"Society and Future" Programme

Final report - Research summary[1]

RESEARCH CONTRACT: TA/00/34

PROJECT ACRONYM: **ELDPOL**

TITLE: "Medical end-of-life decisions: implications for public health policy"

TEAM (please also indicate the institution and the research unit):

CO-ORDINATOR (if applicable):

PROMOTER(S): Luc DELIENS (VUB) in collaboration with Bregje ONWUTEAKA-PHILIPSEN (VU Medisch Centrum Emgo Institute, NL)

RESEARCHER(S): Reginald DE SCHEPPER, Joachim COHEN, Johan BILSEN, Judith RIETJENS, Reginald DESCHEPPER, Roeline PASMAN, Kenneth CHAMBAERE, Rasper RAUS, Isabelle FRANÇOIS

DATE: 30/06/2011

The purpose of this summary is to present the results of the research on the Internet.

---

[1] See art. 5.5.2 of the research contract.

Links to websites referencing the research team's work on the project

www.endoflifecare.be/ZrL

****

Introduction and objectives

This report contains the results of the research that was conducted in the framework of the ELDPOL study '*Medical end-of-life decisions: implications for a public health policy*' ('*Medische beslissingen rond het levenseinde: implicaties voor een public health beleid*'). The study was commissioned by the Programmatorische Federale Overheidsdienst (POD) Wetenschapsbeleid and aims to make a synthesis of the existing data about equality and inequality and medical end-of-life decisions.

During the last decades life expectancy has steadily increased due to improved living conditions and medical-technological developments. Also in the way that people die there has been a considerable evolution. Whereas people used to die shortly after they got ill, for example as a consequence of infectious diseases, people nowadays die not only at an older age, but often after a longer period of illness. There often comes a moment at the end of life, when patients, families, and professional caregivers are confronted with medical end-of-life decisions (ELDs) that possibly or certainly influence the timing of the patient's death. Medical end-of-life decisions with a possible or certain life-shortening effect are usually classified in three main categories:

(1) *Non-treatment decisions*: the withholding or withdrawing of treatment, taking into account the possibility or the certainty that this will hasten the patient's death;
(2) *Intensification of the alleviation of pain and symptoms* by using drugs (e.g. morphine) taking into account a possible life-shortening side effect or with a co-intention to hasten death
(3) *The use of lethal drugs*.

Lethal drugs can be used at explicit request of the patient or without explicit request of the patient. When lethal drugs are administered at the explicit request of the patient the act is classified as *euthanasia* when the physician administers the drugs and as *physician-assisted suicide* when the patient self-administers the drugs. When lethal drugs are administered without the explicit request of the patient the act can be classified as *life-ending without explicit request of the patient*.

Apart from these practices, we can distinguish the practice of *palliative sedation*, which involves keeping the patient in deep sedation until death.
ELDs occur quite frequently; about one in two deaths in Flanders, Belgium was preceded by an ELD in 2007.

The attention given to ELDs has increased in the past twenty years. At the same time, the attention given to social inequalities in care has also increased in society as well as scientifically. Nonetheless, little is known about social inequalities and ELDs.

This report aims to make a synthesis of the existing data about inequality and ELDs. This comprises a systematic literature review about the prevalence of ELDs in different social groups, a secondary analysis of existing databases, the identification of groups at risk or vulnerable groups with regard to information and ELDs, and a policy study about barriers and needs regarding inequality and ELDs. By so doing, we will try to answer the following questions:

(1) What is the prevalence of ELDs in different social groups?
(2) What are the characteristics of the decision-making?
(3) Which groups are at risk for suboptimal involvement in ELD decision- making?
(4) Which initiatives can improve the quality of medical decision-making at the end of life, and what are the priorities?

Inequalities in medical end-of-life decisions for different social groups: the most important findings

1. The effects of age

- The death of elderly patients is more often preceded by non-treatment decisions compared with younger patients and their lives are more often ended without their explicit request.
- Compared with younger patients, the death of elderly patients is less often preceded by decisions to intensify pain and symptom treatment with a possible life-shortening effect, palliative sedation, euthanasia and physician-assisted suicide.
- The ELD is less often discussed with or taken at the request of elderly patients compared with younger patients.

