How far disability life expectancy could be shortened by End of Life Decisions in Europe

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BACKGROUND

- Health expectancy is an important concept which is widely considered.
- Quantification of its levels and trends in various countries is still a challenge and rely mostly on reliable but global mortality measurements from Vital Statistics.
- Data from successive cross-longitudinal surveys in the USA suggest a more important decline of mortality from the disability state than from the disability-free state implying a slow down in Health Expectancy increase [1].
- End of Life Decision (ELD) is an important field of research not only because it concerns two thirds of the deaths but also because the recent legislations is an attempt to react against a tendency to prolong artificially the length of the most disabled at the price of more disability and deterioration of the quality of life.

OBJECTIVES

Obtaining a statistical view of the ELD practices in European countries is a challenge that has been achieved in 6 countries [2] but was facing resistances in France. A first objective was to persuade physicians as well as health authorities that ELD practices in a catholic country like France could be declared in a survey questionnaire [3]. A second and quantitative objective was to prove that illegal practices like Euthanasia would concern only a few percentage of deaths in France [3] and Assisted Suicides even less.

A third objective was the analyze all deaths certificates in order to define and estimate the number of "end-of-life suicides" which could pretend to assistance if such new law was voted in France.

A final objective was to measure the impact of ELD on the shortening of Disability Life Expectancy.

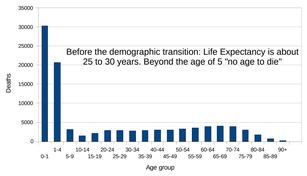
End Of Life a newer concept

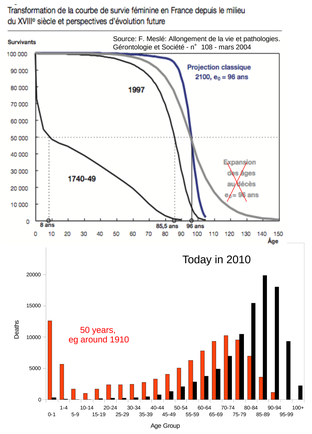
Before the demographic transition, from about -600,000 years up to the end of the XVIIIth century, ie almost 200 years ago, half of the children did not reach the age of 5 but after that age, death could *occur at any age* until the age 60-65 with *equal probability*: there was no 'age to die'. A child was losing his first parent at the age of 14 years. Even more recently, 100 years ago i.e. before the World War I, when life expectancy was 50 years, most people did not 'complete' their life.

Today most people are dying around 85-90, having 'completed their life'. This success is due to the long term medicalization of our societies but hyper medicalization is raising the question of therapeutic obstinacy. The population is going four times less at the cemetery and has forgotten to live with death which now concerns old people only.

A physician is today reluctant to discuss death and possible issues with their patient, sometimes letting nurses doing the job (see figure).

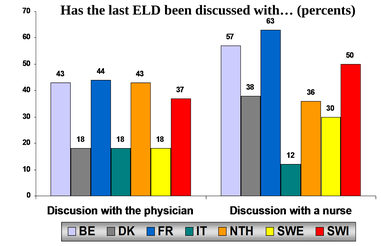
In 200 years only: from a permanent fear of death…to an ever better defined age "to die"

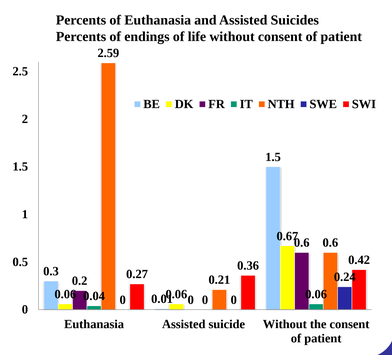




If end-of-life is by definition referring to death, apprehension of death has dramatically changed with the demographic transition and will concern an always smaller age range with the most probable rectangularization of the survival curve. Thus involving continuously new laws to adapt secular views of death to the changing demographic reality.

Results from 7 EURELD surveys: ELD discussions and very rare but most debated issues



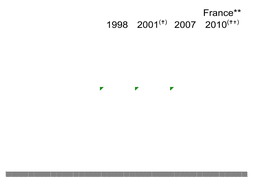


Sources: [2] for Belgium, Denmark, Italy, Netherland, Sweden, Switzerland in 2001 and [4] for France in 2010. Euthanasia (0.3% in Belgium-2001 and 0.2% in France-2010) is defined here by the administration of lethal drugs with the explicit consent of the patient. As administration of drugs is illegal in France, an other definition (see table below) including the other means gives 0.6%.

Medical acts shortening the life

According to the table comparing Belgium and France, an important (48%) and increasing proportion of lives are shortened by medical decisions. 3% are intentionally hastened and 2.6% without the explicit consent of the patient but this proportion is divided by half in Belgium during the 8 years period around the 2001 law which legalized EOL euthanasia.

Euthanasia in France, including not only the administration of life-ending drugs (0.2%) are about 0.6%, i.e. 3000 cases.



End-of-life suicides

We tried to count the number of suicides which could correspond to an end-of-life suicide using all variables that are included in the death certificates: age, sex, marital status, profession, initial cause of death, and associated cause of deaths. They could be around 2000 cases in comparison to 3000 illegal euthanasia.

	Deaths by committed suicide	Mentions
	10456	
No other mention than suicide	4171	
Number of deaths mentioning a suicide	6285	8654

Mental and behavioural disorder	3919
External causes	2778
Disease of the circulatory system	**465**
Disease of the nervous system	**437**
Cancers	**327**
Other causes	**728**
Approximate number of mentions related to a severe illness or disability	**1957**
Total number of mentions	8654

CONCLUSIONS

If end-of-life decisions concern 2/3 of deaths, almost half of them are hastening the death by "withholding or withdrawing life-prolonging treatments" (28%) and "alleviation of pain and symptoms" (19%); but among them, acts which are made with the *explicit intention* of hastening death could concern only 3% (France) to 4% (Belgium) of deaths.

In order to go further and answer the questions on (1) by what amount has life expectancy be shortened in France when the Leonetti law [4] condemning therapeutic obstinacy, was voted in 2005 and (2) how even shorter could DLE be if assisted suicide or euthanasia is authorized in a near future, we can only say that point (2) is affecting very few people but for an *a priori* legal period of maximum of 6 months while the former point (1) already affects a lot of persons, mostly by withholding or withdrawing 'life-prolonging' treatments but without clear quantification to our current knowledge, alleviation of pain having a very short impact.

REFERENCES

[1] Crimmins, E.; Hayward, M. D.; Hagedorn, A.; Saito, Y. & Brouard, N. Change in Disability-Free Life Expectancy for Americans 70 Years Old and Older. *Demography*, 2009, 46, 627-646

[2] Van der Heide A, Deliens L, Faisst K, Nilstun T, Norup M, Paci E, van der Wal G, van der Maas P on behalf of the EURELD Consortium. End-of-life decision-making in six European Countries: descriptive study. *The Lancet* 2003;362:345-350

[3] Brouard N, Aubry R, Monnier A, Pennec S, Pontone S. Dispositif sécurisé de l'enquête sur les pratiques médicales relatives à la fin de vie en France. *Communication at the Soc. Fr. de Statistique* - 16 novembre 2009

[4] Pennec S., Monnier A., Pontone S. Aubry. R - End-of-life medical decisions in France: a death certificate follow-up survey 5 years after the 2005 Act of Parliament on Patients' Rights and End of Life. *BMC Palliative care*, 2012, 11

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