MBPSL BECOMES RSPMB

For the second time in its relatively short life, the research group in Groningen has decided to enlarge the scope of its interests, research activities, and documentary collection. In the early, informal years leading up to publication of *Euthanasia and Law in the Netherlands* (1998), we simply called ourselves the ‘euthanasia group’. In 2000, coinciding with the application for a major grant from the Dutch National Science Foundation, we decided to broaden our interests to cover the whole range of medical behavior in which the earlier death of the patient is an expected result: hence ‘medical behavior that potentially shortens life’ (MBPSL). Under that new flag we have, the past few years, been addressing a wider range of medical behavior (in addition to euthanasia and physician-assisted suicide, also abstention, pain relief, advance directives), and have devoted attention to fundamental problems of regulation involved in all MBPSL: legal knowledge and its interpretation among doctors, juridification of the doctor-patient relationship, self-regulation by the medical profession, decisions of courts in ‘hard cases’.

As this period comes to a close with a number of dissertations, we have decided to spread the net still wider and deal also with the regulation of medical behavior which, similarly to MBPSL, is socially problematic, although not because the death of the patient is involved. At the moment there are members of the group working on organ donation and xeno-transplantation, the experimental use of unused fetuses after IVF, the ‘consent model’ and the role of third parties (especially the family of the patient) in medical decision-making, and the problems of ethical decision-making where the fundamental principles at stake are in conflict (and the possible attractiveness of a more casuistic approach to medical ethics). Continuation of our established line of research will take primarily two forms: research by a new PhD candidate – Sofia Moratti – who will be addressing the meaning(s) and function(s) of the concept of ‘medical futility’; and critically following the fourth national research project concerning the practice of euthanasia and its regulation (see below JOHN GRIFFITHS, *The prospect of a new nationwide MBPSL research*). To reflect the broadening of our interests and activities we have renamed the research group: ‘regulation of socially-problematic medical behavior’ (RSPMB).
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Publications
Developments with regard to end-of-life decisions concerning newborns in The Netherlands

EDUARD VERHAGEN1

In the last couple of months the foreign press (especially in Italy and in the UK) has been full of blood chilling accounts concerning a supposedly new practice in The Netherlands of terminating the life of severely defective newborn babies. These account derived in particular from developments in the University Medical Center of Groningen. The following article describes what has actually happened.


The management of newborns with serious incurable medical conditions is one of the most difficult and problematic aspects of pediatric practice. Although technological developments have provided tools to deal with many consequences of premature birth and congenital anomalies, the decision when to start and when to withhold treatment in individual cases remains very difficult. Even more difficult are the decisions regarding end of life measures in infants who have no hope for improvement and lead a life of unbearable suffering that can not be alleviated. Euthanasia has been legally accepted for adults under certain conditions in the Netherlands since 1985. The question arises whether there are circumstances where deliberate life-ending measures can also be accepted in the case of newborns and infants, although these patients cannot express their own will. At present, the decision whether such a life-ending procedure is going to be criminally prosecuted is left to the Committee of Procurators-General. In order to provide them with the necessary information, and to prevent interrogations by police officers, a protocol was developed in our hospital in collaboration with the local prosecutor for cases of deliberate life-ending decisions involving newborn infants.

Current medical practice

Newborns, in whom end-of-life decisions are considered, can be divided into three categories:2,3

- Group 1 consists of infants who will die shortly despite optimal treatment under the present and local treatment modalities. They are infants with an underlying disease, in whom death is inevitable.
- Group 2 are patients in need of intensive care treatment, who can potentially survive after this treatment period, but for whom the expectations regarding the condition they will be in are very severe. They are patients with severe brain abnormalities or infants with severe brain abnormalities or infants

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with extensive organ damage caused by extreme hypoxemia. When these infants survive it will be with an extremely poor prognosis and severe and endless suffering. Children in this category are expected to die when intensive treatment is withdrawn.

