier F, Deliens L (2007) Changes in medical end-of-life practices during the legalization process of euthanasia in Belgium. *Social Science and Medicine* 65: 803–808.
66. Cohen J, Bilsen J, Hoof P, Deboosere P, van der Wal G, et al. (2006) Dying at home or in an institution: Using death certificates to explore the factors associated with place of death. *Health Policy* 78: 319–329.
67. Cohen J, Houttekier D, Chambaere K, Bilsen J, Deliens L (2011) The use of palliative care services associated with better dying circumstances. Results from an epidemiological population-based study in the Brussels metropolitan region. *Journal of pain and symptom management* 42: 839–851.
68. Desmedt MS, de la Kethulle YL, Deveugele MI, Keirse EA, Paulus DJ, et al. (2011) Palliative patients in general hospitals: a one day observational study in Belgium. *BMC palliative care* 10: 2.
69. Van Rensbergen G, Nawrot TS, Van Hecke E, Nemery B (2006) Where do the elderly die? The impact of nursing home utilisation on the place of death. Observations from a mortality cohort study in Flanders. *Bmc Public Health* 6.
70. Cohen J, Houttekier D, Onwuteaka-Philipsen B, Miccinesi G, Addington-Hall J, et al. (2010) Which patients with cancer die at home? A study of six European countries using death certificate data. *J Clin Oncol* 28: 2267–2273.
71. Van den Block L, Bilsen J, Deschepper R, Van der Kelen G, Bernheim JL, et al. (2006) End-of-life decisions among cancer patients compared with noncancer patients in Flanders, Belgium. *Journal of Clinical Oncology* 24: 2842–2848.
72. Van den Block L, Deschepper R, Driessens K, Bauwens S, Bilsen J, et al. (2007) Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors. *Bmc Health Services Research* 7.
73. Van den Eynden B, Hermann I, Schrijvers D, Van Royen P, Maes R, et al. (2000) Factors determining the place of palliative care and death of cancer patients. *Supportive Care in Cancer* 8: 59–64.
74. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen B, et al. (2010) Place of death in metropolitan regions: Metropolitan versus non-metropolitan variation in place of death in Belgium, The Netherlands and England. *Health & Place* 16: 132–139.
75. Houttekier D, Cohen J, Surkyn J, Deliens L (2011) Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC public health* 11: 228.
76. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, et al. (2010) Place of death of older persons with dementia. A study in five European countries. *Journal of the American Geriatrics Society* 58: 751–756.

77. Van den Block L, Deschepper R, Bilsen J, Van Casteren V, Deliens L (2007) Transitions between care settings at the end of life in Belgium. *Jama-Journal of the American Medical Association* 298: 1638–1639.
78. Cohen J, Bilsen J, Fischer S, Lofmark R, Norup M, et al. (2007) End-of-life decision-making in Belgium, Denmark, Sweden and Switzerland: Does place of death make a difference? *Journal of Epidemiology & Community Health* 61: 1062–1068.
79. Broeckaert B, Claessens P (2003) Physician-assisted death: From euthanasia to the withholding of life-sustaining treatment. [Dutch]. *Acta Hospitalia* 43: 9–20+93.
80. Deliens L, Mortier F, Bilsen J, Cosyns M, Vander Stichele R, et al. (2000) End-of-life decisions in medical practice in Flanders, Belgium: A nationwide survey. *Lancet* 356: 1806–1811.
81. Herremans J (2008) Euthanasie: la loi, quelques notions essentielles, la question du suicide assisté. (Euthanasia: the law, a few notions and the question of assisted suicide.). *Rev Med Brux* 29.
82. Jans J (2005) The Belgian “Act on Euthanasia”: Clarifying context, legislation, and practice from an ethical point of view. *Journal of the Society of Christian Ethics* 25: 163–177.
83. Bilsen J, Cohen J, Chambaere K, Pousset G, Onwuteaka-Philipsen B, et al. (2009) Medical end-of-life practices under the euthanasia law in Belgium. *New England Journal of Medicine* 361: 1119.
84. Chambaere K, Bilsen J, Cohen J, Raman E, Deliens L (2010) Differences in performance of euthanasia and continuous deep sedation by French-and dutch-speaking physicians in brussels, belgium. *Journal of Pain and Symptom Management* 39: e5.
85. Claessens P, Ellen Brugge R, Rita Vannuffelen R, Bert Broeckaert P, Paul Schotsmans P, et al. (2007) Palliative Sedation and Nursing: The Place of Palliative Sedation Within Palliative Nursing Care. *Journal of Hospice and Palliative Nursing* 9.
86. Seymour J, Payne S, Chapman A, Holloway M (2007) Hospice or home? Expectations of end-of-life care among white and Chinese older people in the UK. *Sociology of Health & Illness* 29: 872–890.
87. Onwuteaka-Philipsen BD, Fisher S, Cartwright C, Deliens L, Miccinesi G, et al. (2006) End-of-life decision making in Europe and Australia: A physician survey. *Archives of Internal Medicine* 166: 921–929.
88. Van Wesemael Y, Cohen J, Bilsen J, Onwuteaka-Philipsen B, Distelmans W, et al. (2010) Consulting a Trained Physician When Considering a Request for Euthanasia: An Evaluation of the Process in Flanders and The Netherlands. *Evaluation & the Health Professions*.
89. Van Wesemael Y, Cohen J, Onwuteaka Philipsen B, Bilsen J, Distelmans W, et al. (2009) Role and Involvement of Life End Information Forum Physicians in Euthanasia and Other End of Life Care Decisions in Flanders, Belgium. *Health Services Research* 44: 2180–2192.
90. Van Wesemael Yanna C, Bregje O, Johan B, Luc D (2009) Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium. *Bmc Health Services Research* 9.
91. Bilsen J, Van der Stichele R, Mortier F, Deliens L (2004) Involvement of nurses in physician-assisted dying. *Journal of Advanced Nursing* 47: 583–591.
92. De Bal N, de Casterle BD, De Beer T, Gastmans C (2006) Involvement of nurses in caring for patients requesting euthanasia in Flanders (Belgium): A qualitative study. *International Journal of Nursing Studies* 43: 589–599.
93. Deliens L, Mortier F (2001) Empirical research on end-of-life decisions in medical practice in Belgium (Flanders). *Clinical and Epidemiological Aspects of End-of-Life Decision-Making* 102: 121–133.
94. Denier Y, de Casterle BD, De Bal N, Gastmans C (2009) Involvement of Nurses in the Euthanasia Care Process in Flanders (Belgium): An exploration of two perspectives. *Journal of Palliative Care* 25: 264–274.
95. Denier Y, Dierckx de Casterle B, De Bal N, Gastmans C (2009) “It’s intense, you know.” Nurses’ experiences in caring for patients requesting euthanasia. *Med Health Care Philos*.
