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## Care Setting Transitions at the End-of-Life in the Netherlands

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**Background:** Multiple care setting transitions in the last phase of life could have a negative impact on patients and their carers, thereby suggesting a low quality of dying. Although some of such transitions occur as a result of fluctuations in patients' condition, others could probably be avoided.

**Research question:** To describe the nature and frequency of care setting transitions in the last 90 days of life in the Netherlands and to identify factors relating to same.

**Methods:** Standardised registration forms were sent to all General Practitioners (GPs) within the Dutch Sentinel Network, a representative health surveillance network covering approximately 1% of the population. The GPs registered retrospectively all non-sudden deaths (a mortality follow-back study); of patients aged a year and above occurring between January 2005 and December 2006. Care setting transition was defined as a change in the place of patient care.

**Results:** A total of 718 transitions were made by the 690 non-sudden deaths registered. Two-thirds of these had their place of care changed at least once in the last four weeks of life. Over 80% of the 'hospital' deaths consisted of patients who were 'home' 7 days prior to death. Primary cause of death and patient's preference were related to fewer care transitions.

**Conclusion:** Different transition pathways occur in the last 90 days of life. It was however not possible to determine whether these transitions could have been avoided.

**“Whoever closes the eyes of the dying is considered to have taken his soul” (Mishnah Semahot 1).  
Jewish Perspectives on Euthanasia: ‘Diversity in Unity’.**

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In western bioethical debates the voices of religious minorities remain often absent. After all, these ethical debates are frequently approached from the point of view of the dominant western ideological traditions, the Christian tradition, on the one hand, and the non-religious, humanist tradition on the other. In answer to this challenge, it is the aim of this presentation to bring the voices of an important religious minority, Judaism, to the fore. In this presentation, based on a literature review, we discuss Jewish opinions on euthanasia. Analysing Jewish perspectives on ethical challenges includes an exploration of the methodology of Jewish end-of-life ethics. Addressing the possibilities and challenges of modern medicine, contemporary Jewish end-of-life ethics shows both its specificity and diversity. When confronted with an ethical case all rabbis (orthodox, conservative, reform) address the Jewish textual tradition. In this sense, the methodology of Jewish end-of-life ethics is characterised by a typical halakhic methodology – appealing to the Jewish religious law (halakhah) – and a case-based approach. Nevertheless, there is also clear intra-Jewish diversity here. This is due to the fact that there is no central Jewish authority and to the divergent ways in which the halakhah is perceived, as essentially unchanging or as open to recontextualisation, as either binding or guiding. Thus, although appealing to the same sources, a heterogeneity of interpretations emerge. Whereas most Rabbis oppose euthanasia, we find a few advocates of euthanasia on the liberal (conservative and reform) side. Yet these pro-euthanasia voices remain exceptional. Taking this ‘diversity in unity’ into account, we conclude that a similar (but not identical) methodology can lead to different conclusions. Therefore, the Jewish stance on euthanasia does not exist.

## **Antagonism or synergy between palliative care and legalisation of euthanasia?**

Bernheim Jan, Deschepper Reginald, Distelmans Wim, Bilsen Johan,  
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**Background:** Palliative Care and the legalization of euthanasia are widely viewed as antagonistic societal developments and causes. For example, the European Association for Palliative Care (EAPC) posited that “euthanasia should not be part of the responsibility of PC” because euthanasia legalisation could impede PC development.

**Question:** Is this concern comforted by the Belgian experience?

**Method:** Review of the historical, regulatory and epidemiological data.

**Results:** Belgium, the second country to legalise euthanasia, was second only to the UK in PC development. The highest per capita participation in EAPC conferences was from Belgium. The drives for PC and euthanasia coincided and both had wide public support. Concurrently, many caregivers were pioneers and advocates of both. The eventual euthanasia bill coincided with funding of nation-wide implantation of PC. Physicians trained in PC practice euthanasia no less than their untrained colleagues. The reduction of the incidences of physician-assisted dying (PAD) between 1998 and 2002 and the increase of terminal sedation practices suggest that the expansion of PC and the persuasiveness of its tenets influenced the practice of PAD and other end-of-life decisions. Guidelines by medical and PC professional organisations endorsed the concept of ‘integral palliative care’, including euthanasia.

**Conclusions:** Historical, epidemiological, public funding and regulatory data suggest that the legalisation-of-euthanasia drive reinforced the development of PC. Conversely, a well-developed PC network made the legalisation of euthanasia acceptable. The process of legalisation of euthanasia was ethically, politically and budgetarily linked to the development of PC. Euthanasia can be part and parcel of integral palliative care. This experience may be valuable for other countries.

## **Results from the nationwide SENTI-MELC study: representativity of the sample in terms of place of death**

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**Introduction:** The SENTI-MELC study (Sentinel network Monitoring End-of-Life Care) is a nationwide, population-based study on end-of-life care provision in Belgium. A prerequisite for a meaningful interpretation of the results is to know to what extent the obtained sample of patients, registered by a network of general practitioners, is representative for a general population of dying patients.

**Aims:** This analysis aims to assess the extent to which the sample of deaths registered by the sentinel network is representative in terms of place of death for all deaths occurring within the Flemish and Brussels Region.

**Methods:** A nationwide sentinel network of general practitioners registered weekly, on a standardized registration form, every deceased patient (aged  $\geq 1$  year) in their practice from 01/01/05 until 31/12/06. The subsample of deaths among Flemish and Brussels residents was compared at the individual level to all deaths in 2003 among Flemish and Brussels residents gathered via the official death certificates. The relationship between place of death and registration via the sentinel network was explored through a logistic regression analysis for each place of death.

**Results:** Adjusted for age and sex, the odds of dying at home and at a place other than either home, hospital or elderly/nursing home, were significantly higher among patients registered by the sentinel network compared to deaths gathered via the death certificates (OR: 1.22 [1.10 – 1.37] and 1.84 [1.48 – 2.30] respectively); whereas the odds of dying in a hospital were lower (OR: 0.79 [0.72 – 0.87]). The odds of dying in an elderly/nursing home did not differ (OR: 1.01 [0.89 – 1.15]).

**Conclusions:** Since the sentinel sample was compared to all deaths, only places of death that are underreported are problematic for representativity. This analysis demonstrates that there is underreporting of hospital deaths within the sentinel sample, but not of deaths occurring at home, in an elderly/nursing home or at yet another place.

## **Flemish Palliative-Care Physicians and Euthanasia: An Empirical Study**

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**Aim of the Study:** Several studies have already investigated attitudes of medical professionals towards end-of-life issues. Less research has been conducted concerning the attitudes of palliative care professionals. In 2006 the Interdisciplinary Centre for the Study of Religion and World View (K.U.Leuven) and the Flemish Federation for Palliative Care undertook a quantitative study of attitudes of palliative care physicians towards voluntary and non-voluntary euthanasia.

**Method:** An anonymous questionnaire was sent to all physicians (147) employed in palliative care teams and institutions in Flanders (Belgium). The questionnaire contained a demographic part, and an attitudinal part, consisting of a long series of ethical statements using a five-point Likert-scale.

**Results:** 67.3% of the physicians (n=99) responded. On the basis of traditional cluster algorithm euthanasia clusters were created. 48.5% (n=48) of the physicians belonged to the cluster of staunch advocates of euthanasia. 12.1% (n=12) belonged to the cluster of moderate opponents of euthanasia and 32.3% (n=32) belonged to the cluster of moderate advocates of euthanasia. In all clusters, most physicians considered non-voluntary euthanasia never ethically justified. A majority in all groups believed palliative care puts an end to most euthanasia requests. No significant relation ( $\alpha = 0.05$ ) was found between the clusters and the demographic variables gender, age and years of experience in palliative care.

**Conclusion:** Although a majority of the Flemish palliative care physicians does not want to exclude the possibility of euthanasia in all circumstances, they also believe in the effectiveness of palliative care. Unlike the attitudes of physicians towards euthanasia in earlier surveys, the attitudes of Flemish palliative care physicians were not influenced by the demographic variables gender and age.

## **A comparison of end-of-life decision-making between non-western migrants and Dutch natives in the Netherlands**

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**Introduction:** Currently, 10% of the Dutch population is migrant from non-western origin. As migrant's cultural background plausibly influences their attitudes towards health and healthcare and as this group is growing older right now, end-of-life care increases in importance.

**Methods:** In 2005, random samples from the central death registry of Statistics Netherlands were drawn. We subsequently sent questionnaires to reporting physicians about the medical decisions that preceded the patient's death. The total number of deaths was 9648, of which 627 concerned non-western migrants (response rate: 78). Non-western migrants were defined as persons living in the Netherlands and of whom at least one parent was born in Africa, Latin America or Asia (excluding Indonesia and Japan).

**Results:** Euthanasia took place in 1.3% of all deaths in non-western migrants and in 1.8% of all deaths in the native Dutch (odds ratio=1.1,  $p=0.77$ ). The frequency of the alleviation of symptoms with a potential life-shortening effect was significantly lower in non-western migrants (16% vs. 25%; odds ratio 0.73,  $p=0.01$ ) just like the frequency of morphine use in the last 24 hours before death (32% vs. 42%; odds ratio 0.79,  $p=0.02$ ). Physicians equally decided to forgo potentially life-prolonging treatment in non-western migrants (14%) and Dutch natives (15%; odds ratio=0.85,  $p=0.21$ ) but the type of treatments forgone and underlying reasons differed. Non-western migrants for whom an end-of-life decision was made were more often incompetent than Dutch natives (60% and 45%, respectively).

**Discussion:** Medical decisions at the end of life occurred in a substantial percentage of deceased non-western migrants. Yet, compared to Dutch natives, symptom alleviation was practiced less frequently and forgoing potentially life-prolonging treatment had different underlying characteristics. These findings affirm the assumption that cultural issues are relevant aspects in medical end-of-life decision-making.

## **Cancer in Limburg: what are the challenges and are we ready for it?**

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**Aims:** To describe the quantitative evolution in cancer epidemiology within the Belgian province of Limburg expected for the coming years and the broad qualitative consequences in a large number of fields. To estimate to what extent health planners and health care personnel are ready to face the challenges.

**Methods:** 1 quantitative analyses largely based on the LIKAR registry. 2. Report on a number of discussions with central persons of different disciplines and settings within the Landscape of planning and care for cancer patients in Limburg.