**Group 3** consists of patients who are not dependent on intensive medical treatment, but a life of severe and sustained suffering is expected. An example is the child with the most serious forms of spina bifida for whom many operations are indicated. Also in this group are the infants who have survived due to intensive care, but after stopping intensive care treatment it becomes clear that there is a very severe prognosis as to the condition they will be in. One might not have wanted to start treatment if the outcome in these children had been known.

The decision not to initiate or to withdraw life-prolonging treatment in newborns in group 1 and 2 is considered good practice for physicians in the Netherlands. Both the reports of the CAL and the NVK have clearly shown that for neonatologist in the Netherlands, not only survival of the infant, but also the condition in which the child will survive is extremely important. Most infants in group 1 will die immediately after the treatment has been withdrawn. Administering medication to sedate and to alleviate possible pain in newborns of group 2 with the intention to alleviate pain and suffering in the dying phase is widely accepted by pediatricians in the Netherlands and in Europe. However, there are differences in opinion on the appropriateness of such medication when given with the additional intention to hasten death.

In rare cases, pediatricians and neonatologists are confronted with patients who might survive without intensive medical treatment, but where the prognosis for the child is a life full of suffering without hope for improvement. Both parents and the medical team reach the conclusion that death will be more humane than continuation of life for this patient. Under such conditions an adult could ask for euthanasia in The Netherlands. However, newborns cannot ask for euthanasia, and such a request made by the parents is not considered to be legally valid since life or death

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decisions are not part of the legal parental authority.\textsuperscript{10} Does this mean that deliberate ending of the life of a newborn is always prohibited?

**Deliberate ending of life**

Several studies have reported cases of deliberate ending of life in newborns, however details were unknown.\textsuperscript{11,12} Recently, Van de Maas en van der Wal published their second evaluation of the medical practice regarding end-of-life decisions in The Netherlands.\textsuperscript{13} The results were comparable with the 1995 evaluation: the estimated number of cases of deliberate termination of life in newborns was between 10-20 per year.\textsuperscript{14} However, only 3 cases are reported to the prosecutor yearly.\textsuperscript{15} According to the Law on the Disposal of Corpses (Wet op de Lijkbezorging) it is a doctor’s duty to report the death as ‘non-natural’ in cases of deliberate ending of life of a newborn. The doctor informs the coroner, who then informs the district attorney (DA). The DA’s office reviews each case against the applicable laws or jurisprudence. In last resort, it is left to the Committee of Procurators-General to decide if the physician will be subject to criminal proceedings and the Minister of Justice always has to approve the final decision. Two court cases in the mid-nineties have addressed the issue of deliberate ending of life in infants. In the first case doctor Prins ended the life of a newborn diagnosed with an extreme form of spina bifida.\textsuperscript{16} In the second case, doctor Kadijk deliberately ended the life of a newborn with trisomy-13.\textsuperscript{17} In both cases, there was a very limited life expectancy and extensive suffering that could not be alleviated in a medically acceptable manner. In both cases the doctors were acquitted and in their verdicts the courts approved what the doctors had done as meeting the requirements for good practice in deliberate ending of life in newborns. Since then, many organizations including the Royal Dutch Medical Association and the Dutch Pediatric Association have repeatedly pleaded for clear guidelines and multidisciplinary assessment of all cases of deliberate ending of life in newborns. A committee with a


multidisciplinary expertise (medical, legal, ethical) would be more capable of assessing the cases. The willingness of physicians to report to such a committee is expected to be much higher than in the current situation of reporting to a district attorney.

Guidelines for good practice: the protocol

The decision to install an assessment committee and to come forward with guidelines regarding life-ending measures in newborns has not been taken by the government, despite repeated promises dating from as early as 1997. In our institution, a set of guidelines (protocol) was made in 2002, and all cases of deliberate ending of life since then have been reported using these guidelines. The protocol was made in close collaboration between our institution and the district attorney. It includes the requirements defined in the two court cases mentioned earlier, as well as further requirements contained in 22 cases of deliberate ending of life reported to and assessed by the prosecutor since 1997. The requirements of good practice refer to the 5 main elements of both the decision to deliberately end the life and the preceding decision that treatment is futile: the diagnosis and prognosis including the second opinion of an independent physician, the intolerable suffering, the parental consent, the actual ending-of-life-procedure and good after-care. It was agreed with the district attorney that following the ending of life, all the necessary steps would be taken by him to have a decision on criminal prosecution made as soon as possible. Four cases of deliberate life-ending procedure have been reported by our institution, following the protocol, and none has resulted in prosecution.