96. Dierckx de Casterle B, Verpoort C, de Bal N, Gastmans C (2006) Nurses’ views on their involvement in euthanasia: a qualitative study in Flanders (Belgium). *Journal of Medical Ethics* 32: 187–192.
97. Gastmans C, Lemiengre J, de Casterle BD (2006) Role of nurses in institutional ethics policies on euthanasia. *Journal of Advanced Nursing* 54: 53–61.
98. Inghelbrecht E, Bilsen J, Mortier F, Deliens L (2008) Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: A death certificate study. *International Journal of Nursing Studies* 45: 1022–1031.
99. Inghelbrecht E, Bilsen J, Mortier F, Deliens L (2009) Nurses’ attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium. *Palliative Medicine* 23: 649.
100. Meeussen K, Van den Block L, Bossuyt N, Ehteld M, Bilsen J, et al. (2011) Dealing with requests for euthanasia: interview study among general practitioners in Belgium. *Journal of pain and symptom management* 41: 1060–1072.
101. Verpoort C, Gastmans C, de Casterle BD (2004) Palliative care nurses’ views on euthanasia. *Journal of Advanced Nursing* 47: 592–600.
102. Broeckaert B, Núñez-Olarte JM (2002) Sedation in palliative care. Facts and concepts. In H ten Have, & D Clark (Eds), *The ethics of palliative care European Perspectives* (166–180) Buckingham: Open University Press.
103. Cannaerts N, Dierckx de Casterle B, Grypdonck M (2004) Palliative care, care for life: A study of the specificity of residential palliative care. *Qualitative Health Research* 14: 816–835.
104. Gastmans C, Van Neste F, Schotsmans P (2004) Facing requests for euthanasia: a clinical practice guideline. *Journal of Medical Ethics* 30: 212–217.
105. Lemiengre J, Dierckx de Casterle B, Verbeke G, Guisson C, Schotsmans P, et al. (2007) Ethics policies on euthanasia in hospitals - A survey in Flanders (Belgium). *Health Policy* 84: 170–180.
106. Van Parys T (2003) From Belgium. *Palliative Medicine* 17: 111–112.
107. Smets T, Cohen J, Bilsen J, Van Wesemael Y, Rurup ML, et al. (2011) Attitudes and experiences of Belgian physicians regarding euthanasia practice and the euthanasia law. *Journal of pain and symptom management* 41: 580–593.
108. Abbadie B, Roland M, Cosyns M, Mainil T, Deveugele M, et al. (2006) Processus décisionnels et soins médicaux en fin de vie. *Rev Med Brux* 27: S287–291.
109. Bilsen J, Bauwens M, Bernheim J, Vander Stichele R, Deliens L (2005) Physician-assisted death: attitudes and practices of community pharmacists in East Flanders, Belgium. *Palliative Medicine* 19: 151–157.
110. Cohen J, Chambaere K, Bilsen J, Houttequier D, Mortier F, et al. (2010) Influence of the metropolitan environment on end-of-life decisions: A population-based study of end-of-life decision-making in the Brussels metropolitan region and non-metropolitan Flanders. *Health & Place* 16: 784–793.
111. Cohen J, Marcoux I, Bilsen J, Deboosere P, Van der Wal G, et al. (2006) Trends in Acceptance of Euthanasia among the General Public in 12 European Countries (1981–1999). *European Journal of Public Health* 16: 663–669.
112. Cohen J, Marcoux I, Bilsen J, Deboosere P, Van der Wal G, et al. (2006) European public acceptance of euthanasia: socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. *Soc Sci Med* 63: 743–756.
113. Dierckx K, Schotsmans P, Grubb A, Walsh P, Lambe N (1998) Belgian doctors’ attitudes on the management of patients in persistent vegetative state (PVS): Ethical and regulatory aspects. *Acta Neurochirurgica* 140: 481–489.
114. Gastmans C, Lemiengre J, de Casterle BD (2006) Development and communication of written ethics policies on euthanasia in Catholic hospitals and nursing homes in Belgium (Flanders). *Patient Education and Counseling* 63: 188–195.
115. Gastmans C, Lemiengre J, van der Wal G, Schotsmans P, de Casterle BD (2006) Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders). *Health Policy* 76: 169–178.
116. Lemiengre J, Dierckx de Casterle B, Denier Y, Schotsmans P, Gastmans C (2008) How do hospitals deal with euthanasia requests in Flanders (Belgium)? A content analysis of policy documents. *Patient Education and Counseling* 71: 293–301.
117. Lemiengre J, Dierckx de Casterle B, Denier Y, Schotsmans P, Gastmans C (2009) Content analysis of euthanasia policies of nursing homes in Flanders. *Med Health Care Philos* Epub ahead of print.
118. Miccinesi G, Fischer S, Paci E, Onwuteaka-Philipsen BD, Cartwright C, et al. (2005) Physicians’ attitudes towards end-of-life decisions: a comparison between seven countries. *Social Science & Medicine* 60: 1961–1974.
119. Mortier F, Bilsen J, Stichele R, Bernheim J, Deliens L (2003) Attitudes, sociodemographic characteristics, and actual end-of-life decisions of physicians in Flanders, Belgium. *Medical Decision Making* 23: 502–510.
120. Servais O, Legros E, Hiernaux J-P (2001) Changing Attitudes toward Euthanasia. Between the Disposition of Self and Respect for Others. *Recherches Sociologiques* 32: 65–78.
121. Van den Block L, Deschepper R, Bossuyt N, Drieskens K, Bauwens S, et al. (2008) Care for patients in the last months of life - The Belgian Sentinel Network Monitoring End-of-Life Care study. *Archives of Internal Medicine* 168: 1747–1754.
122. Vincent JL (1990) European attitudes towards ethical problems in intensive care medicine: Results of an ethical questionnaire. *Intensive Care Medicine* 16: 256–264.
123. Cartwright C, Onwuteaka-Philipsen BD, Williams G, Faisst K, Mortier F, et al. (2007) Physician discussions with terminally ill patients: A cross-national comparison. *Palliative Medicine* 21: 295–303.
124. Deschepper R, Bernheim JL, Van der Stichele R, Van den Block L, Michiels E, et al. (2008) Truth-telling at the end of life: A pilot study on the perspective of patients and professional caregivers. *Patient Education and Counseling* 71: 52–56.
125. Houtepen R, Hendriks D (2003) Nurses and the virtues of dealing with existential questions in terminal palliative care. *Nursing Ethics* 10: 377–387.
126. Klastersky J (2004) Humaniser l’annonce d’un cancer (editorial). *Rev Med Brux* 25: 69–70.
127. Levorato A, Stiefel F, Mazzocato C, Bruera E (2001) Communication with terminal cancer patients in palliative care: are there differences between nurses and physicians? *Supportive Care in Cancer* 9: 420–427.
