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EVIDENCE on BILL 52: An Act respecting end-of-life care

INTRODUCTION

As former CEO of the Dutch Right to Die Society NVVE (retired) and now Communications Director for the World Federation of RtD Societies WFRtDS, I consider myself as having extensive experience in the field of legalization of assisted dying by physicians. I have been involved in the discussions around the Dutch Euthanasia Bill, right from the moment it was introduced in the Dutch Parliament in 1999, up to its endorsement by the Senate in 2001 and its implementation in 2002 and later evaluations.

I have been in the position to explain to great extents the ins and outs of our law in many countries in the world in general and Europe in particular. My thus built experience has learnt me to understand on one side the impossibility to export Dutch Law to other countries one-in-one (how much our sister societies would like to) because of different cultural and juridical/legal systems, but also on the other side it has taught me that "our" experience (now some 37 years of tolerated and legalized practice) forms a sound basis and even may provide valuable concrete contributions for other jurisdictions to design their own law; to design a system in which – this turned out in The Netherlands to offer the most important effect – the quality of end of life care could be improved, also because the patient had a real choice at the end of his/her life.

COMMENDS

Reading your Bill 52 I want to commend you on the idea to depart from the use of "end-of-life care" as basic principle, incorporating in this term a large number of issues that time and again appear in debates around the world when countries and jurisdictions, fed by public opinion (most polls find large majorities in favor of "aid-in-dying" legalization) start having political and parliamentary debates about it. This Bill incorporates both sides of opposing views when it comes to either palliative care or medical aid in dying (avoiding a difficult defining discussion on terms as euthanasia), and also incorporates issues as patient autonomy (the right to ask for respect of their final wishes) as well as mercy (the legal possibility for doctors to provide professional and humane aid when patients so request).

By pursuing the whole specter of end-of-life decisions in greater depth the Bill rightly prescribes specific requirements and criteria for (terminal) palliative sedation and (medical) aid in dying. Doing so I believe the two sides are and should be considered as a continuum: the one cannot exist without the possibility for the second. Doctor-patient communication and professional expertise in this field will be strengthened by this Bill, in favor of patients at the end of their life and of doctors confronted with the suffering that can accompany the end of such life.

COMMENTS

Of course every Bill – certainly in such delicate and ethical issues as end-of-life decisions - always contain articles and argumentations that can be discussed: a balance between what is felt necessary by one side and what is considered professionally, ethically and politically appropriate on the other has to be found.

Looking at your Bill I want to give the following comments in consideration when you have your Parliamentary debate:

- Is the use of “end-of-life” in this Bill in my opinion positive, evading superfluous and ineffective discussions about whether either palliative care or medical aid in dying should be the only answer to suffering people asking their doctors for aid in their dying, the negative aspect is whether this term is reserved for medical (physical, somatic and psychiatric) conditions only or also includes a non-medical issue as “completed life”. Multi interpretation could lead to a situation in which even well-defined cases may not receive the legal assistance they ask for, because the situation is considered not to be “and-of-life”.
- It is a pity that the text of *Chapter IV, Division I, article 25* does not specifically provide for the application of palliative sedation in acute situations, such as extensive lung bleedings, as the consent of the patient has to be given (even in writing). Discussion about this possibility long before hides the danger in itself to mix the two (palliative sedation and euthanasia) and cause a kind of disturbance the Bill seems to try to evade. In my opinion palliative (terminal) sedation must be seen as medical/professional decision taken – if possible – in communication with the patient or the next of kin.
- *Chapter IV, Division II, article 26* unfortunately covers the medical aid in dying in cases of incurable, serious illness, excluding – as stated before – the criterion suffering in general. It is a pity the Bill did not choose to use the formulations as used in the BeNeLux law (unbearable and hopeless suffering) which have proven to be sound; the autonomy of the patient is covered by the criterion “unbearable”, since it is only the patient that can say a suffering (from whatever illness) is unbearable, while the criterion “hopeless” provides for medical scrutiny. When the two “meet” the situation complies with the (BeNeLux) criteria.
- In the same *article 26* my advice would be to implicitly describe the existence of a request (oral or – when no longer competent – in writing in an Advance Directive) as a precondition to obtain medical aid in dying.

- I agree with the text in *article 28, sub <1.c>*, stressing the importance of communication, not only in time-span, but also in quality. One must be careful this article is not misused in what I would call “delay-attitude”: suggesting the intervals are not spaced enough yet.
- My advice is to change the wording in *article 28, sub <3>*: as consultant it is important to check and assess the diagnosis and ‘treatment’ by the doctor. For this is not necessary to examine the patient as consultant.
- I wonder why a physician providing end-of-life care must give notice to the council of which the physician is a member (*article 33*) and cannot suffice with the reporting to the Special Commission sur les soins de fin de vie (*Chapter V, article 35*) ?

ADDITIONAL COMMENTS

One of the ever returning discussion points when in debate with “opponents” of this choice possibility was the (deliberate?) misuse of the figures on the end-of-life practice in The Netherlands, presented by The Netherlands self. Since 1995 we have produced regular scientifically sound (world renowned statistics!) figures about our practice, repeated more or less every five years, in 2010 for the last time. These figures include amongst others also figures on doctors actions at the end of life of persons, which are against our law then as now (the number of euthanasia case without request, happily misused by opponents); but, these figures have decreased by some 50% since our law was put into force.

People in The Netherlands (as in Quebec) rather live then die, but want to have (and in The Netherlands now are lucky to have) the possibility to ask for medical support when they find the end of their life is inhumane because of futile suffering. The Dutch have since seen no increase in numbers, no increase in misuse (if at all in substantial numbers), no decrease in trust in doctors and all that despite internationally recognized high level of Dutch palliative care! A human being does not ask easily for help to die; the legal possibility to do so facilitates the asking, facilitates the civilized conversation about this last phase of someone’s life and – in my experience – sooner prolongs life than shortens it; prevents ill-considered decisions from desperate humans and leads to better end-of-life care for all, palliative care included!

In no country in the world there is so much openness on medical decisions around the end of life as in the Netherlands. The scientifically well renowned reports of 1990, 1995, 2001, 2005 and 2010 (Remmelink, Van der Wal, Onwuteaka) are statistically sound and show no signs of a slope downwards, let alone a slippery slope:

- a. the absolute numbers of euthanasia and physician assisted suicide have shown to be rather stable, being about 2% of all death cases per year;
- b. the percentage of *reported* euthanasia cases has grown from 18% in 1990 to 80% in 2010;
- c. the same reports even showed the decisions without requests (also in our eyes to be incorrect!) also to dramatically go down from 0,8% in 1990 to 0,2% in 2010 (some of them being termination of the life of severely multi-handicapped new-borns)

- d. since 2001 there was a significant rise in percentage of Palliative Sedation (PS), a development in the opposite direction of that of Euthanasia.

The lessons from the Netherlands can be that legalisation of medical aid in dying (Euthanasia) turned into a better quality of all end-of-life care, a higher level of Palliative Care and a continued high level of trust between doctors and patients.

Now, as WF Communications Director and as webmaster of its website www.worldrtd.net , I regularly see many false arguments reappear, and my big fear is that wrongly used statistics from The Netherlands might be the reason for NOT accepting this Quebec Bill 52. It is in the interest of patients to have real choices and those are only there where and if a legalized possibility is in existence.

Knowing the complexities in this and realizing the limitations of written evidence, I wish you wisdom in your decisions,

Rob Jonquière, MD

WF Communications Director.