Conclusion

In extreme situations, deliberate ending of life in newborns can be accepted. In our opinion all cases should be reported and evaluated, preferably by a multidisciplinary committee. We hope that nation-wide use of our protocol will contribute to increase the willingness of physicians to report all cases of deliberate ending of life of newborns.

The project of a new nationwide MBPSL research

JOHN GRIFFITHS

The Dutch Ministry of Health has issued an invitation for the submission of proposals for a new national research project, to take place in 2005 and 2006. While it is on the one hand seen as a continuation of the research first done in 1990 and then again in 1995 and 2002, this time the focus is to be on the functioning of the euthanasia law of 2002 and in particular on the Regional Assessment Committees. The RSPMB group has decided not to submit a formal proposal at this time, but it has presented to the committee responsible for selecting a proposal its views on the questions that should be covered in the new research. These include:

1) A quantitative study of a sample of deaths, to be carried out by the Central Bureau of Statistics as in the past, in order to establish the basic quantitative data on euthanasia and other medical behavior that potentially shortens life. In our view, some changes need to be made in the existing instrument in order
to deal with problems in interpretation of the data in the past (e. g. the ‘grey area’ between euthanasia and pain relief), and some new items need to be added (e. g. on the choice between euthanasia and physician-assisted suicide).

2) A multi-pronged study of the functioning of the Regional Assessment Committees.

3) A study of developments in the frequency of reporting and the development of a model that will permit an annual estimate of that frequency. The problem of distinguishing between false reporting and honest differences in the classification of behavior - to which G. den Hartogh has called attention will have to be solved. Albert Klijn has lead the way in showing how a yearly frequency could be calculated without the need for massive national research.\(^1\)

4) A new evaluation of the functioning of the institutionalized system of consultation (SCEN), in particular to assess the extent to which SCEN might develop into a system for ex ante testing of proposed cases of euthanasia.

5) A study of abstention practice. Abstention accounts for roughly a fifth of all deaths and can raise many of the problems involved in other sorts of medical behavior that potentially shortens life, such as euthanasia. It has so far attracted neither much attention nor much (self) regulation.

6) A study of the actual extent of death due to the use of opiates (for pain relief or for ‘hidden’ euthanasia) and sedatives (‘terminal sedation’).

7) A study of the relationship between euthanasia and physician-assisted suicide.

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**Report on the international symposium on Physician-assisted Suicide held in Giessen, Germany.**

**HELEEN WEYERS**

From 19th to 22nd March an international symposium took place in Giessen, Germany. This symposium, with guests from Germany, Switzerland, Oregon (USA) and the Netherlands, offered an excellent opportunity to get acquainted with the German and Swiss situation with respect to euthanasia and assisted suicide and therefore, John Griffiths and I attended the conference.

The Swiss Criminal Code prohibits killing on request. What is more, the law explicitly prohibits killing on request on compassionate grounds. Assistance with suicide, however, is only punishable if done for selfish reasons. The Swiss right-to-die societies have used this loophole and developed a practice of assistance with suicide, a practice in which doctors play only a marginal role. Although it is a doctor

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\(^1\) G. DEN HARTOGH, ‘Mysterieuze cijfers’, Medisch Contact 2003: 58. (Den Hartogh’s suspicion that classification differences are the bigger part of the problem, and that the rate of honest reporting is closer to 90% than to the 50% that emerged from the national research in 2002, has received important confirmation in D. van Tol’s empirical research in the RSPMB program. An early version in English of Klijn’s analysis of the frequency of reporting is in his article ‘Will doctors’ behaviour be more accountable under the new Dutch regime?’ in A. Klijn, M. Otłowski and M. Trappenburg, ed., Regulating Physician-Negotiated Death, ’s Gravenhage: Elsevier 2001.
who has to prescribe the lethal drug, the person accompanying the patient is a volunteer of a right-to-die society.