128. Nys H, Schotsmans P (2000) Professional autonomy in Belgium. [see comment]. *Theoretical Medicine & Bioethics* 21: 425–439.
129. Pardon K, Deschepper R, Vander Stichele R, Bernheim J, Mortier F, et al. (2009) Preferences of advanced lung cancer patients for patient-centred information and decision-making: A prospective multicentre study in 13 hospitals in Belgium. *Patient Education and Counseling* 77: 421–429.

130. Timmermann M, Naziri D, Etienne AM (2009) Defence Mechanisms and Coping Strategies among Caregivers in Palliative Care Units. *Journal of Palliative Care* 25: 181–190.
131. Aujoulat I, Libion F, Bois H, Martin F, Deccache A (2002) Communication difficulties of healthcare professionals and family caregivers of HIV infected patients. *Patient Education and Counseling* 47: 213–222.
132. Deschepper R, Van der Stichele R, Bernheim JL, De Keyser E, Van der Kelen G, et al. (2006) Communication on end-of-life decisions with patients wishing to die at home: the making of a guideline for GPs in Flanders, Belgium. *British Journal of General Practice* 56: 14–19.
133. Cosyns M, Deveugele M, Abbadie B, Roland M (2008) [Decision-making and end of life care]. *Rev Med Brux* 29: 77–88.
134. Delfosse M (2008) [Advance directives: what are the ethical choices in Belgium?]. *Bull Soc Sci Med Grand Duché Luxemb* 3: 299/ 303.
135. Herremans J (2008) [Advance directives: the legal situation in Belgium]. *Bull Soc Sci Med Grand Duché Luxemb* 3: 302–310.
136. Meeussen K, Van den Block L, Ehteld M, Bossuyt N, Bilsen J, et al. (2011) Advance care planning in Belgium and The Netherlands: a nationwide retrospective study via sentinel networks of general practitioners. *Journal of pain and symptom management* 42: 565–577.
137. Backe G, Wils JP, Broeckart B (2011) 'We are (not) the master of our body': elderly Jewish women's attitudes towards euthanasia and assisted suicide. *Ethnicity & health* 16: 259–278.
138. Becker G, Sarhatic R, Olschewski M, Xander C, Momm F, et al. (2007) End-of-life care in hospital: Current practice and potentials for improvement. *Journal of Pain and Symptom Management* 33: 711–719.
139. Bickel H (1998) Das letzte Lebensjahr Eine Repräsentativstudie an Verstorbenen. I. Wohnsituation, Sterbeort und Nutzung von Versorgungsangeboten. *Z Geront Geriat* 31: 193–204.
140. Nyhsen C, Weber M, Schuz J, Faust G (1999) Dying through the hand of men or taken by the hand of men? Results of an opinion poll concerning active euthanasia and the hospice movement. *Medizinische Klinik* 94: 536–540.
141. Pinzon LC, Weber M, Claus M, Fischbeck S, Unrath M, et al. (2011) Factors influencing place of death in Germany. *Journal of pain and symptom management* 41: 893–903.
142. Ewers M, Schaeffer D (2007) Dying in Germany -consequences of societal changes for palliative care and the health care system. *Journal of Public Health* 15: 475–465.
143. Heller A, Dinges S, Heimerl K, Reitingner E, Wegleitner K (2005) Palliative culture in the stationary care for the elderly. *Zeitschrift für Gerontologie und Geriatrie* 36: 360–365.
144. Justinger C, Richter S, Moussavian MR, Serrano Contreras T, Schilling MK (2009) [Advance health care directives as seen by surgical patients.]. *Chirurg* 80: 455–461.
145. van Oorschot B, Hausmann C, Köhler N, Leppert K, Schweitzer S, et al. (2004) Patientenverfügungen aus Patientensicht. *Ethik in Der Medizin* 16: 112–122.
146. Borasio G, Weltermann B, Voltz R, Reichmann H, Zierz S (2004) Attitudes towards patient care at the end of life. A survey of directors of neurological departments. *Der Nervenarzt* 75: 1187.
147. Burchardi N, Rauprich O, Hecht M, Beck M, Vollmann J (2005) Discussing living wills. A qualitative study of a German sample of neurologists and ALS patients. *J Neurol Sci* 237: 67–74.
148. Kuhnlein P, Kubler A, Raubold S, Worrell M, Kurt A, et al. (2008) Palliative care and circumstances of dying in German ALS patients using non-invasive ventilation. *Amyotroph Lateral Scler* 9: 91–98.
149. Sahn S, Will R, Hommel G (2005) Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff. *Journal of Medical Ethics* 31: 437–440.
150. Sahn S, Will R, Hommel G (2005) Would they follow what has been laid down? Cancer patients' and healthy controls' views on adherence to advance directives compared to medical staff. *Medicine, Health Care and Philosophy* 8: 297–305.
151. Schgal A, Weisheit C, Miura Y, Butzlaff M, Kielstein R, et al. (1996) Advance directives and withdrawal of dialysis in the United States, Germany, and Japan. *JAMA* 276: 1652–1656.
152. Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM (1998) End-of-life decisions and advance directives in palliative care: A cross-cultural survey of patients and health-care professionals. *Journal of Pain and Symptom Management* 16: 153–162.
153. Jox R, Krebs M, Bickhardt J, Hessdorfer K, Roller S, et al. (2008) How strictly should advance decisions be followed? The patients' opinion. *Palliative Medicine* 22: 675.
154. Sahn S, Will R, Hommel G (2005) What are cancer patients' preferences about treatment at the end of life, and who should start talking about it? A comparison with healthy people and medical staff. *Supportive Care in Cancer* 13: 206–214.
155. Van Oorschot B, Simon A (2006) Importance of the advance directive and the beginning of the dying process from the point of view of German doctors and judges dealing with guardianship matters: results of an empirical survey. *Journal of Medical Ethics* 32: 623–626.
156. Kirschner R, Elkeles T (1998) [Physician practice patterns and attitudes to euthanasia in Germany. A representative survey of physicians]. *Gesundheitswesen* 60: 247–253.
157. Müller-busch H, Oduncu F, Woskanjan S, Klaschik E (2005) Attitudes on euthanasia, physician-assisted suicide and terminal sedation—A survey of the members of the German Association for Palliative Medicine. *Medicine, Health Care and Philosophy* 7: 333–339.
158. Beck S, van de Loo A, Reiter-Theil S (2008) A "little bit illegal"? Withholding and withdrawing of mechanical ventilation in the eyes of German intensive care physicians. *Med Health Care Philos* 11: 7–16.
159. Sahn SW (2000) Palliative care versus euthanasia. The German position: the German General Medical Council's principles for medical care of the terminally ill. *The Journal of medicine and philosophy* 25: 195–219.
160. Schildmann J, Doyal L, Cushing A, Vollmann J (2006) Decisions at the end of life: an empirical study on the involvement, legal understanding and ethical views of preregistration house officers. *Journal of Medical Ethics* 32: 567–570.