**Main results:** Incidence and (even more) prevalence of most cancers will increase. Cancer is becoming a chronic disease as well as a disease of the old. Important challenges are to deal with the increasing age of cancer patients (both in treatment and in caring), to find solutions for the insufficient psycho-social support of cancer patients; to find better ways for coöperation between carers of different disciplines and settings.

**Conclusions:** It is time to face the serious challenges we will have to deal with. Some initiatives will be running before the symposium.

## **Studying medical end-of-life decisions via death certificates in Flanders and Brussels, Belgium: a research protocol**

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**Background:** Medical end-of-life decisions (ELDs) have become an important issue in medical and societal debate. However, studying these ELDs is not evident, especially because of methodological difficulties. In 2007 we will conduct a study in Flanders and in Brussels to establish the incidence and characteristics of ELDs. The methodology of this study is outlined in this report.

**Method:** Similar to two earlier conducted studies (in 1998 and 2001), and in close cooperation with the Flemish and Brussels authorities, we investigate ELDs by using death certificates. Questionnaires are sent to the physicians who signed a representative sample of death certificates (deceased of 1 year or older) in Flanders as well as in Brussels. In the Flemish survey, a stratified sample is used. In the Brussels survey, a random sample is taken. Anonymity of both patients and physicians is guaranteed through a rigorous mailing procedure, involving a lawyer as intermediary between the responding physicians and researchers. To increase the response we use the Total Design Method. The questionnaire used in this study is nearly identical to the questionnaires used in the previous studies, and is tested and validated thoroughly. Its translation from Dutch to French is done via a comprehensive forward-backward translation procedure.

**Discussion:** Death certificate studies are appropriate in nationwide studies on incidence and characteristics of ELDs. Earlier studies in Belgium and other countries have shown the reliability and validity of this methodology. High response levels show that the anonymity and mailing procedure is trustworthy, which leads to results that are representative for all deaths in the years studied.

## **Hospital deaths in six European countries: population-based cross national study of factors associated with dying in hospital**

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**Background:** This population-based study examined the proportion of hospital deaths in six European countries (Belgium, England, Scotland, Sweden, the Netherlands, Wales), and to what extent country-variation in proportion of hospital deaths is related to demographic, epidemiologic, and health care factors.

**Methods:** Data of all deaths in 2003 of the studied countries (2002 in Sweden) were gathered via official death certificate data, linkage with other population data files, and linkage with regional healthcare statistics, and were integrated into one common database (N=891,780) for analyses.

**Results:** Of all deaths, 33.9% in the Netherlands to 62.8% in Wales occurred in hospital.

The large country differences in hospital death rate were only partly explained by availability of care home beds and (to a lesser extent) availability of hospital beds.

Country differences were strikingly large in older patients and cancer patients. Older patients had a higher probability to die in hospital in Sweden, Scotland, England, and Wales than in Flanders and (in particular) the Netherlands. Cancer patients often died in hospitals in Sweden (OR of dying in hospital versus outside hospital=4.07), but less frequently so in the Netherlands (OR =0.60), and England (OR=0.67).

**Interpretation:** Country differences in proportion of patients dying in hospital are only in part the result of differences in health care provision, and are in particular large for certain patient populations, suggesting country-specific end-of-life practices in these populations. Our findings can contribute to a rational planning of policy aimed at reducing hospital deaths for specific patient populations in the studied countries.

**Care for elderly at the communal level in Belgium:  
the role for Public Centres of Social Welfare (OCMW / CPAS)**

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In this presentation we describe the continuum of social and health care for elderly at the level of the semi-rural Belgian commune of Kruikebeke. The distinction at local level between social and health care is sometimes blurred. The care continuum ranges from informal home care by relatives and friends at one end, to specialised professional care (incl. palliative care) in an elderly home at the other end of the spectrum. No hospital operates on the territory of the commune. The provision of care in the commune of Kruikebeke is pluralistic of nature with a mix and variety of private and public, informal and formal, care providers. The role of the Public Centre of Social Welfare (PCSW), next to its contribution in providing part of the local care, is to coordinate the interventions of the various players in this care landscape. Current legislation of the Flemish regional government, via the 2004 Decree on Local Social Policy, offers the legal basis for the development of such a stewardship function. The challenge for the PCSW is to develop an 'integrated' local social system, in which the different operational actors play their specific role in a complementary way, and where one common objective is pursued – the provision of adequate and accessible care to all elderly in need. PCSWs face the following challenges in the organisation and coordination of social care: 1) the need to develop an adequate and effective communication policy that informs the elderly on the complete range of care available at the local level; 2) the creation of an institutional environment that facilitates the exchange and collaboration between the different local care providers; 3) the liaising with and lobbying at the level of regional and federal authorities in order to obtain support and funding for the needed expansion of the current resthome infrastructure.

## Nursing Home Policies regarding Advance Care Planning

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**Objectives:** Recently advance care planning at the end of life (ACP) becomes more important, especially in nursing homes where residents are often incompetent at the end of life. Contrary to some other countries, Belgian legislation does not regulate ACP in health care institutions.

The aim of this study is to describe how many nursing homes have a policy (institutional guidelines and/or patient-specific forms/files) regarding ACP and the characteristics of these policies.

**Methods:** A structured mail questionnaire was sent to the nursing home administrator of all nursing homes in Flanders (Belgium) at the end of 2006. They were asked about the existence and content of their policy regarding ACP.

**Results:** The questionnaire was returned by 345 nursing home administrators (58%). Of all nursing homes 95% had a policy regarding ACP (64% had guidelines and patient-specific forms/files, 29% had only patient-specific forms/files and 2% had only guidelines). More than half of the documents were developed since 2002. Whether or not to transfer residents to a hospital is the most frequent issue in guidelines (90%) as well as in patient-specific forms/files (97%), closely followed by other kinds of treatment-decisions. Euthanasia and terminal sedation is discussed in about half of the guidelines. Respectively 21% and 32% of the patient-specific forms/files had a space for notes about euthanasia and terminal sedation. Appointment of a legal representative is mentioned in 40% of existing guidelines and 29% of all nursing homes had standard forms for this act.

**Conclusions:** Almost all nursing homes have a policy regarding ACP, mostly developed since 2002, the year the Patients' Rights Act and the Law on Euthanasia was implemented. Although treatment-decisions are most frequently discussed in policies, euthanasia and terminal sedation are already discussed quite often. More attention should be given in policy-documents to appointment of a legal representative for the resident.

## **The recent evolution of life expectancy by educational level in Belgium (1991-2004)**

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The aim of this paper is to measure and evaluate trends in life expectancy by educational level in Belgium. The impressive inequity in health by socio-economic status (SES) in our welfare societies is well known, but much less information exists about the evolution of health by socio-economic status.

Census data for 1991 and 2001 cover the population at baseline by gender, age and educational level as indicator of SES. These data have been linked to migration and mortality information in the Belgian population register. Person-years at risk are calculated for two follow-up periods of three years (1991-1994 and 2001-2004), allowing for the exact calculation of life expectancy by educational level at age 25. The research design avoids typical problems of selectivity or numerator-denominator bias by using a population wide register-based individual record linkage.

Life expectancy increased for all educational groups as well among men as among women. The increase over the period studied extends from 0.87 years for women without education to 2.36 years for men with tertiary education. The existing gradient in inequity by education seems to be reinforced by the gradient in life expectancy increase. The gap in life expectancy between men and women is decreasing for all educational levels.

The results are alarming for the groups at the bottom end of the educational attainment spectrum. However, for a correct assessment of the evolution of health inequity these results have to be related to the relative importance of the respective educational attainment levels inside the population.

The combination of gain in life expectancy and reduction of health inequality in public health policy is not a given fact and the conciliation of these objectives requires a better understanding of the complex interaction of the processes involved. In the discussion we try to contribute to the clarification of these interactions.

## **Legal implications of decision-making regarding the withholding and/or withdrawing of intensive care in extremely premature infants**

Delbeke Evelien

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**Objective:** Neonatology has evolved quickly over the past few decades. Whereas 30 years ago, the margin of viability of a newborn was set at a gestational age of 28–30 weeks, nowadays infants born at 23–24 weeks gestation are surviving thanks to advances in medical technology. However, studies have shown that extremely premature infants often have significant physical and mental disabilities. When deciding whether or not to start and/or continue intensive care, neonatologists struggle with questions about the (future) quality of life of these infants. Sometimes the newborn's parents do not agree with the physician's decision and conflicts end in court.

The aim of this study is to develop a legal framework regarding the withholding and/or withdrawing of intensive care in extremely premature infants, and analyse whether parents have a right of veto concerning this end-of-life decision for their newborn.

**Methods:** A thorough study of the existing relevant regulations, guidelines, case law and doctrine of several countries has been carried out. Medical and ethical literature was also examined.

**Results:** There are different approaches towards this issue. Some physicians do not start intensive care in infants born before a certain gestational age. Others start intensive care in all infants, regardless of their gestational age or prognoses. Sometimes the issue is approached on a case by case basis and the decision to start intensive care depends on the diagnoses and prognoses of individual infants.

Denying a right of veto to the parents gives rise to additional problems, such as 'wrongful life' claims, where parents claim damages from physicians for giving intensive treatment to a severely disabled infant against parental wishes.

**Conclusions:** Final conclusions are expected at the end of October, and will be presented at the 9th Public Health Symposium.

## **The involvement of terminal patients in end-of-life care research: why and how?**

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A challenge for evidence-based health care is to incorporate patients' perspectives and shared decision-making. This is especially important in end-of-life decisions, when quality of life may take precedence over life prolongation. Patients facing death are likely to have different views, preferences and values than non-terminal patients. Therefore, it is necessary to involve terminal patients in end-of-life care research.

However, a number of ethical, practical, and methodological problems may arise. Patients can be potentially harmed by emotional reactions caused by confronting questions (e.g about euthanasia or the imminence of death). Therefore, selection of patients dully informed about their diagnosis and prognosis is often necessary. This has practical consequences, as it makes selection and informed consent procedures particularly laborious and delicate. Methodological problems are selection bias, lack of adequate and validated instruments for terminal patients, the possibility of response shift in the course of the (pre)terminal phase, and the loss of cognitive and physical ability in many terminal patients.

Quantitative research is often hampered by the feasibility of recruitment of sufficiently large sample sizes. Qualitative methods have some advantages, such as validity (or credibility) with lower sample sizes, and the possibility to adapt the questions to the emotional capabilities of the individual participant, e.g. by letting the patients tell their story. In participant observation, the researcher has the opportunity to build a trustful relation with the patient. Furthermore, it is usually less burdensome for the patient.