In the German Criminal Code, killing on request is prohibited but assistance with suicide is not. At first sight, the German Criminal Code leaves more room for a doctor to help a patient to die than Swiss and Dutch law. However, although assistance with suicide is not prohibited by law, in practice it is legally problematic for at least three reasons. (1) The difference between assistance with suicide and euthanasia is not always clear, and therefore doctors who assist their patients with suicide run the risk of being prosecuted for euthanasia. (2) If the patient unfortunately does not die or the dying process takes an unacceptably long time, doctors’ hands are bound; they cannot put an end to the situation. From the Dutch experiment it is known that such a situation occurs regularly. (3) And finally: the Bundesgerichtshof – the German Supreme Court – made clear in the Wittig-ruling that, after a suicide-attempt, a doctor, even if having assisted the patient, is obliged to try to rescue the life of the patient. This obligation is found in the Garantenstellung, the idea that the doctor is responsible for the patient and therefore has to act. An omission makes the doctor an offender (Wechseltäterschaft). Furthermore, although killing on request is prohibited in both Germany and the Netherlands the German criminal system leaves less room for a doctor because in Germany – by contrast with the Netherlands – in cases of killing on request an appeal to necessity will be rejected. Judges will stress that the duty to respect life dominates other duties, including the duty to relieve pain. Furthermore, it is thought that developments in palliative care make killing on request superfluous and that actively ending a life is not an appropriate way to end the hopeless situation of a patient.1

The conference made clear that countries differ with respect to the choice between assistance with suicide and euthanasia. Without much discussion the Dutch and the Belgians have largely chosen for killing on request and therefore for a bigger role of the doctor. In Giessen, however, the majority of the speakers at the conference took the position that only assistance with suicide would be a possible legitimate option in their countries. Some of the speakers would rather avoid the word ‘euthanasia’ because of its association with the extermination program of the Nazis. This association seems stronger in Germany and Switzerland than in the Netherlands. As in earlier Dutch meetings with German counterparts, it was discussed whether replacing ‘euthanasia’ with other words for example, ‘Freitod’ or ‘Sterbehilfe’, would ease the German discussion. A more fundamental objection to euthanasia entails the doubt whether euthanasia and self-determination fit together. These doubts arise because of the dominant role of the doctor in cases of killing on request. Such a role requires that patients trust their doctors. Visitors at the conference thought that German patients do not trust their doctors as much as Dutch patients seem to do. This failure is partly due to the past and partly caused by the fact that German patients do not have a long-standing relationship with their GPs.

Besides criminal prohibitions, medical ethics is sometimes an important hindrance for physician-assisted death. German medical associations normally take the position that doctors ought not to play a role in assisted suicide: the Bundesärztekammer for example

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calls assistance with suicide "unärtzlich", i. e. inconsistent with what being a doctor basically means. However, only in Bavaria is this view included in the Medical Code of Conduct and, therefore, the only medical disciplinary case on assisted death took place in that region. The Swiss medical association - the Schweizerische Akademie der Medizinische Wissenschaften – is changing its viewpoint. Until recently, the association has taken the position that assistance with suicide is not compatible with medical ethics, but since the beginning of this year, a discussion has been started on a possible softening of this view.

In Germany discussion about the doctor-patient relationship concerns not so much assisted dying as informed consent and advance directives. Many visitors at the conference complained about the ‘medical culture’ in Germany and doctors were described as supercilious. Furthermore, although in Germany medical treatment is only legitimate if the patient consents to it, doctors are said to continue treating patients far beyond their wishes. The requirement that a doctor must treat a patient in an emergency sometimes has as a result that a dying person is taken to hospital for treatment.