161. Solem PE (1981) The death taboo in Norway. [Norwegian]. *Tidsskrift for Norsk Psykiologforening Suppl* 1 7–15.
162. Telje J (1990) Care for the Dying in General Practice. *Tidsskrift for den Norske Laegeforening* 110: 1954–1956.
163. Hov R, Hedelin B, Athlin E (2007) Being an intensive care nurse related to questions of withholding or withdrawing curative treatment. *Journal of Clinical Nursing* 16: 203–211.
164. Husebø B, Husebø S (2005) Nursing homes as arenas of terminal care—how do we do in practice? *Tidsskrift for den Norske lægeforening: tidsskrift for praktisk medicin, ny række* 125: 1352.
165. Kaarbo E (2011) End-of-life care in two Norwegian nursing homes: family perceptions. *Journal of clinical nursing* 20: 1125–1132.
166. Jordhøy M, Fayers P, Loge J, Ahlner-Elmqvist M, Kaasa S (2001) Quality of life in palliative cancer care: results from a cluster randomized trial. *Journal of Clinical Oncology* 19: 3884.
167. Jordhøy M, Fayers P, Loge J, Saltnes T, Ahlner-Elmqvist M, et al. (2001) Quality of life in advanced cancer patients: the impact of sociodemographic and medical characteristics. *British Journal of Cancer* 85: 1478.
168. Jordhøy M, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, et al. (2000) A palliative-care intervention and death at home: a cluster randomised trial. *The Lancet* 356: 888–893.
169. Norum J (1993) Cancer patients who want to die at home. *Tidsskrift for den Norske Laegeforening* 113: 1102–1103.
170. Ringdal G, Jordhøy M, Kaasa S (2002) Family satisfaction with end-of-life care for cancer patients in a cluster randomized trial. *Journal of Pain and Symptom Management* 24: 53–63.
171. Sorbye LW (1999) Cancer patients who prefer to die at home - Characterizations of municipalities with several or few occurrences of home deaths. *Scandinavian Journal of Caring Sciences* 13: 102–108.
172. Schaffer MA (2007) Ethical problems in end-of-life decisions for elderly Norwegians. *Nursing Ethics* 14: 242–257.
173. Ringdal G, Ringdal K, Jordhøy M, Ahlner-Elmqvist M, Jannert M, et al. (2004) Health-related quality of life (HRQOL) in family members of cancer victims: results from a longitudinal intervention study in Norway and Sweden. *Palliative Medicine* 18: 108.
174. Romoren TI (2003) The carer careers of son and daughter primary carers of their very old parents in Norway. *Ageing and Society* 23: 471–485.
175. Norum J, Wist E (1993) When cancer patients die at home: The care provider's experience. *Tidsskrift for den Norske Laegeforening* 113: 1107–1109.
176. Ringdal G, Jordhøy M, Ringdal K, Kaasa S (2001) Factors affecting grief reactions in close family members to individuals who have died of cancer. *Journal of Pain and Symptom Management* 22: 1016–1026.
177. Hurst SA, Perrier A, Pegoraro R, Reiter-Theil S, Forde R, et al. (2007) Ethical difficulties in clinical practice: experiences of European doctors. *Journal of Medical Ethics* 33: 51–57.
178. Lorensen M, Davis A, Konishi E, Bunch E (2003) Ethical issues after the disclosure of a terminal illness: Danish and Norwegian hospice nurses' reflections. *Nursing Ethics* 10: 175.
179. Sorbye LW (2000) A longitudinal study on dying in a Norwegian hospital. *Int J Palliat Nurs* 6: 71–79.
180. Forde R, Aasland OG, Steen PA (2002) Medical end-of-life decisions in Norway. *Resuscitation* 55: 235–240.
181. Tallgren M, Klepstad P, Petersson J, Skram U, Hynninen M (2005) Ethical issues in intensive care a survey among Scandinavian intensivists. *Acta Anaesthesiologica Scandinavica* 49: 1092–1100.
182. Hynninen M, Klepstad P, Petersson J, Skram U, Tallgren M (2008) Process of foregoing life-sustaining treatment: a survey among Scandinavian intensivists. *Acta Anaesthesiologica Scandinavica* 52: 1081–1085.
183. Pettilä V, Ala-Kokko T, Varpula T, Laurila J, Hovilehto S, et al. (2002) On what are our end-of-life decisions based? *Acta Anaesthesiologica Scandinavica* 46: 947–954.
184. Pedersen R, Nortvedt P, Nordhaug M, Stetteba A, Grothe KH, et al. (2008) In quest of justice? Clinical prioritisation in healthcare for the aged. *Journal of Medical Ethics* 34: 230–235.
185. Torjuul K, Nordam A, Sorlie V (2005) Action ethical dilemmas in surgery: an interview study of practicing surgeons. *BMC Med Ethics* 6: E7.
186. Forde R, Aasland O, Falkum E (1997) The ethics of euthanasia—attitudes and practice among Norwegian physicians. *Social Science & Medicine* 45: 887–892.

187. Solheim K, Kjolseth I, Nordal HL, Molaug M (1990) Euthanasia and Terminal Care in Hospital Tidsskrift for den Norske Lægeforening 110: 1957–1959.
188. Lindseth A, Marhaug V, Norberg A, Uden G (1994) Registered Nurses and Physicians Reflections on their Narratives about Ethically Difficult Care Episodes. *Journal of Advanced Nursing* 20: 245–250.
189. Nordam A, Sorlie V, Forde R (2003) Integrity in the care of elderly people, as narrated by female physicians. *Nursing Ethics* 10: 388–403.
190. Uden G, Norberg A, Lindseth A, Marhaug V (1992) Ethical reasoning in nurses' and physicians' stories about care episodes. *Journal of Advanced Nursing* 17: 1028.
191. Tranoy KE (1988) Medical ethics in Norway: Modern medicine. Traditional morality.
192. Schou K, Alvsvag H, Blaka G, Gjengedal E (2008) The (dis)appearance of the dying patient in generalist hospital and care home nurses' talk about the patient. *Nursing Philosophy* 9: 233–247.
193. Bunch EH (2002) High technology and nursing: ethical dilemmas nurses and physicians face on high-technology units in Norway. *Nurs Inq* 9: 187–195.
194. Belderrain BP, García Busto B, Castanon Quinones EC (1999) [Health care and communication with the terminal cancer patient and his family in a health area]. *Aten Primaria* 24: 285–288.
195. Catalan-Fernandez JG, Pons-Sureda O, Recober-Martínez A, Avella-Mestre A, Carbonero-Malberti JM, et al. (1991) Dying of cancer. The place of death and family circumstances. *Medical Care* 29: 841–852.