**Conclusion:** Terminal patients are indispensable in end-of-life care research but there are several limitations, especially in case of large-scale quantitative research.

**Paediatric Palliative liaison teams:  
precious links between all the caregivers!**

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In Belgium since 1982 the focus of palliative care and medicine has been very much on adults. However, children die as well and quite a lot has to be done to meet the needs of severely ill children, especially when the family decides to go back home with the child! Palliative care is less well developed in paediatrics for several reasons. Firstly, the number of children dying is relatively small which makes the development and maintenance of expertise difficult. Secondly, palliative care may be needed for children with a range of diseases or disorders, many of which are rare, some of them familial and encountered only in paediatric practice. For some children palliative care may be needed from early infancy and extend over many years. The involvement of parents as caregivers and decision-makers increases the complexity of care. In Belgium we do not have paediatric community nurses and the general community nurses for adults do not have a paediatric palliative care (PPC) qualification or experience. Lack of accessible PPC expertise is a barrier to good care at home.

To make the transition from hospital to home as straightforward as possible a French paediatric palliative interuniversity liaison network has been created in Brussels and Liège since 2002. Three teams of palliative paediatric health professionals have been developed to bridge any gap between hospital paediatric wards and home care providers. Those teams encourage and facilitate strong links between the paediatric specialists and the family doctor. They offer a 24-hour availability of specialist advice on PPC and an on-call support day and night throughout illness, death and bereavement without any financial contribution from the families. Increased continuity shortens the discharge delay in patients after prolonged hospitalisation and reduces inadequate readmission to emergency or paediatric units.

For adult patients, palliative interventions are well reimbursed but paediatric liaison teams offering an interdisciplinary shared expertise for severely ill children are badly paid by the Ministry of Public Health. This

leads to the lack of availability of PPC in our country and to lack of respect of the European charter protecting the rights of the sick children. To alleviate the suffering and burden of the parents and the primary care givers respite care has to be emphasized also and organised as a standard for care for children with severe motor disability and life-threatening illnesses. Governmental policies have to be created to abolish this inequality and to emphasize this ecology of love and expertise for the smallest amongst us!

## **Prevalence of several end-of-life care quality improvement initiatives in Flemish health care institutions**

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**Introduction/Objective:** Little is known about the different end-of-life care quality improvement initiatives undertaken by health care institutions. The approval of the Euthanasia law in Belgium in 2002 caused a growing need for and interest in the development of end-of-life care policies and guidelines. As a consequence an increased awareness concerning end-of-life care quality can be expected. The objective of this study is to determine the prevalence of different end-of-life care services, end-of-life care education/training, and end-of-life care measurement tools in different health care institutions in Flanders (academic, general and psychiatric hospitals, elderly homes, and residential facilities for handicapped people).

**Design and setting:** We conducted a full population postal survey across Flanders from May to October 2007, using a sixteen-page questionnaire with regard to end-of-life care policies and guidelines. The first part of this questionnaire (3 pages) concerned the measurement of different quality improvement initiatives with regard to end-of-life care.

**Participants:** Member of the Board of Directors of all academic, general and psychiatric hospitals, and Managing directors of all elderly homes and all residential facilities for handicapped people in Flanders (including Flemish-speaking institutions in Brussels), excluding institutions not providing intramural care.

**Main outcome measures:** Prevalence of different end-of-life care services, end-of-life care education/training, and end-of-life care measurement tools, by institution type and institution characteristics.

**Results and conclusions:** Preliminary results and conclusions regarding this study are not available yet, but will be presented at the symposium. Data are being collected at the moment in the different settings.

**Life End Information Forum - physicians (LEIF - artsen):  
advice on and support for end-of-life issues**

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**Introduction:** In Belgium, the law on euthanasia was implemented in September 2002. It is officially confirmed that 80% of the euthanized patients suffered from terminal cancer. However, a lot of physicians still lack communication skills when confronted with end-of-life issues of cancer patients.

**Purpose:** A platform was founded with more than 200 physicians in Flanders (the Flemish speaking part of Belgium; 60% of the Belgian population). They are trained in ethical decision making and palliative care for cancer patients. The physicians are called 'LEIF - artsen' (Life End Information Forum - physicians). They are meant to advise and support their colleagues in difficult end-of-life issues.

**Methods:** Recently, a questionnaire has been sent to all LEIF-physicians to get an interim report on their activities.

**Conclusions:** The LEIFartsen-platform in Flanders may be the reason of the higher willingness for officially reporting euthanasia-cases by the Flemish physicians (more than 80%) in contrast (less than 20%) with their Walloon colleagues (Wallonia: French speaking part of Belgium containing 40% of the Belgians). Other conclusions will be reported.

**Acknowledgements:** The LEIF project is granted by the Federal Belgian government, Recht op Waardig Sterven and the Vlaamse Liga tegen Kanker.

## **Characteristics and symptoms of patients dying at home: results from the Senti-MELC interview study**

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**Background:** Most patients express a preference to die at home, resulting in an important role for the general practitioner (GP) in providing adequate end-of-life care. However, little is known about characteristics and symptoms of patients dying at home.

**Objectives:** To describe the characteristics of patients dying at home, and to study the prevalence, frequency and burden of their symptoms in the last week of life.

**Method:** A nationwide mortality follow-back study was carried out in Belgium. Data were collected within the SENTI-MELC study – the study on Monitoring end-of-life Care via the nationwide Sentinel Network of GPs. All GPs reported weekly, on a standardized registration form, every deceased patient in their practice (>1year). For all non-sudden deaths occurring at home between January 2005 and March 2006, trained interviewers conducted a face-to-face interview with the GPs. During the interview, GPs scored the Memorial Symptom Assessment Scale-Global Distress Index (MSAS-GDI).

**Results:** For 205 of 229 eligible non-suddenly deceased patients, the GP participated in the interview (89.5%). The patients had a mean age of 75.4 years ( $\pm 14.3$ ) and 62.4% were male. The most reported cause of death was cancer (59.3%). The most prevalent physical symptoms included lack of energy (96.3%), lack of appetite (91.0%), feeling drowsy (75.7%), shortness of breath (58.7%) and pain (57.7%). In more than 50% of the patients experiencing lack of energy and/or shortness of breath, burden was considered as “quite a bit” or “very much”. For more than 50% of the patients experiencing the other symptoms, the GP reported at least “somewhat” burden. The most prevalent psychological symptoms included feeling sad (55.0%), worrying (50.3%) and feeling nervous (46.0%). More than 60% of the patients feeling sad or worrying experienced these symptoms “frequently” or “almost constantly” according to the GP.

**Discussion:** Many patients dying at home in Belgium appear to suffer from severe pathologies, and experience many untreated symptoms. Adequate symptom alleviation at the end of life is an important future challenge for GPs.

## **End of life pathways. Quality of life, satisfaction and empowerment.**

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**Context:** Studies have indicated that three quarters of the Belgians prefer to die at home, while in practice, this is not the case for the majority of them.

The AIMS OF THE STUDY are:

- to investigate the satisfaction and the perceived quality of care in situations of end of life;
- to explore the well-being and the quality of (end of) life;
- to examine the patient's autonomy at the end of his life, looking at decision processes, concepts of empowerment and resiliency with respect to cure, care and care pathway decisions;
- to consider the potential role of the Mutualités Chrétiennes (MC) in this complex issue.

The **Method** relies on retrospective qualitative research. The study occurs in two steps:

- In a first step, the prevailing array of ideas, opinions, preferences and problems related to end of life care pathway decisions and experiences are collected via focus groups of relatives of recently deceased MC members. Participants are recruited by a call for collaboration disseminated via the MC's own weekly journal and via the MC networks. Six focus groups are planned: 3 in Wallonia, 3 in Flanders.
- During the second step, a survey will take place in a panel of CM's members with the same characteristics, in order to quantify the results of the first phase.

**Results:** were not yet available at submission of the abstract. The results of the focus group discussions will be presented in december.

## Suicide assisted by two Swiss right-to-die organisations

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**Background:** In Switzerland, non-medical right-to-die organisations offer personal guidance in committing suicide to members suffering from incurable diseases. Four right-to-die organisations get involved with assisted suicides: 'Exit Deutsche Schweiz', 'Exit ADMD' ('Association pour le droit de mourir dans la dignité'), 'Dignitas' and 'Exit international'. Unlike the two Exit organisations 'Exit Deutsche Schweiz' and 'Exit ADMD', 'Dignitas' and 'Exit international' offer assistance to foreign people.

**Objective:** First, to examine differences in assisted suicides between the two right-to-die organisations 'Exit Deutsche Schweiz' and 'Dignitas' which are active in the German speaking area of Switzerland. Second, to investigate whether the practice of Exit has changed since the Nineties.

**Methods:** This study analyses all reported cases of assisted suicide which were investigated at the Institute of Legal Medicine of the University of Zurich (ILMZ) occurred between 2001 and 2004 offered by right-to-die organisations 'Exit Deutsche Schweiz' (n=147) and 'Dignitas' (n=274). Furthermore, the data from the Exit-study which investigates all cases of assisted suicide during the period 1990-2000 are used (n=149).

**Results:** Among both organisations an overrepresentation of female decedents were reported. In comparison to Exit, Dignitas assisted suicides more often for foreigners, younger people, and people suffering from fatal diseases such as multiple sclerosis and amyotrophic lateral sclerosis. Since the 1990s the proportion of elderly people suffering from non-fatal diseases and women among suicides assisted by Exit has been increased.

**Conclusions:** A fully medicalized system is inclined to focus on 'medical' reasons such as uncontrollable symptoms at the end of life as precondition for assistance in dying. In contrast, a system where right-to-die organisations play an important role primarily focuses on personal autonomy. Elderly people's wish to die often has no direct link to a medical condition. It comes as no surprise that these individuals are more likely in the latter than in the first system to get access to assistance in dying.

## **The prevalence of policies and guidelines on euthanasia and physician-assisted suicide and other medical end-of-life decisions in Dutch health care institutions**

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**Aim of the study:** To describe the prevalence of policies and guidelines on euthanasia and physician-assisted suicide (EAS) and other medical end-of-life decisions (ELDs) in Dutch health care institutions and the acquaintance with and use of the guidelines on EAS in medical practice.