Elderly patients die in a different medical and social context than younger patients: they are more often lower educated, women, single, and stay in a nursing home prior to their death. They also more often die as a consequence of non- cancer diseases and are more often seen as incompetent with regard to medical decision-making at the end of life.

In our study, some important differences were found in the prevalence of ELDs between older and younger patients. First, the death of elderly patients is more often preceded by non-treatment decisions. Elderly patients often experience different end-of-life trajectories compared with younger patients because of which not all medical interventions at the end of life may be useful for them. As a consequence of the multimorbidity from which elderly patients often suffer, more treatment decisions can be made and thus also non-treatment decisions. The differences that we found might also be related to differences in the preferences between older and younger patients for treatments aimed at improving quality of life versus treatments aimed at prolonging life.

Second, life-ending without the explicit request of the patients occurs more often in elderly patients than in younger patients. This could possibly be related to the fact that elderly patients are more often incompetent at the end of life and thus unable to participate in the decision-making. Alternatively, it is possible that older people put more value on the authority of the physician and trust the physician to make important care decisions for them.
Third, euthanasia and physician-assisted suicide occur relatively seldom in the elderly. Euthanasia is most often performed in cancer patients, while elderly patients are known to die more often from non-cancer diseases.

Fourth, intensification of pain and symptom treatment and palliative sedation are also less often practiced in elderly patients. Younger patients more often suffer from cancer, which causes severe suffering that necessitates the use of opioids in very high dosages. Another explanation could be that older patients are less well able to express their suffering because they are more often incompetent at the end of their lives. It is also possible that they have become used to the suffering because of the symptoms they may have experienced for a long period of time.

The ELD is also less often discussed with or taken at the request of elderly patients compared with younger patients. This is likely related to the fact that elderly patients are more often incompetent at the end of life. Moreover, in elderly patients the physician less often discusses ELDs with the family of the patient, with a colleague physician, a palliative care physician or a nurse.

2. The effects of sex

- In men, death is more often preceded by decisions to intensify pain and symptom treatment, euthanasia, and physician-assisted suicide compared with women.
- In women, non-treatment decisions are more often made.
- Competent women are somewhat more often involved in decision-making than competent men. Most ELDs taken in women are also more often discussed with a caregiver specialized in palliative care and a nurse.

Women generally die at an older age compared with men, but the years that women live longer are often spend in worse health conditions. Women are also more frequently widowed, die more often in a nursing home, are more often lower educated, and more often die of cardiovascular diseases, while men more often die of cancer.

In our study, we found that men and women also differ in the decisions that are taken at the end of their lives. While in men death is more often preceded by decisions to intensify pain and symptom treatment, euthanasia, and physician-assisted suicide, in women non-treatment decisions are more often made.

However, controlled for the effects of age, educational attainment, civil status, place of death and cause of death, the differences between men and women disappeared for the most. This means that the differences between men and women in these variables for the most part explain the differences in ELDs. Civil status and place of death are the most important factors explaining the differences between men and women in end-of-life care. Women more often spend the last phase of their lives in a nursing home than men. It is known that in patients in nursing homes pain and symptom treatment is less often intensified and euthanasia is less often performed, while non-treatment decisions are more often made. Our findings are in line with this.

The decision-making about ELDs also differs between men and women: the physician somewhat more often involves competent female patients in the decision-making than competent male patients. This finding is in line with literature on gender differences in communication in health care. It is known that female patients ask more questions and present more symptoms than men and are as a consequence more often involved in medical decision-making.

Most ELDs taken in women are more often discussed with a caregiver specialized in palliative care and a nurse compared with men. This could be explained by the fact that female patients more often die in a nursing home, where such caregivers are often part of the team of caregivers than in the home situation.

3. The effects of socio-economical position

- Euthanasia and palliative sedation are more often performed in patients with a higher socio-economical position, while life-ending without the explicit request of the patient more often occurs in patients with a lower socio-economical position.
- We found no clear pattern of differences with regard to communication and decision-making.