196. Gomez-Batiste X, Viladiu P, Fontanals Ma D, Borrás J, Lafuerza A, et al. (2001) Cancer death in Catalonia: Population study about the last month of life in cancer patients (1993–94). [Spanish]. *Medicina Paliativa* 8: 134–137.
197. Jimeno Aranda A, Catalán R, García Ruiz M, Benedi E, Fernández Picó A, et al. (1993) ¿Dónde fallece el paciente terminal? *Atención Primaria* 11: 120.
198. Lafuerza A, Alcalde R, Roca J, Lozano A, Borrás J, et al. (1998) Morir de cáncer en Cataluña. Encuesta a cuidadores de pacientes fallecidos por cáncer. *Estudio multicéntrico de la utilización de morfícos en pacientes terminales. Oncología (Barcelona)* 21: 91–94.
199. Olano Espinosa E, Alonso Perez JL, Crespo Garzon A, Sionis A, Sabugal Rodelgo G, et al. (1997) [Care for the terminal cancer patient in a primary care district]. *Aten Primaria* 19: 483–486.
200. Ramon I, Alonso J, Subirats E, Yanez A, Santed R, et al. (2006) Place of death of elderly person in Catalonia. *Revista Clinica Espanola* 206: 549–555.
201. Arana M, Martín I, Guillén MV, Ibero JL, Marzo J, et al. (1993) Actitudes ante la enfermedad terminal. Encuesta a usuarios de un centro de salud. *Aten Primaria* 12: 523.
202. CIS (2009) Atención a pacientes con enfermedades en fase terminal. Estudio 2803. Madrid: CIS.
203. Fernandez Díaz R, Perez Suarez MC, Cossio Rodriguez I, Martinez Gonzalez P (1996) ACTITUD ANTE UNA ENFERMEDAD INCURABLE. *Atención Primaria* 17: 389–393.
204. Fernández Suárez A, Fernández Alvarez T, Alonso Arruquero C, Marcilla Escotet M, Cortina Viesca A, et al. (2002) Actitud de los usuarios de centro de salud ante el diagnóstico de enfermedad terminal. *Atención Primaria* 30: 449–454.
205. Wanden-Berghe C, Guardiola-Wanden-Berghe R, Sanz-Valero J, Red de Malnutrición en Iberoamerica (2009) [Population wills about the decisions and cares at the end of life]. *Nutricion Hospitalaria* 24: 732–737.
206. Bajo García J, García García JA, Landa Petralanda V, Marijuán Arcocha L, Rodríguez Salvador JJ (1990) Cuidado del enfermo terminal visto por el médico de familia. *Atención Primaria* 7: 538.
207. Osuna E, Perez-Carceles MD, Esteban MA, Luna A (1998) The right to information for the terminally ill patient. *Journal Of Medical Ethics* 24: 106–109.
208. Porta M, Busquet X, Jarid M (1997) Attitudes and views of physicians and nurses towards cancer patients dying at home. *Palliative Medicine* 11: 116.
209. Sanz de la Torre JC (2000) Actitudes del enfermero/a ante el paciente terminal. *Enfermería Científica* 0: 17–20.
210. Blanco Toro L, Librada Flores S, Rocafort Gil J, Cabo Domínguez R, Galea Marin T, et al. (2007) Perfil del cuidador principal del enfermo en situación terminal y análisis del riesgo de desarrollar duelo patológico. *Medicina Paliativa* 14: 164–168.
211. Molina Linde JM, Romero Coteló J, Romero Rodríguez R, Rodríguez Sañudo RM, Gálvez Mateos R (2005) Alteraciones emocionales en el cuidador del enfermo oncológico terminal. *Medicina Paliativa*. pp 83–87.
212. Molina Linde JM, Romero Coteló J, Romero Rodríguez Y, Rodríguez Sañudo RM, Gálvez Mateos R (2006) Encuesta de satisfacción a cuidadores en una Unidad de Cuidados Paliativos. *Medicina Paliativa* 13: 11–17.
213. Gil García E, Escudero Carretero M, Prieto Rodríguez MA, Frias Osuna A (2005) Vivencias, expectativas y demandas de cuidadoras informales de pacientes en procesos de enfermedad de larga duración. *Enfermería Clínica*. pp 220–226.
214. Palomar Gallardo C, Merino Navarro D, Palanco González I, Perez Cambriles JM, Reyes Bautista JR (2002) El apoyo socio-sanitario prestado a los pacientes terminales en domicilio y grado de satisfacción de los mismos. *Medicina Paliativa* 9: 3–5.
215. Uceda ME, Rodríguez JN, Mora JI (2007) Pilot study of family and social aspects perceived by caregivers of palliative cancer outpatients. *Medicina Paliativa* 14: 69–74.
216. Fainsinger RL, Waller A, Bercovici M, Bengtson K, Landman W, et al. (2000) A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients. *Palliative Medicine* 14: 257–265.
217. Rio-Valle J, Paz M, Caro G, Juarez R, Pena D, et al. (2009) Bad news for the patient and the family? The worst part of being a health care professional. *J Palliat Care* 25: 191–196.
218. Ruiz-Benítez de Lugo MA, Coca MC (2008) El pacto de silencio en los familiares de los pacientes oncológicos terminales. *Psicooncología* 5: 53–69.
219. Astudillo W, Casado Da Rocha A, Mendinueta C (2005) Alivio de las situaciones difíciles y de sufrimiento en la terminalidad. San Sebastián: Sociedad Vasca de Cuidados Paliativos.
220. Centeno Cortes C, Nunez Olarte JM (1998) [Studies about the communication of the diagnosis of cancer in Spain]. *Med Clin (Barc)* 110: 744–750.
221. Holland JC, Geary N, Marchini A, Tross S (1987) An international survey of physician attitudes and practice in regard to revealing the diagnosis of cancer. *Cancer Investigations* 5: 151–154.
222. Surbone A (1993) Information to the cancer patient: psychosocial and spiritual implications. *Supportive Care in Cancer* 1: 89.
223. Thomsen OO, Wulff HR, Martin A, Singer PA (1993) What do gastroenterologists in Europe tell cancer patients? *Lancet* 341: 473–476.
224. Centeno-Cortes C, Nunez-Olarte JM (1994) Questioning diagnosis disclosure in terminal cancer patients: A prospective study evaluating patients' responses. *Palliative Medicine* 8: 39–44.
225. Fainsinger RL, Nunez-Olarte JM, Demoissac DM (2003) The cultural differences in perceived value of disclosure and cognition: Spain and Canada. *Journal of Palliative Care* 19: 43–48.
226. Formiga F, Chivite D, Ortega C, Casas S, Ramón JM, et al. (2004) End-of-life preferences in elderly patients admitted for heart failure. *QJM: Monthly Journal Of The Association Of Physicians* 97: 803.
227. Gómez Pavón FJ (2002) Características del anciano con enfermedad oncológica en fase terminal en el medio hospitalario sociosanitario. Madrid: Universidad Complutense de Madrid, Servicio de Publicaciones.