**Methods:** The data were collected in two sub studies. First, in October 2005, questionnaires were sent to all Dutch health care institutions (response 68%, n=306). The questionnaire contained questions about the prevalence of policies and guidelines on EAS and other ELDs (life-terminating without explicit request; palliative sedation; symptom and pain control; do-not-resuscitate (DNR) decision; and withdrawing or withholding treatment on medical grounds) and the content of the EAS policies. Second, physicians of 12 hospitals with a guideline on EAS, received a questionnaire about their acquaintance with and use of the guidelines in practice (response 52%, n=322).

**Results:** Seventy percent of the Dutch health care institutions had a written policy on EAS, 74% of these policies indicated that EAS is permitted under conditions and in 17% EAS is never permitted. Almost two third of the institutions worked out their policy in a guideline on EAS. Institutions also frequently had guidelines on DNR decisions (63%), but much less on other ELDs (21-34%). Of the physicians, 75% knew about the existence of the guideline on EAS in their hospital. When physicians did know about the guideline and had used it before, they usually felt supported by it (91%).

**Conclusions:** Considering that physicians attach importance and support to institutional guidelines, it is recommended that health care institutions take care of the development of actual and qualitative good guidelines and disseminate them.

## **Body Mass Index and contacts with general practitioners (GP) in elderly**

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**Purpose:** To examine the impact of BMI (Body Mass Index) on GP contacts by the elderly.

**Methodology:** The study relied on data from the Belgian Health Interview Survey of 1997, 2001 and 2004. Data of 7414 respondents aged 65 and over were analysed to examine the differences in GP contacts in the last two months in relation with BMI.

**Results:** There are significant differences in GP contacts by BMI category. Of the elderly with a BMI 20-25; a BMI < 20 and a BMI > 25, 69.4%, 75.5% and 76.6% ( $p=0.000$ ) had a contact with a GP, respectively. After controlling for age, gender, chronic diseases and functional limitations, elderly with a BMI > 25 had a 1.6 times higher odds of contact with a GP than elderly with a BMI 20-25 ( $p=0.000$ ). The impact of BMI on GP contacts differed according to functional limitations. Among the elderly with no functional limitations, people with a BMI < 20 had 1.2 times more contact with a GP ( $p=0.000$ ) and people with a BMI > 25 had 1.7 times more contact with a GP ( $p=0.000$ ) than elderly with a BMI 20-25.

Moderately limited elderly with a BMI < 20 had less GP contacts (OR 0.80;  $p=0.000$ ) and those with a BMI > 25 had 1.3 times more GP contacts ( $p=0.000$ ) than those with a BMI 20-25. Of the severely limited, elderly with a BMI > 25 had 2.1 times more GP contacts ( $p=0.000$ ) and elderly with a BMI < 20 had 1.04 times more GP contacts ( $p=0.005$ ) than elderly with a BMI 20-25.

**Conclusion:** There is evidence of significant differences in GP contacts by the elderly in Belgium according BMI-group, even after controlling for age, gender, chronic diseases and functional limitations.

## **Determinants of the place of death in the Brussels metropolitan region**

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**Objectives:** To examine the factors influencing home death and care home death vs. hospital death, for all natural deaths and for cancer deaths only, in the Brussels metropolitan region. To compare place of death in Brussels with metropolitan Antwerp and the rest of Flanders.

**Design:** Analysis of population based death certificate data and health care supply data.

**Setting:** Metropolitan regions of Brussels and Antwerp and the region of Flanders (2003).

**Subjects:** Natural deaths in the metropolitan region of Brussels (N= 9530), Antwerp (N=5213) and the rest of Flanders (N= 49063).

**Main Outcome Measures:** Percentage of home death, hospital death and care home death. Odds ratio's for home death vs. hospital death and care home death vs. hospital death, adjusted for clinical, social-demographic, residential and local health care system factors.

**Results:** In Brussels, 17.2% were home deaths; 56.7% hospital deaths and 25.4% care home deaths. Home death was less likely for people suffering from hematologic malignancies and acute lower respiratory infections, who are older and living in low SES districts, and for single cancer patients. Care home residents suffering from diseases of the nervous system or heart diseases were more likely to die in the care home if they were at an advanced age, married and lived in a district with high SES and higher availability of skilled nursing facility beds. Cancer patients living in Antwerp or Brussels were more likely to die in a hospital, compared to the rest of Flanders.

**Conclusions:** In Brussels, the cause of death is most predictive for the place of death. However, people living in a prosperous community, married or living in a household, are more likely to die in their familiar surroundings. Availability of skilled nursing facilities seems to decrease the likelihood of care home residents being transferred to a hospital at the end of life. End-of-life care quality in metropolitan regions requires more attention, in particular in backward districts.

## Characteristics of palliative patients in homes for the elderly

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**Introduction:** Up till today there is only little information available about the palliative care of patients in the homes for the elderly in Belgium. The aim of this study is to describe the palliative indications, treatments en problems among palliative patients in the homes for the elderly.

**Methods:** The results were collected between September 2000 and March 2007 in five homes for the elderly in Brussels. All patients who were considered palliative in their medical record were included. In a questionnaire the palliative indications as well as the medication during inclusion and at the end-of-life were included. Thereupon the problems during palliative care were recorded.

**Results:** In total 120 patients (61% women) were recorded. The median age at the moment the patients were considered palliative was 80.3 year. The median age at death was 81.9 year. The average time between the start of the palliative care and death was 8.7 week (median 2.1w).

Sixty percent of the patients had a neurological disease (38% Alzheimer, 8% another dementia). An evolutive carcinoma was present in 28% of the patients, a cardiovascular disease in 13%, a pulmonary disease in 11% and another disease in 8%.

At the moment the patients were considered palliative, 56% received painkillers, 20% had a venous catheter, 9% an urinary catheter, and 5% a gastric tube. At the end-of-life, 83% received pain killers, 25% had a venous catheter, 11% an urinary catheter and 6% a gastric tube.

The most common problems during end-of-life care were: pain (38%), respiratory problems (35%), nutrition problems (21%), skin problems (16%), infections (9%), urinary problems (6%) and psychological problems (4%).

**Conclusion:** Half of the patients die within two weeks after they were considered palliative. Neurological diseases and evolutive carcinoma are the most common palliative indications. Pain and pain treatment are the most common problems encountered.

## Mortality of Bereavement

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We researched the mortality of bereavement using longitudinal data (Changing Lives of Older Couples Study) from a cohort of 1227 initially married (never widowed) elderly individuals. Risk for mortality was examined in a series of survival analyses (6 and 12 months following loss of spouse) among 225 individuals who became widowed during the study time (5 years). We examined whether widowhood affects the risk of mortality for the recently bereaved and the extent to which factors such as age, gender, income, education, instrumental support provided and received, emotional support within the marriage, marital satisfaction, religious involvement mediate the risk of mortality following bereavement while controlling for race, physical health, mental health, and financial stress.

The risk for mortality following bereavement was:

- (1) higher for widowed than married persons;
- (2) higher for widowers than widows;
- (3) highest during the first 6 months of bereavement and higher in the first year of widowhood compared to the period after 12 months;
- (4) higher for the widowed under 70 years of age compared to those 70 years of age and older;
- (5) higher for the widowed in a low income group (<\$20,000 vs. > \$20,000 annually);
- (6) higher for the widowed with less emotional support within the marriage;
- (7) higher for the widowed with higher levels of religious involvement;
- (8) higher for the widowed with lower levels of marital satisfaction.

This supports previous findings that individual reactions to bereavement vary widely and that certain categories of bereaved elderly are more at risk for negative outcomes. If those who have frequent contact with individuals facing the death of a spouse and recently bereaved become more aware of these risk factors through their own training or public health education programs they may be better able to assist elderly bereaved individuals and prevent some bereavement related mortalities.

## Medical end-of-life decisions in Belgian pediatric intensive care units: nurses' involvement and attitudes

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**Objective:** End-of-life decisions with a possible or certain life-shortening effect (ELDs) occur at pediatric intensive care units (PICUs). It is, however, not clear how nurses are involved in those decisions. The aim of this study is to investigate to what extent nurses are confronted with ELDs and involved in the initiation, decision-making and implementation, and to explore their attitudes towards those decisions.

**Method:** Anonymous questionnaires were distributed to all nurses working at five of the seven PICUs in Belgium (N=141). Nurses were asked to recall the most recent child they have cared for and for whom an ELD had been taken, and to describe their role. Attitudes were asked by means of statements and using a Likert-scale.

**Results:** Response rate was 63% (N=89). Most nurses (86%) had cared for a child for whom an ELD was taken. Nurses initiated the decision in 17%, participated in the decision-making in 50%, and had a particular role in the implementation in 90% of all ELDs. In 61% nurses were involved in the administration of life-ending drugs with the physician's presence and in 31% without the physician's presence. Few nurses (6%) would not participate in any form of life termination in children and most nurses (78%) were prepared to cooperate in the administering of life-ending drugs. The majority of nurses (89%) was also in favor of an adaptation of the law, making termination of life legally possible in some cases.

**Conclusions:** Belgian PICU nurses are often involved in the implementation of ELDs, even in administering life-ending drugs, while their participation in the decision-making process is rather limited. They think life-termination among terminally ill children must be possible and legally regulated in certain circumstances. Given their crucial role, those nurses should be involved more actively in the discussion about these decisions.

## **Palliative care in hospitals: a multidisciplinary approach**

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**Introduction:** After evaluation of the palliative care practises in Dutch hospitals by Agora, it became clear hospitals are struggling to develop the best palliative care possible. Various initiatives are being taken throughout the Netherlands leading up to a practise known for its diversity. There is no question palliative care requires a multidisciplinary work field and therefore would benefit by a multidisciplinary guideline. A best practise based guideline is indispensable in choosing the best way to implement a fitting structure regarding palliative care in any particular hospital. Target area's are: transfer of terminal patients, casemanagement, interventions and palliative terminal care in hospitals.

**Aim:** By integration of the various initiatives into a guideline, hospitals receive a tool to test and adapt the quality of their palliative care practices. Implementation of this guideline enables hospitals to deliver the best qualitative palliative care available.

**Research question:** How can a multidisciplinary guideline contribute to the best palliative care a hospital can provide?

**Methods:** Agora, the Dutch national support centre for palliative care gathers representatives of various disciplines together to develop a 'best practise based' guideline. This in alignment with current government policies regarding best practices. The various initiatives hospitals take will be reduced to models and described in a multidisciplinary guideline. This guideline supports hospitals in developing palliative care policies, providing best end-of-life care possible, improving quality of live and diminishes costs. A multidisciplinary taskforce has been initialized and a multidisciplinary expert team will follow. Purpose will be: development support, determination of quality criteria and guideline implementation aiming at enhancing broad support for a multidisciplinary approach to palliative care.