People with a lower socio-economical position appear to be often in worse health condition than people with a higher socio-economical position. However, based on the analyses of different databases and existing literature we found little significant differences with regard to the prevalence of most ELDs, with the exception of euthanasia and palliative sedation. These practices are more often performed in patients with a higher socio-economical position. Life-ending without explicit request of the patient, on the other hand, seems to occur less often in this social group, while it occurs more often in the group of patients with a lower socio-economical position. There are several possible explanations for this. First, it is known that people with a higher education have more positive attitudes towards euthanasia than people with less education. Second, this difference may indicate differences in the way that patients are involved in medical decision-making and in communication. It is sometimes hypothesized that there are fewer cultural barriers in the communication between physicians and patients in patients with a higher education. Socially skilled and verbally gifted patients would have more chance to have their request for euthanasia granted than patients who miss such talents. Because of the 'power distance' between physician and patient in patients with a lower education it is possible that physicians are more tended to act paternalistically towards this patient group.

We found no clear pattern of differences with regard to communication and decision-making. However, this does not mean that there would be no difference in the way the physician communicates or discusses matters with the patient. This should be further investigated.

4. The effects of cultural factors

- Only palliative sedation is significantly less often performed in foreigners than in Belgians. For the other ELDs the differences were not significant.
- The practice of palliative sedation occurs more often in the French-speaking community of Belgium than in the Dutch-speaking part.

Cultural background influences how people deal with dying. Still, there are little robust data in Belgium about the role of cultural factors in ELDs. Four culturally determined factors appear in the international literature: communication of diagnosis and prognosis, views about patient autonomy, planning of the end of life and attitude towards foregoing of treatments and life-ending.

Data from Belgium suggest that the intensification of pain and symptoms occurs about equally often in Belgian foreigners (ie. persons who live in Belgium but who do not have the Belgian nationality) than in Belgians. Non-treatment decisions are taken only slightly more often in foreigners than in Belgians. The differences for euthanasia and life-ending without the explicit request of the patients are larger, but for all these ELDs the differences are not statistically significant. Palliative sedation is performed significantly less often in foreigners than in Belgians.

Next to cultural differences between natives and immigrants, there are also differences in the prevalence of ELDs between the French-speaking and the Dutch-speaking communities of Belgium, especially with regard to the practice of palliative sedation. Palliative sedation is more often practiced in the French-speaking community. Euthanasia is more frequently performed in the Dutch-speaking community, although this difference is not statistically significant.

Our findings indicate that cultural background can have an influence on the attitudes towards ELDs. It is necessary to develop enough cultural competence in order to adequately deal with the increasing cultural diversity that is also reflected in end-of-life decision-making.

5. The effects of disease

- Euthanasia, physician-assisted suicide and the intensification of pain and symptom treatment occur more frequently in cancer patients than in patients suffering from other diseases.
- Non-treatment decisions occur more frequently in patients with other diseases than in cancer patients.
- Life-ending without the explicit request of the patient and palliative sedation occur equally often in both patient groups.
- Non-treatment decisions and decisions to intensify pain and symptom treatment are more often discussed with cancer patients than with patients suffering from other diseases.

Cancer is one of the most important causes of death in Belgium, as it is in other countries. Because of the specific course of the disease, cancer patients and their physicians may be confronted with ELDs at some time during the illness trajectory.

Euthanasia, physician-assisted suicide and the intensification of pain and symptom treatment occur more frequently in cancer patients than in patients suffering from other diseases. The opposite is true for non-treatment decisions. Life-ending without the explicit request of the patient and palliative sedation occur equally often in both patient groups. It also appears that patients with cancer more often request euthanasia than non-cancer patients and that a request for euthanasia from a cancer patient is more likely to be acceded.

That the intensification of pain and symptom treatment and euthanasia occur more often in cancer patients can be explained by the characteristics of the disease. First, many cancer patients experience severe pain. Second, cancer patients remain competent until very late in the illness trajectory, which makes that they are longer in the opportunity to request euthanasia. It is therefore not surprising that the number of euthanasia performances is higher in cancer patients than in other patients. The question however remains whether apart from the characteristics of the disease, cancer patients have better access to the intensification of pain and symptom treatment, for example because palliative care was first developed for cancer patients and these patients have better access to palliative care in general. Euthanasia may also occur more frequently because the practice is more accepted for cancer patients.

With regard to communication about ELDS with the patients, we found that non-treatment decisions and decisions to intensify pain and symptom treatment are more often discussed with cancer patients than with patients suffering from other diseases. This is probably also related to the fact that cancer patients more often remain competent until late in the illness trajectory compared with patients suffering from other diseases.
The intensification of pain and symptom treatment is significantly more often discussed with the family, a colleague physician and a nurse in non-cancer patients compared with cancer patients. Non-treatment decisions on the other hand are more often discussed with a nurse in non-cancer patients than in cancer patients.