228. Poveda de Agustín J (1992) Información al paciente terminal: un reto antropológico. *Jano* 1009: 93–106.
229. Domínguez B, Urraca Martínez S (1985) Opiniones de los médicos y enfermeras sobre el dolor y la muerte de pacientes terminales. *Jano* 654-H: 57–68.
230. García Caro MP, Rio-Valle JS, Quintana FC, Peña DP, Vinuesa AM, et al. (2008) Terminal illness. Death... in the words of professionals. A qualitative study based on in-depth interviews with health professionals [Spanish]. *Revista Rol de Enfermería* 31: 54–58.
231. Lopez de Maturana A, Morago V, San Emeterio E, Gorostiza J, Arrate AO (1993) Attitudes of general practitioners in Bizkaia, Spain, towards the terminally ill patient. *Palliative Medicine* 7: 39.
232. Pacheco R, Osuna E, Gómez Zapata M, Luna A (1989) Attitudes of medical personnel (doctors and nurses) toward informing the terminal patient. *Medicine And Law* 8: 243.
233. Simon-Lorda P, Tamayo-Velazquez MI, Barrio-Cantalejo IM (2008) Advance directives in Spain. Perspectives from a medical bioethicist approach. *Bioethics* 22: 346–354.
234. CIS (2002) Actitudes y opiniones de los médicos ante la eutanasia. Estudio 2451. Madrid: CIS.
235. Angel-Lopez-Rey E, Romero-Cano M, Tebar-Morales JP, Mora-García C, Fernandez-Rodriguez O (2008) [Knowledge and attitudes of the population about the living wills]. *Enferm Clin* 18: 115–119.
236. Lorente López M (2004) Las voluntades anticipadas en el ámbito de la salud: opiniones y actitudes de la población de la zona de salud urbana Torre Ramona de Zaragoza. *Trab Soc y Salud* 49: 83–122.
237. Miró G, Pedrol E, Soler A, Serra Prat M, Yébenes JC, et al. (2006) Conocimiento de la enfermedad y de los documentos de voluntades anticipadas en el paciente sepropositivo por el VIH. *Medicina Clínica* 126: 567–572.
238. Solsona JF, Sucarrats A, Maull E, Barbat C, García S, et al. (2003) Taking decisions at the end of life. A survey of the attitude of critically ill patients against death. *Medicina Clinica* 120: 335–336.
239. Cohen J, Marcoux I, Bilsen J, Deboosere P, van der Wal G, et al. (2006) European public acceptance of euthanasia: Socio-demographic and cultural factors associated with the acceptance of euthanasia in 33 European countries. *Social Science and Medicine* 63: 743–756.
240. CIS (1995) Perfiles actitudinales en la sociedad española. Estudio 2203. Madrid: CIS.
241. CIS (2008) Religiosidad. Estudio 2752. Madrid: CIS.
242. Fissell RB, Bragg-Gresham JL, Lopes AA, Cruz JM, Fukuhara S, et al. (2005) Factors associated with “do not resuscitate” orders and rates of withdrawal from hemodialysis in the international DOPPS. *Kidney International* 68: 1282–1288.
243. Sprung C, Cohen S, Sjøkvist P, Baras M, Bulow H, et al. (2003) End-of-Life Practices in European Intensive Care Units The Ethicus Study. *Am Med Assoc*. pp 790–797.
244. Vincent JL (1998) Information in the ICU: are we being honest with our patients? The results of a European questionnaire. *Intensive Care Medicine* 24: 1251–1256.

245. Vincent JL (1999) Forgoing life support in western European intensive care units: The results of an ethical questionnaire. *Critical Care Medicine* 27: 1626–1633.
246. Abizanda Campos R, Almendros Corral L, Balerdi Perez B, Socias Crespi L, Lopez Ferre J, et al. (1994) Limitación Del Esfuerzo Terapéutico. Encuesta Sobre El Estado De Opinión De Los Profesionales De La Medicina Intensiva. *Medicina Intensiva* 18: 100–105.
247. Esteban A, Gordo F, Solsona JF, Alía I, Caballero J, et al. (2001) Withdrawing and withholding life support in the intensive care unit: a Spanish prospective multi-centre observational study. *Intensive Care Med* 27: 1744–1749.
248. Nunez Olarte JM, Guillen DG (2001) Cultural issues and ethical dilemmas in palliative and end-of-life care in Spain. *Cancer Control* 8: 46–54.
249. Palomar Gallardo C, Merino Navarro D, González de Grado M, Palanco González I, Pérez Cambriles JM, et al. (2001) ¿Qué entienden los cuidadores principales de pacientes oncológicos en domicilio sobre 'muerte digna'? Primeras Jornadas Nacionales de la Sociedad Científica Española de Licenciados en Enfermería. Universidad de Alicante: Available: [http://www.scle.enfe.ua.es/web\\_scle/1\\_jornad.htm](http://www.scle.enfe.ua.es/web_scle/1_jornad.htm). pp 37–41.
250. Del Nogal Saez F (2006) Opiates at the end of life in an emergency department in Spain: euthanasia or good clinical practice? *Intensive Care Med* 32: 1086–1087.
251. Barrio Linares Md, Jimeno San Martín L, López Alfaro P, Ezenarro Muruamendiáraz A, Margall Coscojuela MA, et al. (2007) Cuidados del paciente al final de la vida: ayudas y obstáculos que perciben las enfermeras de cuidados intensivos. *Enfermería Intensiva* 18: 3–14.
252. Bayés R, Limonero JT, Buendía B, Burón E, Enriquez N (1999) Evaluación de la ansiedad ante la muerte. *Medicina Paliativa* 6: 140–143.
253. Perez-Carceles MD, Esteban MA, Osuna E, Luna A (1999) Medical personnel and death. *Medicine And Law* 18: 497.
254. Cherny NI, Baselga J, De Conno F, Radbruch L (2010) Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative. *Annals of Oncology* 21: 615–626.
255. Mahtani-Chugani V, Gonzalez-Castro I, de Ormijana-Hernandez AS, Martin-Fernandez R, de la Vega EF, et al. (2010) How to provide care for patients suffering from terminal non-oncological diseases: barriers to a palliative care approach. *Palliative Medicine* 24: 787–795.
256. Alonso Babarro A, Varela Cerdeira M, Sánchez del Corral Usaola F, Cano JM, Tordable Ramírez A, et al. (2002) La atención a pacientes inmigrantes en Cuidados Paliativos. Un problema emergente. *Medicina Paliativa* 9: 161–166.
257. Rodríguez R (2005) Inmigración y cuidados paliativos, a propósito de...¿ un caso? *Medicina Paliativa* 12: 3.
258. Cata Del Palacio E, Hernandez Nunez-Polo M, Perez Martinez A, Ramirez Orellana M, Madero Lopez L (2007) End of life in a cross-cultural context - Immigrant children with end-stage cancer. [Spanish]. *Medicina Paliativa* 14: 236–242.