**Results:** Momentarily a further analysis regarding the different initiatives takes place to visualize how the target area's fit in different models. Results of this analysis will be available shortly after summer.

## **Ethics policies on euthanasia in hospitals - A survey in Flanders (Belgium)**

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**Objective:** To determine the prevalence, development, stance, and communication of written institutional ethics policies on euthanasia in Flemish hospitals.

**Methods:** Cross-sectional mail survey of general directors of all hospitals (n=81) in Flanders, Belgium

**Results:** Of the 81 hospitals invited to participate, 71 (88%) completed the questionnaire. Of these, 45 (63%) had a written ethics policy on euthanasia. The Belgian Act on Euthanasia and centrally developed guidelines of professional organisations were the most frequently mentioned reasons for and sources used in developing ethics policies on euthanasia in hospitals. Up to one-third of hospitals reported that they developed the policy upon request from physicians or nurses, or after being confronted with a euthanasia request. Development and approval of institutional ethics policies occurred within a multidisciplinary context involving clinicians, ethicists, and hospital administrators. Euthanasia was permitted only in exceptional cases (in accordance with legal due care criteria and additional palliative care procedures) in 75%, 57% and 50% of hospitals in case of competent terminally ill, incompetent terminally ill and non-terminally ill patients, respectively. Euthanasia was not permitted in 2%, 23% and 32% of hospitals in case of competent terminally ill, incompetent terminally ill and non-terminally ill patients, respectively. Private Catholic hospitals, in particular, were more likely to be restrictive: euthanasia is not permitted or is permitted only in exceptional cases. Of hospitals, 91% and 82% took the initiative to communicate the policy to hospital physicians and nurses, respectively.

**Conclusions:** Since the enactment of the Belgian Act on Euthanasia in 2002, the debate on how to deal with euthanasia requests has intensified in Flemish hospitals. The high prevalence of written institutional ethics policies on euthanasia and other medical end-of-life decisions is one possible outcome of this debate.

## **Bereavement support group can be benefit for parents who experience the death of a child**

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Pediatric care in oncology and in particular palliative care for children have been improved to provide better support and attention to the child and its family. However, after the child death, numbers of parents claim a feeling of progressive isolation and growing difficulties when sharing their pain with others who have not experienced child mourning.

Several bereavement support groups exist already in Belgium as in other European countries. But those groups gather families with various experiences such as teenager suicide, sudden accidental child death or chronic degenerative diseases. In our pediatric oncology center, care givers and families identified the need of a support group exclusively focused on parents that lost a child with cancer disease. Based on the parent apprehension of going back in the pediatric hospital or of meeting again the team who treat their child, this support group has been organized under the supervision of two independent psychologists. The mother of a deceased child has joined the organizer team. The group meets every 3 months and happens in a neutral location outside the hospital. The psychologists attend to create a climate of respect and security but in any case they act as therapists. Their role is also to allow everyone to speak without taboo. The place of the deceased children is central and they are symbolically represented by a photo brought by the families. The success of this support group confirms our postulate that there is not a single way to resolve his grief. Rather than counseling, sharing can be benefit for parents who experience the death of a child.

## Dying at the place of wish: results from the SENTI-MELC study

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**Aim:** As primary caregiver, the general practitioner (GP) can play a key role in honouring the patient's wishes at the end of life. We investigated how well GPs are informed about the patient's preference for place of death and the congruence between the preferred and actual place of death. In Belgium, reliable data on this subject are lacking.

**Methods:** A one-year nationwide mortality follow-back study in 2006 in Belgium. Data were collected within the SENTI-MELC study – the study on Monitoring end-of-life Care via the nationwide Sentinel Network of GPs. All GPs reported weekly, via a standardized registration form, every deceased patient in their practice (>1 year). For all non-sudden deaths, the GPs were asked what the preferred and actual place of death was, and who had informed them.

**Results:** The 174 GP practices registered 818 non-sudden deaths. The GP was informed about the patient's preference for place of death, in 45.6% of the cases. If informed, the GP obtained this information directly from the patient in 62.6% of the cases. More than half (59.7%) preferred to die at home, 30.7% preferred to die in a care home and 9.7% in a hospital or palliative care unit. Overall, 81.5% of these patients died at the place of their wish: 71.8% for home deaths, 92.9% for deaths in a care home and 100% for deaths in a hospital or palliative unit.

**Conclusions:** Although communication about patients' preferences is an important prerequisite to achieve 'a good death', GPs are often unaware of their patients' preference for place of death. However, if GPs are informed, patients very often die at their place of wish. These findings emphasize the importance of timely discussion about patient's wishes and the crucial role of the GP in the management and coordination of care at the end of life.

## **Determinants of poor self rated health in a population of elderly people: results of a Belgian survey**

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**Objectives:** To identify medical, behavioural, and socio-demographic factors associated with poor self rated health (SRH) among elderly.

**Methodology:** The results are based on observations of the “Quality of life after 65” study carried out as a follow-up study among participants of the “Belgian Interuniversity Research on Nutrition and Health” (Belgium 1979 – 1984; random sample stratified by age and gender) aged 65 years or more on 1st January 1994.

Two questionnaires (one self administrated - one administrated by an investigator) were completed by 2184 (1002 women – 1182 men) non institutionalised subjects (65 – 92 years).

Poor (fair – bad – very bad) SRH was studied in both genders separately, according to socio-demographic data, smoking status, morbidity, functional and cognitive status, and social support.

**Results:** Poor SRH is reported by 36,3% of women and 28,8% of men.

Independently of age (except for instrumental activities of daily living), women consume more medications, present more chronic diseases, more cognitive disorders, and more difficulties in activities of daily living and in mobility; whereas men report more difficulties in instrumental activities of daily living and were more often hospitalised .

If low education is associated with poor SRH in both genders, the association with age and marital status (widowed women have the highest risk) is seen for women only. Morbidity and low functional and cognitive status are associated with poor SRH in both genders. Low social support is associated with poor SRH in both genders.

All these associations are statistically significant ( $p < 0.05$ ).

**Conclusion:** This study confirms the links existing between poor SRH and chronic morbidity and disability, and brings new paths of understanding by outlying the importance of social support when considering the health and well-being of elderly and the existence of social inequalities in health (measured by education) in this population.

**Continuous care of children at home:  
Pilot experience in the French community of Belgium**

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Improving the quality of life of infants and children living with life-threatening or terminal conditions and their families remains a goal in our society. In 2002, a network between the French Universities was developed to try to provide equitable and effective support for curative, life-prolonging, and palliative care for children with severe diseases at home. We report the activity of the three paediatric nurse's teams during two years. 260 children (mean age of 2 years) were enrolled during this period. 53 children suffered from cancer or malignant blood diseases, 134 were followed for severe neurological and/or metabolic diseases and 73 had other conditions like cardiac malformations, chronic diseases (renal, digestive ...). They lived in the different French areas of the country. The nurses performed 93536 km and 6081 telephone calls were reported.

During this period, 2870 visits (1381 at the hospital and 1489 at home) were performed by the paediatric nurses to the children. The goal of these visits concerned: evaluation and management of a symptom, dissemination of pharmacological and non-pharmacological treatments, education of home nurses and supportive care of the child and his family. Practical aspects included also oxygen or pumps delivery. 2305 meetings were necessary to follow these children: organisation of the care at home, contacts between the health professionals, and discussions about the treatments.

54 children died. 26 of them died at home. In all the cases, the parents recognised the benefit to be at home during the disease and the end of life of their children.

This experience is innovative in Belgium. The paediatric nurse's teams were able to assume an important link between hospital, home and institutions and strongly improve the quality of life of the children, their families and the health professionals.

## Physicians' labeling of end-of-life acts: a study of hypothetical cases

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**Introduction:** In the Netherlands, physicians are legally allowed to perform euthanasia, which is defined as the administration of drugs with the explicit intention to end life at the patient's request. Physicians are required to report cases of euthanasia or ending of life to judicial authorities in order to increase transparency. However, sometimes difficulties arise in distinguishing between euthanasia and the alleviation of symptoms with hastening of death as potential side effect. We investigated which factors contributed to physicians' labeling of an act as euthanasia or ending of life.

**Methods:** In 2006, questionnaires were sent out to a random, stratified sample of 2100 Dutch physicians (response rate: 56%). Physicians were randomly presented three cases out of 47 pre-constructed cases that varied according to the (1) type of medication, (2) the physician's intention, (3) the kind of patient request, (4) the patient's life expectancy and (4) the time until death. Physicians were asked which term described the act in the presented case best. Logistic regression was done to assess the relative importance of each characteristic for the physicians' choice.

**Results:** The factors that contributed most to physicians' labeling of cases as euthanasia or ending of life were the administration of muscle relaxants (odds ratio=264,  $p=0.00$ ) and the administration of disproportional morphine (odds ratio=4.8,  $p=0.00$ ) as compared to cases labeled as symptom alleviation or palliative sedation. Other significant predictors were an intention to hasten death and a life expectancy of a couple of months.

**Conclusion:** The use of muscle relaxants is by far the most important factor that contributed to physicians' label 'euthanasia or ending of life'. However, other factors seem related to their labeling as well. These factors demand attention and reflection in the debate about which end-of-life decisions should be legally evaluated.

## **ADL dependency and dementia were determinants of survival**

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**Background:** The Qualidem study investigated the use of standardized assessment instruments for determining the need for care and its evolution in people with and without dementia in primary care and nursing homes. An important proportion of study subjects died during the follow-up.

**Objectives:** To determine the contribution of dependency in activities of daily living (ADL) and the dementia status on the survival of older people in primary care.

**Methods:** Prospective cohort study using annual follow up during three years. ADL dependency was measured using the Belgian evaluation scale for home care nursing and nursing homes. A three stage diagnostic procedure using simple ADL and instrumental ADL assessments, the Mini-Mental State Exam and the CAMDEX-R was used for the diagnosis of dementia. Kaplan-Meier survival curves were compared using the Wilcoxon test and the Log-Rank test and Bonferroni correction for different levels of the combination of the dichotomized dependency level and the dementia status: dependency or no dependency and dementia or no dementia.