Decisions to perform euthanasia are always discussed with the patient regardless of diagnosis, but are more often discussed with the family in cancer patients than in patients suffering from other diseases.

Conclusions and recommendations

- ELDs that involve the foregoing or withdrawing of potentially life prolonging treatments are more frequently performed in vulnerable social groups.
- ELDs that involve the administration of a drug with a potential or certain life-shortening effect are less often performed in vulnerable social groups.
- The findings regarding life-ending without the explicit request of the patient are less consistent.

Based on the findings from the literature review and the analyses of the databases that were described in this report, we indeed found several differences in the prevalence of ELDs between different social groups. However, we did not find differences that are really alarming. The differences are small and it is not the case that in the more vulnerable groups,certain ELDs are systematically being performed that indicate suboptimal end-of-life care. Moreover, the question of whether or not the differences in ELDs are desirable or not is difficult to answer and depends for the larger part on the preferences of the patients themselves.

Based on our findings we can conclude the following:
First of all, we can conclude that the findings from the systematic literature review are in line with the findings from the analyses of the databases. This means that the situation in Belgium is not quite different to that in other countries with regard to ELDs. However, we have to take into account the lack of data from Walloon. For the death certificate study, only data from Flanders were available. Based on the available data from the French-speaking part of Belgium, we have no reasons to assume that the situation of vulnerable groups differs in the French-speaking Belgian population. However, additional research is required, especially because we found important regional differences in the incidence of ELDs.

Second, we can conclude that ELDs that involve the foregoing or withdrawing of potentially life prolonging treatments (ie. non-treatment decisions) are more frequently performed in social groups that are considered as vulnerable groups in our research: the elderly, women, persons with a lower socio-economical position, or persons suffering from other diseases than cancer.

Third, ELDs that involve the administration of a drug with a potential or certain life-shortening effect appear to be less often performed in vulnerable social groups.
Finally, the findings regarding life-ending without the explicit request of the patient are less consistent. While the literature review shows that these ELDs occur less frequently in vulnerable groups, the analyses for Belgium/Flanders show either no clear difference in the prevalence of these ELDs between vulnerable and less vulnerable groups, or the tendency seems to be that these ELDs occur somewhat more frequently in socially vulnerable groups such as the elderly and persons with a lower socio-economical position. This means that extra vigilance is needed in Belgium and that the underlying reasons why decisions to end life without the patient's explicit request are made need to be further investigated.
The fact that some ELDs occur more and others less frequently in vulnerable groups, however does not say much about the desirability of this. Preferences of patients are crucial in determining whether or not an ELD is desirable or not.

Differences in the preferences of patients offer the first possible explanation for the differences in the prevalence of ELDs. It is for example known that the elderly less often prefer to receive burdensome life-prolonging treatments. When the observed differences are the result of differences in preferences then there are actually no problems. However, we should take into account that even autonomous decisions are always made in a certain context that influences how decisions are made.

A second important factor that can explain the differences that we found is the fact that the communication about ELDs between physicians and patients seems to be different in vulnerable patient groups than in less vulnerable patient groups. First of all, it appears that physicians more often estimate elderly patients, women, and patients with a lower socio-economical position to be incompetent. This implies that these patients are less well able to take part in decision-making and that medical decisions are made by the family and the caregivers based on the presumed preferences of the patient. In the literature there are also indications that the communication between caregivers and the elderly, foreigners, or persons with a lower socio-economical position is less elaborate and less clear, and that there is more ‘power distance’ between the physician and the patient. This leads to the hypothesis that differences in communication between vulnerable and less vulnerable patients lead to the fact that decisions that involve the active involvement of the physician such as the administration of opioids, palliative sedation, or euthanasia are less frequently performed in less emancipated patients. These patients would be less well able to make their suffering and their wishes known or to convince their physician of their needs and wishes.

To conclude, several recommendations are made in the report to improve the quality of medical-decision making at the end of life. These include giving more attention to advance care planning and providing proper education to physicians and other caregivers with regard to communication skills. Furthermore, more attention is needed for continuity of care at the end of life, for optimal financing of care, and for palliative care for patients with diseases other than cancer.

*

* *