259. Oliver C (2004) Cultural influence in migrants' negotiation of death: The case of retired migrants in Spain. *Mortality* 9: 235–254.
260. Casillas Santana L (2004) Interculturalidad en una unidad de cuidados intensivos. *Educare* 21: 6.
261. García Orellán R (2003) Antropología de la muerte: entre lo intercultural y lo universal. In: Astudillo W, Orbegozo A, Latiegi A, Urdeneta E, eds. *Cuidados paliativos en enfermería*. Donostia: Sociedad Vasca de Cuidados Paliativos. pp 305–322.
262. Piqué Prado E, Pozo Flórez JÁ (1999) Nursing and the terminal patient: anthropological perspective [Spanish]. *Metas de Enfermería* 2: 47–51.
263. Rodríguez Rodríguez C (2001) Death and mourning, representation systems [Spanish]. *Cultura de los Cuidados* 5: 45–48.
264. Centeno C, Clark D, Lynch T, Rocafort J, Prail D, et al. (2007) Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC task force. *Palliative Medicine* 21: 463–471.
265. De Conno F, Blumhuber H (1996) Meeting reports. Cross-cultural advances in pain treatment and palliative care. *European Journal of Palliative Care* 3: 38–39.
266. Monti M, Cunietti E, Castellani L, Merli M, Cruciatì F (2004) Ten years' activity of the first Italian public hospice for terminally ill patients. *Supportive Care in Cancer* 12: 752–757.
267. Beccaro M, Costantini M, Rossi PG, Miccinesi G, Grimaldi M, et al. (2006) Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *Journal of Epidemiology and Community Health* 60: 412–416.
268. DiMola G, Borsellino P, Brunelli C, Gallucci M, Gamba A, et al. (1996) Attitudes toward euthanasia of physician members of the Italian Society for Palliative Care. *Annals of Oncology* 7: 907–911.
269. Costantini M, Beccaro M, Higginson IJ (2008) Cancer Trajectories at the End of Life: is there an effect of age and gender? *Bmc Cancer* 8.
270. Rodríguez G, De Leo C, Girdler N, Vitali P, Grossi E, et al. (2003) Psychological and social aspects in management of Alzheimer's patients: an inquiry among caregivers. *Neurological Sciences* 24: 329–335.
271. Rossi Ferrario S, Cardillo V, Vicario F, Balzarini E, Zotti AM (2004) Advanced care at home: caregiving and bereavement. *Palliative Medicine* 18: 129–136.
272. Rossi PG, Beccaro M, Miccinesi G, Borgia P, Costantini M, et al. (2007) Dying of cancer in Italy: impact on family and caregiver. The Italian Survey of Dying of Cancer. *Journal of Epidemiology and Community Health* 61: 547–554.
273. Rossi Ferrario S, Zotti AM, Ippoliti M, Zotti P (2003) Caregiving-related needs analysis: A proposed model reflecting current research and socio-political developments. *Health Soc Care Commun* 11: 103–110.
274. Morasso G, Costantini M, Di Leo S, Roma S, Miccinesi G, et al. (2008) End-of-life care in Italy: personal experience of family caregivers. A content analysis of open questions from the Italian Survey of the Dying of Cancer (ISDOC). *Psycho-Oncology* 17: 1073–1080.
275. Dataanalysis La comunicazione della diagnosi e prognosi in oncologia. Available in [Saluteeuropa.it](http://saluteeuropa.it) website. Available: [http://saluteeuropa.it/index.php/salute\\_europa/News/La\\_comunicazione\\_della\\_diagnosi\\_e\\_prognosi\\_in\\_oncologia](http://saluteeuropa.it/index.php/salute_europa/News/La_comunicazione_della_diagnosi_e_prognosi_in_oncologia). Accessed 23 July 2009..
276. Giannini A, Pessina A, Tacchi EM (2003) End-of-life decisions in intensive care units: attitudes of physicians in an Italian urban setting. *Intensive Care Medicine* 29: 1902–1910.
277. Grassi F, Giraldo T, Messina EG, Magnani K, Valle E, et al. (2000) Physicians' attitudes to and problems with truth-telling to cancer patients. *Supportive Care in Cancer* 8: 40–45.
278. Surbone A, Ritossa C, Spagnolo AG (2004) Evolution of truth-telling attitudes and practices in Italy. *Critical Reviews in Oncology Hematology* 52: 165–172.
279. Andruccioli J, Montesi A, Di Leo S, Sarti D, Turci P, et al. (2009) Illness awareness in hospice: application of a semi-structured interview. *American Journal of Hospice & Palliative Medicine* 26: 384–391.
280. Andruccioli J, Montesi A, Raffaelli W, Monterubbianesi MC, Turci P, et al. (2007) Illness awareness of patients in hospice: psychological evaluation and perception of family members and medical staff. *Journal of Palliative Medicine* 10: 741–748.
281. Caruso A, Di Francesco B, Pugliese P, Cinanni V, Corlito A (2000) Information and awareness of diagnosis and progression of cancer in adult and elderly cancer patients. *Tumori* 86: 199–203.
282. Corli O, Apolone G, Pizzuto M, Cesaris L, Cozzolino A, et al. (2009) Illness awareness in terminal cancer patients: an Italian study. *Palliative Medicine* 23: 354–359.
283. Morasso G, Alberisio A, Capelli M, Rossi C, Baracco G, et al. (1997) Illness awareness in cancer patients: A conceptual framework and a preliminary classification hypothesis. *Psychooncology* 6: 212–217.
284. Pronzato P, Bertelli G, Losardo P, Landucci M (1994) What do advanced cancer patients know of their disease? A report from Italy. *Supportive Care in Cancer* 2: 242–244.
285. Veronesi A, Busato C, Annunziata MA, Magri MD, Foladore S, et al. (1995) Prospective analysis of the information level of Italian cancer patients. *European Journal of Cancer* 31A: 425–426.
286. Welshman A (2003) From Italy. *Palliative Medicine* 17: 122–123.
287. Locatelli C, Piselli P (2010) Telling bad news to the elderly cancer patients: the role of family caregivers in the choice of non-disclosure. *Journal of Geriatric Oncology* 1: 73–80.
288. Annunziata M, Talamini R, Tumolo S, Rossi C, Monfardini S (1996) Physicians and death: comments and behaviour of 605 doctors in the north-east of Italy. *Supportive Care in Cancer* 4: 334–340.
289. Dataanalysis (2003) La comunicazione della diagnosi e prognosi in oncologia.
290. Lucchiarri C, Masiero M, Pravettoni G, Vago G, Wears RL (2010) End-of-life decision-making: A descriptive study on the decisional attitudes of Italian physicians. *Life Span and Disability* 13: 71–86.