**Results:** Of the 1321 study subjects, 538 (40.7%) died between 1 October 2001 and 31 December 2004. Univariate analyses demonstrated that Kaplan-Meier survival curves were significantly different, both for different ADL dependency levels and for subjects with or without dementia. When the dichotomized dependency level and the dementia status were combined into one variable with four levels, Bonferroni correction demonstrated that there were three significantly different survival curves: no dementia and no dependency; dementia and no dependency; dementia or no dementia and dependency. Follow-up until 25% of the subjects in these three levels died was respectively 31 months (95% CI: 38 – missing), 26 months (95% CI: 18 – 30), and 17 months (95% CI: 15 – 18).

**Conclusion:** Survival probability was mainly determined by ADL dependency. In subjects with low ADL dependency, dementia was a strong determinant of survival probability.

## **Patient participation in medical decisions at the end of life: a study protocol**

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**Background:** Health care provision and decision making become more and more patient centered. This is reflected in deontological, legal and societal changes. The physician is no longer seen as the person who knows best, but as the person who informs and supports the patient. Hence, models of “shared decision making” are preferred above the paternalistic model. However, it can be questioned whether all patients want to be informed and participate in medical decision making. This study longitudinally examines: 1. the preferred versus actual information and participation level of terminally ill patients and 2. the effect on the outcome-measures quality of life (i) and satisfaction with the decision-making process (ii). The presentation will outline the study design.

**Methods/design:** During a one year period, pneumology physicians in 3 university hospitals and 12 general hospitals in Belgium ask consecutive patients with an initial diagnosis of non-small cell lung cancer stage IIIb or IV to participate in the study. Subsequently, patients who give their informed consent are interviewed every two months by trained interviewers until the patient dies or until one year after inclusion. The questionnaire consists of self-developed instruments on the basis of literature (information and participation) and internationally validated instruments: QLQ-C15-PAL (i), ACSA (i), and COMRADE (ii). The interviews are audio taped enabling follow-up of the interviewers. The study also has a prospective part: when the patient dies, the hospital physician and general practitioner fill in a questionnaire on implemented end-of-life-decisions and quality of death. Data collection started in February 2007 and will continue until January 2009.

**Discussion:** Longitudinal designs are scarce in end-of-life research. On June 15th 2007, 51 patients of an intended 100-150 were included in the study. Major challenges in this study are the motivation of caregivers, the recruitment of patients and the ethical aspects of involving vulnerable patients.

## Quality Indicators for palliative care: a systematic review

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**Aim of the study:** Get an overview of quality indicators developed for palliative care

**Methods:** Studies were identified by searches in Medline (1966-March 2007), PsycINFO (1967-March 2007), EMBASE (1966-March 2007) and CINAHL (1982-March 2007). We combined keywords and medical subject headings for palliative care with keywords and medical subject headings for quality indicators. The citations we found were screened on relevance for our study by two reviewers independently. We included citations when the main focus of the publication was the description or development of quality indicators (or measures) especially for palliative care. A single quality indicator was included in the study when a numerator and denominator were defined for outcome indicators or when a performance standard was given for process or structural indicators.

**Main results:** The Medline search identified 310 potential useful references. Additional searches in PsycINFO, EMBASE, CINAHL (in this order) identified respectively 206, 22 and 42 additional publications. Out of these 580 publications, 21 seemed to fulfill the selection criteria based on title/abstract and 12 fulfilled the selection criteria based on reading full text of these publications. Reference tracking of these publications did not result in additional publications. These references contained 1 review focussing on quality indicators for symptom management in palliative care and 6 sets of quality indicators: 2 concerning palliative cancer care, 1 concerning ICU end-of-life care, 1 concerning vulnerable elderly in end-of-life care, 1 concerning palliative nursing home patients, and 1 concerning home palliative care. In total about 100 (partly overlapping or similar) indicators were found, which covered all aspects of palliative care (physical, psychosocial, spiritual and general). The majority of the indicators concerned the process of palliative care.

**Conclusions:** Quality indicators are available for assessing quality in palliative care. Most indicators concern the process of care and only a few measure the outcome of care.

## Attitudes of Flemish secondary school students towards end-of-life decisions

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**Aim of the study:** In Belgium, inequalities exist in minor and adult patients' rights in end-of-life decision-making (e.g. minors cannot legally request euthanasia, even when competent). The study aimed to investigate the attitudes of minors towards acceptability of end-of-life decisions with a possible or certain life-shortening effect (ELDs) in minors, including non-treatment decisions (NTD), potentially life shortening alleviation of pain and symptoms (APS) and euthanasia.

**Methods:** Randomly selected second and fourth grade-pupils, aged 12 to 16, of 20 Flemish secondary schools in the academic year 2000-2001 completed a questionnaire, assessing their attitudes towards acceptability of requests for ELDs by 5 minor patients. All five cases included an explicit request for an ELD, by a 14 year old patient suffering from chronic disease. Type of suffering (pain, loss of dignity or deterioration of capacities), prognosis (terminal vs. not terminal) and nature of the painfulness (reversible vs. irreversible) were varied. In a sixth case, participants were asked about right and willingness to know about terminal prognosis.

**Main results:** 1769 pupils participated (52.6% female). Overall, acceptance was highest for NTDs, varying from 60% (not terminal, reversible suffering) to 69% (terminal, irreversible suffering). APS was acceptable for 49% (not terminal, irreversible suffering) to 59% (terminal, irreversible suffering) of participants. Acceptance of euthanasia varied from 17% (not terminal, irreversible suffering), to 37% (not terminal, reversible suffering), to 60% (terminal, irreversible suffering). 78.3% of participants would like to be informed about terminal prognosis when faced with a similar situation, while 90% think the minor patient has the right to know.

**Conclusions:** Minors find NTD and APS more acceptable than euthanasia. Acceptability of ELDs varies with case characteristics, with greater support for ELDs in terminal situations with irreversible suffering. The results demonstrate considerable acceptability by minor patients of autonomous end-of-life decision-making. Public health policy should continue to develop frameworks to improve and monitor autonomy of minor patients.

## Assessing the performance of meta-analytic methods and the continuity correction values on rare events data

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**Aim of the study:** Perinatal mortality (PM) is one of the rare events which some of its outcomes lead to zero counts. Due to the rareness of PM and the zero counts, the application of relative measures of effect, odds ratio (OR) may be difficult without correcting for the zero counts. The aim of this study is to assess the performance of meta-analytic methods and the continuity correction values using the data on treatment procedures for cervical pre-cancer lesions and perinatal outcomes.

**Methods:** 15 studies were selected for meta-analysis if data were provided on severe obstetrical or neonatal outcomes in women with or without a history of treatment for cervical pre-cancer lesions. Out of these 15 studies, one study was excluded due to total zero counts in the treated and untreated group of women. The continuity correction value  $k = 0.5$ ,  $k =$  the reciprocal of opposite treatment arm size, and  $k =$  value derived from the information from other studies without zero counts in the meta-analysis were applied to correct the zero events in some of the studies. We applied meta-analytic methods: Mantel-Haenszel, inverse variance-weighted, and Peto's methods including classical, and Bayesian approach for pooling OR to investigate the adverse effect of the treatment procedures for preventing cervical pre-cancer lesions in women.

**Results:** The sub-groups pooled results for the three corrections values were similar. For the individual study odds ratio, only  $k = 0.5$  continuity correction gives the least biased estimates. On the meta-analytic methods, there is no much difference in the sub-groups pooled odds ratio across all the treatment procedures. In addition to this, the individual study odds ratio for both the Mantel-Haenszel method and inverse variance method are similar to each other but the Peto's method gives a biased odds ratio. The results from the logistic and the Bayesian approaches give the unbiased pooled odds ratio after controlling for the effect of treatment procedures heterogeneity.

**Conclusions:** None of the three continuity correction values is superior to the other on the sub-group pooled OR. On the individual study OR,  $k = 0.5$  continuity correction outperformed other two correction values. The sub-groups pooled results of the three meta-analytic methods were similar but the Peto's method gives a misleading odds ratio on individual study level. The logistic and Bayesian methods performed well and give unbiased results.

## What do sickness funds claims data tell about healthcare utilization and care pathways at the end of life?

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On average, the highest healthcare expenses in life occur during its last year and especially during the last months. Some of this care might be futile or a hallmark of overmedicalisation.

The **Purposes** of this study are to describe the healthcare utilisation during the last year of life, including the patient's pathway between different healthcare settings, and to analyse the corresponding cost patterns.

**Methods:** The study population is composed of all Mutualité Chrétienne (MC) members, aged 40 or older, who died between July 2005 and June 2006 ( $n = 42,421$ ). The population is described in terms of its sociodemographic characteristics on the basis of available membership and insurance entitlement data.

Healthcare utilisation and care pathways during the year before death are inferred from reimbursement claims, including information on diagnostic and therapeutic procedures, institutional and home care and reimbursed drugs and other care materials.

A matched control population was randomly selected from MC members not having died during the study period. Matching variables were age (5-years categories), sex and arrondissement of residence.

**Results:** The study population is composed of 49% of men and 51% of women; their residence was predominantly (72%) in Flanders; 24% lived in Wallonia and in 4% Brussels, matching the MC membership distribution. At the moment of death, 9% were between 40 and 59 years old, 34% between 60 and 79 and 65% older than 80.

More elaborate descriptive data on healthcare consumption, pathways and cost were not yet available at the moment of abstract submission, but will be presented at the conference.

## **The use of continuous deep sedation for patients nearing death in the Netherlands**

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**Aim of the study:** To study current practices of continuous deep sedation in 2005 in the Netherlands, and compare these with findings from 2001.

**Methods:** In 2005, random samples were drawn from the central death registry of Statistics Netherlands. Reporting physicians received a questionnaire about the medical decisions that preceded the patient's death (response: 78%; studied deaths n=9965). This study was a replication of a study done in 2001 (response: 74%; studied deaths n=5189). Main outcome measures were frequency and characteristics of continuous deep sedation (e.g. drugs used, duration) and characteristics of patients receiving continuous deep sedation (demographics, cause of death, symptoms).

**Main results:** Continuous deep sedation was used in 8.2% of all deaths in the Netherlands in 2005. In 86% of these cases, it was used in conjunction with possible hastening of death. This concerned 7.1% of all deaths as compared to 5.6% in 2001 (OR=1.47, p=0.00). This increase was mostly due to an increased use of continuous deep sedation by general practitioners and clinical specialists, especially for cancer patients (47% of sedated patients had cancer in 2005 versus 33% in 2001). Compared to all non-sudden deaths in 2005, patients for whom continuous deep sedation was used more often suffered from dyspnea (48% versus 31%), pain (42% versus 19%) and anxiety (21% versus 9%) in their last 24 hours of life, despite treatment. Sedation was in 81% of the cases induced by benzodiazepines, in 94% with a duration of less than one week.

**Conclusions:** In end-of-life care in the Netherlands, physicians frequently and increasingly use continuous deep sedation for patients nearing death who suffer from severe symptoms. Further research is needed to elucidate the underlying motives for the use of continuous deep sedation and to study its effects on the quality of dying for patients and relatives.

## Trends in the drugs used for euthanasia and the relationship with notification

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**Aim:** To study how often opioids are used to perform euthanasia in the Netherlands and what the notification rate of euthanasia is in relation to the type of drugs used.

**Methods:** A death certificate study was done in 2005 that was similar to studies done in 2001 and 1995. For the 2005 study, a questionnaire was sent to a sample of 6860 physicians who had attended a death that had occurred from August through November 2005, about the characteristics of the case, the drugs given and possible end-of-life decisions. Response rate: 74%.

**Main results:** The overall notification rate of euthanasia and assisted suicide had increased from 18% in 1990, 41% in 1995, 54% in 2001 to 80% in 2005. The notification rate for euthanasia with opioids however continued to be below 5% in 2005 as it was in 2001 and 1995. The increase in the overall rate was mainly due to an increase in the notification rate of euthanasia with the drugs recommended for euthanasia (barbiturates and muscle relaxants) from approx. 70% in 1995 and 2001 to 99% in 2005, and to a smaller extent to the decrease of opioid use in euthanasia cases from 23% in 2001 to 15% in 2005. Physicians who performed euthanasia with opioids almost never labelled their action as euthanasia (99% of the cases) although they did think that they had hastened the end of life of the patient at his/her explicit request.

**Conclusions:** The overall notification rate of euthanasia and assisted suicide has increased to 80%, but the notification rate of euthanasia with opioids remains very low (below 5%). Physicians who use opioids in cases of euthanasia do not recognize that they should report such cases and remain unaware that they should adhere to the requirements of due care for euthanasia and assisted suicide.

## Legal aspects of written end-of-life care policies in Flemish health care institutions

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**Introduction/Objective:** Although Belgium has certain laws that are applicable to end-of-life decisions (hereafter “ELDs”), at present there exists, except for euthanasia, no comprehensive legal framework (yet) that regulates all legal aspects of the end-of-life decision-making process. Nevertheless, health care institutions are increasingly developing their own internal ELD-policies, going from orally formulated opinions or statements to extensive written practical ELD-guidelines, DNR-protocols, DNR-codes, advance directives, standard consent forms, therapy restriction forms and fully integrated advance care planning mechanisms. This evolution is not only noticeable in hospitals, but also in elderly homes, nursing homes, residential facilities for handicapped patients and home care services.

The aim of this study is to analyse the exact legal scope, status, role and implications of written ELD-policies applied in Flemish health care institutions, as well as their conformity with the existing laws and regulations.

**Methodology:** To study the legal aspects of written ELD-policies, a thorough analysis and evaluation of the existing laws and regulations is conducted, as well as the jurisdiction and jurisprudence in this field.

**Conclusions (with reservation):** Due to the lack of a comprehensive legal framework for the ELD-decision making process, ELD-policies can play an important role in medical liability issues (e.g. in assessing the scope of the right of patients to informed consent or the right of health care providers to professional autonomy). It can be expected that the legal implications of ELD-policies shall increase within the upcoming ‘no fault’ medical liability-system (anno 2008).

Furthermore, a lot of formal and substantive varieties can be noticed among written ELD-policies applied in Flemish health care institutions. These differences have major influences on the legal status of ELD-policies and their implications for medical practice.

Since the study still has to be completed, final conclusions are expected by autumn 2007.

## Euthanasia upon psychic suffering in Belgium

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**Aim:** Since 2002 the Federal Government of Belgium has made the law concerning euthanasia applicable. A yearly evaluation of the application is added. The registration of applied euthanasia shows that the reason for application based upon psychic suffering is extremely rare. The request for euthanasia only for psychic reasons needs specific attention and care. We will analyze in depth two cases from our own practice and enlighten the moments of decision within the therapeutic process of the requestor for help and the caretaker. Both are looking for the answer whether the request for euthanasia is legally admissible and therapeutically acceptable.

**Methods:** Primarily the judgment of the psychic illness and/or disease, according to legal standards, as not curable and serious, causes a lot of problems and urges a specific expertise. We will formulate in the first case the problem as an approach for preventing suicide and a better way of dying with dignity. The second case merges from the request for euthanasia and the original acceptance of this request on to a serious improvement for the patient. Her incurable pain from the start changed into giving a meaning to her life. If this positive evolution perseveres, the question remains if the acceptance of the request for euthanasia was a wrong diagnosis of the prognosis. Or is there a chance that the patient by accepting the quest is touched so existentially that this acceptance causes a change of quality of life? The fundament of this question puts astray the basic attitude of the caretaker of the request for euthanasia.

Concluding, we will plea for a deeper insight into and consciousness of the attitude of the caretakers who act euthanasia in order to approach the end of life with dignity as well as to improve the quality of life of the patient.

## **The legal practice of euthanasia in Belgium and the Netherlands: Notification, control and evaluation procedures**

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**Objective:** To describe and compare notification, control and evaluation procedures for euthanasia in Belgium and the Netherlands and to discuss implications of the most important differences.

**Method:** We studied official Belgian and Dutch documents: legislation on euthanasia, registration forms, reports from the review Committees, and parliamentary documents as a result of debates on the Committee reports.

**Results:** As a means to control whether physicians have satisfied legal due care criteria in case of euthanasia, physicians are required to notify a review committee by means of a registration form. Belgian physicians report each case directly to the Federal Control and Evaluation Committee; Dutch physicians notify the municipal coroner, who in turn notifies one of 5 Regional Review Committees Euthanasia. Dutch physicians, unlike the Belgian, are required to enclose additional documents (e.g. report of consulted physician) when notifying. The Belgian notification procedure is anonymous, whereas the Dutch one is nominative. Unlike in Belgium, the Dutch Committee decisions are made public. In both countries societal evaluation is acquired through committee reports that are debated in Parliament. The Belgian Committee reports directly to Parliament; the Dutch Committees report jointly to the Ministers of Welfare and Justice who in turn report to Parliament. Unlike the Belgian procedures, the Dutch have been scientifically evaluated twice.

**Conclusions:** As the Dutch notification dossiers are more extensive, Dutch Committees dispose of more information than the Belgian one to reach grounded decisions. Due to the anonymous character of the Belgian notification procedure physicians do not receive feedback about Committee decisions in most cases. Dutch physicians do receive feedback. This may have initially caused Dutch physicians to be more reluctant to report, but on the other hand the receiving of feedback and the Dutch Committee decisions being made public can contribute to physicians' understanding of the interpretation of due care criteria and promote quality of the euthanasia practice.

## **End-of-life care and caregivers in Belgium: results from the nationwide SENTI-MELC study**

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**Background:** End-of-life care is a growing public health concern. However, nationwide, population-based data on how care is organized for the dying, have been scarcely gathered. This study describes the end-of-life care goals and caregivers involved in patient care, for a population-based sample of dying patients in Belgium.

**Methods:** We performed a one-year nationwide mortality follow-back study in 2005. Data were collected within the SENTI-MELC study, the study on monitoring end-of-life care in Belgium via the nationwide Sentinel Network of General Practitioners (GPs), an existing epidemiological surveillance system representative of all 10,578 Belgian GPs. All 205 GPs registered weekly every death in their practice. For all “non-sudden” deaths, care goals (treatment aim, treatments, physical/psychosocial/spiritual focus of care) and (in)formal caregivers in the last three months of life were surveyed.

**Results:** For most of the 892 non-sudden deaths, GPs, nurses and informal caregivers were often involved; specialized palliative care in less than half of all cases. For respectively 37% and 47% of the patients, a palliative treatment aim or palliative treatments were present three months before death, increasing to respectively 81% and 82% of the patients in the last week of life. Life-prolonging treatments increased from 31% to 54%. Psychosocial and spiritual care was limited to a minority of patients. Cause and place of death, and region of Belgium were strongly related to caregivers and care goals.

**Conclusions:** For many dying patients in Belgium, palliative care becomes an important component of care when death approaches. However, a transition from an active treatment approach to palliative care is often implemented late in the dying process, or sometimes does not occur at all. Specialized palliative care and psychosocial-spiritual care are often not accessed. The principles of good palliative care are not yet applied for all patients.

Acknowledged: Sabien Bauwens

## **Elderly Moroccan Muslims in Antwerp (Belgium) on End-of-Life Decision Making**

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Islamic End-of-Life decision making remains an under developed research area both in Belgium and in Europe. This exploratory qualitative research (Grounded Theory Methodology) is based on in-depth interview techniques (n=30) with male Moroccan elderly (<60) Muslims living in Antwerp, with local imams, Moroccan GP's in Antwerp and with a Moroccan nurse working in an Antwerp palliative care ward in a hospital setting. We found an extremely dismissive attitude (haram) towards every form of active termination of life: Allah is the only one to decide upon the life of a patient. No human being is allowed to interrupt the divine plan by performing euthanasia or assisted suicide. The majority of our respondents would permit withdrawing or refusal of life sustaining treatment only if every treatment alternative has been tried without cure as a result of this. To them, in case of illness, every Muslim has the duty to look for treatment, treatment being the most important way through which Allah can cure the patient. An important finding is that our interviewees did not regard the withholding of artificial food and fluids as a medical decision: to them it is forbidden to starve a patient to death. From this research we conclude that our elderly respondents share ideas on medical futility that diverge from established Western views and that all type of respondents share the view that 'patience' presents the bottom line to every ethical decision at the end of life. To them, the wellbeing of the patient is central, with an integration of both the physical level – being without pain – and the spiritual level – as shown in the importance of a good relationship with Allah.

## End-of-life practices in the Netherlands under the euthanasia act

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**Aim:** In 2002, an act regulating the ending of life by physicians at the request of a seriously suffering patient came into effect in the Netherlands. We performed a follow-up study of the practice of euthanasia, physician-assisted suicide and other end-of-life decisions.