291. Bock M, Ciarrocchi V, Wiedermann CJ (2007) Case involving end-of-life decision issues in Italy. *Intensive Care Medicine* 33: 1041–1042.
292. Maggiore SM, Antonelli M (2005) Euthanasia, therapeutic obstinacy or something else? An Italian case. *Intensive Care Medicine* 31: 997–998.
293. Servillo G, Striano P (2008) End-of-life: Still an Italian dilemma. *Intensive Care Medicine* 34: 1333–1335.
294. Zamperetti N, Proietti R (2006) End of life in the ICU: laws, rules and practices: the situation in Italy. *Intensive Care Medicine* 32: 1620–1622.
295. van der Heide A, Deliens L, Faist K, Nilstun T, Norup M, et al. (2003) End-of-life decision-making in six European countries: descriptive study. *Lancet* 362: 345–350.
296. Benini F, Fabris M, Pace DS, Verno V, Negro V, et al. (2011) Awareness, understanding and attitudes of Italians regarding palliative care. *Annali dell'Istituto superiore di sanità* 47: 253–259.
297. Beccaro M, Caraceni A, Costantini M (2010) End-of-Life Care in Italian Hospitals: Quality of and Satisfaction With Care From the Caregivers' Point of View—Results from the Italian Survey of the Dying of Cancer. *Journal of Pain and Symptom Management* 39 (6): 1003–1015.
298. Costantini M, Ripamonti C, Beccaro M, Montella M, Borgia P, et al. (2009) Prevalence, distress, management, and relief of pain during the last 3 months of cancer patients' life. Results of an Italian mortality follow-back survey. *Annals of Oncology* 20: 729–735.
299. Costantini M, Viterbori P, Flego G (2002) Prevalence of pain in Italian hospitals: results of a regional cross-sectional survey. *Journal of Pain & Symptom Management* 23: 221–230.
300. Ripamonti C, Zecca E, Brunelli C, Groff L, Boffi R, et al. (2000) Pain experienced by patients hospitalized at the National Cancer Institute of Milan: Research project "Towards a Pain-Free Hospital". *Tumori* 86: 412–418.

301. Toscani F, Di Giulio P, Brunelli C, Miccinesi G, Laquintana D (2005) How people die in hospital general wards: a descriptive study. *Journal of Pain and Symptom Management* 30: 33–40.
302. Trentin L, Visentin M, de Marco R, Zanolin E (2001) Prevalence of pain in a public hospital: correlation between patients and caregivers. *Journal of Headache & Pain* 2: 73–78.
303. Mercadante S, Salvaggio L (1996) Cancer pain knowledge in southern Italy: data from a postgraduate refresher course. *J Pain Symptom Manage* 11: 108–115.
304. Porzio G, Aielli F, Narducci F, Valenti M, Varrassi G, et al. (2003) Knowledge and attitudes of Italian medical oncology residents toward the approach and treatment of pain [2]. *Journal of Pain and Symptom Management* 26: 590–592.
305. Visentin M, Trentin L, et al. (2001) Knowledge and attitudes of Italian medical oncology residents toward the approach and treatment of pain. *J Pain Symptom Manage* 22: 925–930.
306. Field A, Maher P, Webb D, Field A, Maher P, et al. (2002) Cross cultural research in palliative care. *Social Work in Health Care* 35: 523–543.
307. French J, Schwartz DR (1973) Terminal care at home in two cultures. *Am J Nurs* 73: 502–505.
308. Safonte-Strumolo N, Dunn AB (2000) Consideration of cultural and relational issues in bereavement: The case of an Italian American family. *The Family Journal* 8: 334–340.
309. Wood WA, McCabe MS, Goldberg RM (2009) Commentary: Disclosure in oncology – to whom does the truth belong? *Oncologist* 14: 77–82.
310. Costantini AS (2000) Geographical variations of place of death among Italian communities suggest an inappropriate hospital use in the terminal phase of cancer disease. *Public Health* 114: 15–20.
311. Hedayat KM (2002) Pediatric biomedical ethics: Introducing Italian pediatrician to the Islamic perspective. *Italian Journal of Pediatrics* 28: 112–120.
312. Goncalves JA (2001) A Portuguese palliative care unit. *Support Care Cancer* 9: 4–7.
313. Instituto Nacional de Estatística de Portugal (2005) Óbitos por distribuição geográfica de residência (NUTS II) e sexo, segundo a causa de morte. Lisboa: Instituto Nacional de Estatística de Portugal.
314. Pinto C, Santos L (2009) Prestador de cuidados: Quais são as suas necessidades? *ONCONEWS* 3: 16.
315. Goncalves JF, Alvarenga M, Silva A (2003) The last forty-eight hours of life in a Portuguese palliative care unit: does it differ from elsewhere? *J Palliat Med* 6: 895–900.
316. Pimentel FL, Ferreira JS, Real MV, Mesquita NF, Maia-Goncalves JP (1999) Quantity and quality of information desired by Portuguese cancer patients. *Supportive Care in Cancer* 7: 407–412.
317. Goncalves JA (2010) Attitudes toward end-of-life situations other than euthanasia and assisted suicide among Portuguese oncologists. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer* 18: 1271–1277.
318. Fonseca AM, Goncalves DC, Pereira SM (2010) Working family carers in Portugal: between the duty and the burden of caring for old vulnerable people. *International journal of palliative nursing* 16: 476–480.
319. Pereira SM, Fradique E, Fialho R, Cerqueira M, Pereira A, et al. (2011) Advance directives: Portuguese palliative care professionals' views. *International journal of palliative nursing* 17: 373–380.
320. National Institutes of Health (NIH) (2004) National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care. USA: National Institutes of Health.
321. Bennet M, Davies E, Higginson I (2010) Delivering research in end-of-life care: problems, pitfalls and future priorities. *Palliative Medicine* 24: 456–461.
322. ten Have H, Clark D (2002) The ethics of palliative care: European perspectives. Buckingham: Open University Press. - p.
323. Menaca A, Evans M, Andrew EVW, Toscani F, Finetti S, et al. End of life care across southern Europe: a critical review of cultural similarities and differences between Italy, Spain and Portugal. *Critical Reviews of Oncology and Haematology*.
324. The AM (2009) *Verlossers naast god. Dokters en euthanasie in Nederland*. Amsterdam: Uitgeverij Thoenis.
325. Gysels M, Higginson I (2007) Systematic reviews. In: Addington-Hall J, Bruera E, Higginson I, Payne S, eds. *Research methods in palliative care*. Oxford: Oxford University Press.
326. Payne SA, Turner JM (2008) Research methodologies in palliative care: a bibliometric analysis. *Palliative Medicine* 22: 336–342.
327. Aoun S, Kristjanson L (2005) Challenging the framework for evidence in palliative care research. *Palliative Medicine* 19: 461–465.