**Methods:** We mailed questionnaires to physicians attending 6860 deaths that were identified from death certificates. The response rate was 78%.

**Results:** In 2005, the frequencies of euthanasia, assisted suicide and ending of life without an explicit patient request were substantially lower as compared to 2001. The frequency of deep sedation in conjunction with possible hastening of death had increased. Of all 2005 cases of euthanasia and assisted suicide, 80% were reported to the review committees.

**Conclusions:** The decrease in the rates of euthanasia and physician-assisted suicide may have resulted from increased application of other end-of-life care interventions, such as palliative sedation, and a general tendency in the medical profession to attribute opioids less life-shortening potential.

**Workshop:** In the workshop we will further explore several issues:

End-of-life decision making in non-western migrants (see abstract Buiting et al).

Trends in the drug used for euthanasia and the relationship with notification (see abstract Rurup et al).

Policies and guidelines on end-of-life decisions in Dutch health care institutions (see abstract Hanssen-de Wolf et al).

Palliative sedation (see abstract Rietjens et al).

## **Socioeconomic inequalities in lung cancer mortality in Europe. Results from the EUROTHINE project**

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**Objectives:** The objectives of this study are: (1) to describe socioeconomic inequalities in lung cancer mortality in 16 European populations; (2) to explore the magnitude of inequalities in lung cancer mortality in Belgium in comparison with those from other European countries (3); to get further insight into socioeconomic inequalities in lung cancer mortality in different European populations by relating these to socioeconomic inequalities in smoking within the same or reference populations.

**Methods:** Harmonized datasets were constructed in the framework of the EUROTHINE project. Educational inequalities in lung cancer were assessed by direct standardization and calculation of two indices of inequality: the Relative Index of Inequality (RII) and the Slope Index of Inequality (SII). SII's were used to calculate the contribution of inequalities in lung cancer mortality to inequalities in total mortality. Within the age group 40-59 years indices of inequality for lung cancer mortality were compared with indices of inequalities in smoking.

**Results:** In most countries there are important inequalities in lung cancer mortality. Among men inequalities are largest in the Eastern European and Baltic countries, among women inequalities are largest in Northern European countries. Among Southern European women lung cancer mortality rates are higher among the high educated. Compared to other European countries inequalities in lung cancer mortality in Belgium are quite large among men, but rather small among women. Among Belgian men inequalities in lung cancer mortality are much larger than inequalities in smoking. Among women both types of inequalities are of the same magnitude.

**Conclusions:** Continuous efforts are necessary to tackle socioeconomic inequalities in lung cancer mortality in all European countries. Based on current patterns of smoking inequalities, it is anticipated that during the coming decades in some European countries, among which Belgium, inequalities in lung cancer mortality will decrease among men, but will persist among women.

## **Complications in ethical consultation or ethical decision making in nursing homes**

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**Background:** Considering the ageing of the population and the high technological evolutions in health care, nurses are more and more confronted with ethical questions.

**Objective:** The aim of this study is to investigate the experiences of nurses and to discover possible complications in ethical consultation or ethical decision making in nursing homes, particularly if residents have advanced directives or living wills.

Given that interdisciplinary teamwork is a basic value in care, it is important to know if there are conflicting views between professions and also if it is indispensable to understand them.

The final purpose is the development of guidelines to optimise the communication between nurses and physicians.

**Design:** The organisation and the problems in ethical consultation in nursing homes are discussed by means of focus groups with nurses.

Transcripts of these discussions will be analysed using coding categories created from the transcripts. This method allows the active stimulation of the interaction between the participants which results in larger face validity as what is stated by participants can be confirmed, strengthened or rejected by the other participants.

**Participants:** Different criteria are used by composing the focus group, nurses have to work in different nursing homes, they have to have had special education or to have experience with palliative care and/or ethical support, they may not have an executive function and over the last twelve months, they should have been confronted at least with one problematic case of a resident with advanced directives. We selected patients with a question for euthanasia, patients with do-not-resuscitate (DNR) status and patients receiving artificial administration of fluids and food in advanced disease.

We have had to extend the period from three months to twelve months because little residents in nursing homes have advanced directives.

## **Inequalities in alcohol-related mortality by educational level in 16 European populations**

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**Objective:** To evaluate the difference in inequalities by educational level of alcohol-related mortality (alcohol-related diseases and alcohol-related injuries) between 16 European populations covering the North, Continental, South, East and Baltic region.

**Methods:** Data on mortality (ages 30-79) were obtained from 12 European Member States, 2 regions (Basque Country and Madrid) and 2 city-wide mortality registers (Barcelona and Turin). Data from 11 populations were from a longitudinal design. For Czech Republic, Estonia, Hungary, Lithuania and Poland only unlinked cross-sectional data were available.

Alcohol-related mortality was defined following the National Institute on alcoholabuse (US) definitions. The socio-economic position of the individuals was defined by the highest educational attainment following the ISCED classification.

Data were analyzed stratified by gender for each of the 3 alcohol-related mortality causes. Age-standardized mortality rates were computed using the EU-standard population. Via Poisson regression, the Relative Index of Inequality (RII) and Slope Index of Inequality (SII) was estimated as a summary of the relative and absolute magnitude of the socio-economic inequalities in alcohol-related mortality.

**Results:** Large socioeconomic inequalities were observed. Differences were more pronounced in males, ranging between 2 and 5 with 2 outliers (Hungary (6.0) and Czech Republic (8.6)), whereas in females the RII range is between 1.3 and 4.4. The highest RIIs were observed in the East and Baltic Region and among males also in Switzerland. The pattern of the RIIs in alcohol-related mortality and alcohol-related injuries was similar but the inequalities in alcohol-related injuries were in most countries smaller.

The contribution of the socioeconomic differences in alcohol-related mortality in man to the overall mortality inequality was substantial. Only in 4 of the 16 populations it was lower than 10% and in 6 of the 16 populations it was at least 15%. Large contributions were observed in

populations with both large and with small SII's. In women, large % contributions (> 10%) were observed in Slovenia, Hungary and the Baltic region but also in Basque Country.

**Conclusion:** The educational inequalities in alcohol-related mortality were the highest in the East and Baltic region. The observation that the contribution of alcohol to the overall mortality inequality was also substantial in populations with small alcohol-related differences in mortality may challenge the claimed beneficial impact of alcohol on mortality.

## Continuity of (end of life) care by Hospital Support Teams (HSTs) in Flanders (Belgium)

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**Background:** HSTs are regulated by law and are an important form of Palliative Care (PC) provision in Belgium.

Little is known about the views held by HST-professionals on the policies of care for the terminally ill. We looked at the HSTs and the views held by their staff on PC, palliative medicine (PM) and terminal care (TC). Objectives are to provide representative conclusions for HSTs in Flanders about the number of employees and their profession, organization of care, activities and views on PC, PM and TC.

**Methods:** A postal survey was conducted among the coordinators of all 72 HSTs in Flanders.

**Results:** We compared the legal obligation of  $\frac{1}{2}$  FTE MD, nurse and psychologist per 500 beds and the legally prescribed tasks. 57 coordinators (79.2%) provided us with a representative response.

Only 13% of the HSTs have a sufficient official number of appointed professionals. About 35 to 60% of the professionals (MDs, RNs, psychologists, social workers and others) working in a HST is officially appointed.

Some of the legal obligations are reported to be met by all HSTs: to spread the culture of PC and to advise on PC. 94% report to organize training, 82% is coordinating admission and 76% provides the management with advice on policy.

Other reported tasks are not legally prescribed such as taking care of family (95%), coaching professionals (92%), providing bedside care (84%), coordinating voluntary work (36%), scientific research (22%).

**Conclusions:** Only a minority of the HSTs have a sufficient official number of professionals. Most HSTs show a considerable amount of professional voluntary work and take on more than the legally prescribed tasks.

## A world full of Solace

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### “A world full of Solace”

#### Children and Loss

These two words seem irreconcilable. Losing one’s child is the hardest thing there is, and children are protected from loss. No one wants children to be sad because of loss. And yet...

The question is whether children and loss are not more closely entwined than we adults may think.

Because children do encounter loss.

Monday morning...

Eline (6-years-old) enters the classroom crying: her mother has been hospitalised.

“Teacher, is mommy going to die now?” She’s heard the word ‘cancer’; she doesn’t know what it is, but does feel it’s something serious. Fear, sadness, impotence, anger...

#### ‘A World Full of Solace’

‘A World Full of Solace’ is a package that provides materials and methods that can be used to communicate with children between five and twelve years old about loss. This package is oriented towards a multitude of experiences involving loss that children may encounter (illness, death of a relative, someone missing, loss of an important item, ...).

An overview of the materials

‘Room for Sadness - Dealing with Children in Situations Involving Loss’

Fan of Feelings

The Pocket Book

CD-Rom ‘Loss... Sharing It’

Short film ‘Victor’

Video ‘Testimonies’

Stories/Puppet plays/Poems

These were written especially for ‘A World Full of Solace’ by:

- Stories (20): Jories Denoo and Rien Broere
- Puppet plays (5): Annemie Deschamps
- Poems (15): Geert De Kockere

Art/Thematic Drawings

Music: The music-CD was put together and composed by Jan Goovaerts.

Illustrated Book 'Grandpa Lasts Forever'

Activity Cards

## Monitoring Location of Death Statistics for Canada - Tracking Trends for Public Health

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**Aim:** Timely access to health care has become a key issue in Canada. A past analysis of 20th century Canadian mortality trends and their historical influences revealed the rising use of hospitals until 1994 by dying persons was in large part an outcome of limited community-based resources to assist them when they needed end-stage care. A subsequent study found dying rural Canadians were more often hospitalized, and for longer periods of time, than dying urbanites. Furthermore, most high users of hospitals (78%) in the last 5 years of life were rural residents. The aim of this consecutive project was to examine 1994-2005 location-of-death patterns, a time period initiated by the first year that a decline in hospital death rates were noted.

**Methods:** SPSS analysis of national administrative dataset supplied upon request.

**Main Results:** This current study is seeking to determine if hospital deaths continued to decline, increased, or remained static in select provinces and nationally. Rates will be compared on the basis of decedent age, gender, marital status, death cause, and the degree of provincial rurality identified by the Canadian Rural Partnership (<http://www.rural.gc.ca/>).

**Conclusions:** Provinces with the lowest hospital death rates could be expected to have the greatest need for community-based P/EOL programs –such as case management, informal caregiver support, and formal home care services.