In this respect, international research suggests that the Swiss and the Dutch medical attitudes are different from for example Belgium, Sweden and Italy\(^2\) in that death is quite often preceded by a decision not to treat the patient: 20% of all death in the Netherlands and 28% in Switzerland.\(^3\) In both countries hospitals are not the most usual place for dying: 33% of all deaths in the Netherlands and 37% in Switzerland.\(^4\)

Studies in Oregon show that the majority of the people who end their lives with the assistance of a doctor are by and large well-educated and well-to-do patients suffering from cancer. Furthermore, the Dutch and Oregon data show that euthanasia and assistance with suicide are not very frequent and that the numbers are not increasing. Data from the German-speaking part of Switzerland also indicate that the majority of people who are assisted with their suicide are well-educated patients with cancer. To date, the right-to-die society Exit – in the German-speaking part of Switzerland - has helped 748 Swiss to die. The number of Exit deaths tripled from 110 (1990-1993) to 389 (1997-2000) amounting to 0.2% of all deaths on a yearly basis.\(^5\)

Presumably German doctors also help their patients to die. From research in 1996 it is known that 50% of all doctors have been asked at least once by a patient to help him or her to die. Of all doctors, 40% answered that they could approve active aid in dying and 10.5% said that they were familiar with a case of a doctor-assisted dying.\(^6\)

It is believed that in Germany as well as in many other countries, a doctor is not prosecuted even if the authorities are aware of his or her having assisted death. A recent exception to this policy has been the prosecution of a doctor in Hannover who was taken into custody after a colleague called

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\(^2\) Unfortunately these figures come from a research that does not involve Germany (AGNES VAN DER HEIDE et al, ‘End-of-life decision-making in six European countries’ The Lancet 2003: 345-352).

\(^3\) To compare: in Italy 4%, in Sweden and Denmark 14%, and in Belgium 15% of all deaths were preceded by a non-treatment decision.

\(^4\) To compare: in Belgium 49-53%, in Sweden 43% and in Denmark 39-50% of all deaths took place in hospital.

\(^5\) GEORG BOSSHARD, ESTHER ULRICH and WALTER BÄR, ’748 cases of suicide assisted by a Swiss right-to-die organization. ‘ Swiss Medical Weekly 2003: 310-317.

attention to the large number of people who had died in her practice. The doctor in question denies killing on request because, on her view, these patients died from pain relief. The doctor currently is at home and awaiting trial, she has to report to the police twice a week. During the conference, a German psychiatrist described how he accompanied two women who were assisted with their suicide in Zurich. In the corridors of the conference he talked about the immense pressure his employer brings him to bear ever since.

The case of ‘Maria’: Refusal of Treatment in Italy

SOFIA MORATTI

The Facts

On 25 January 2004, a 62 year-old woman was admitted to the S. Paolo hospital of Milan. There she was found to be suffering from severe diabetes that had been neglected for a long time. The diabetes was so advanced that her right foot was already gangrenous, and needed to be amputated in order to avoid septicemia. The doctors explained her condition to the woman and requested her informed consent for the amputation. They clearly stated that, without this operation, she would die within a few days. However, the patient hated the prospect of being “cut into pieces”, as she later explained to a nephew of hers, and firmly refused. A psychological examination found the woman to be fully competent and clearly aware of her condition and of the consequences of her decision. The internal ethical committee of the hospital discussed the case and confirmed that a refusal of treatment from a competent patient must always be respected: all that could be done in this case was to offer her some counselling. The counselling was arranged, but the woman consistently declined the proposed amputation.

At this point, the doctors concerned sought advice from the local prosecutorial authorities. Although Italian law fully recognizes the patient’s right to refuse a life-saving treatment, the doctors were surprised by the decision of the woman and somewhat unsure of their legal position. The prosecutor attached to the tribunal of Milan declared that “intervening in such cases does not fall within the duties of the prosecutorial authority”. Nevertheless, he did take a position on the case, stating that the will of the woman certainly had to be respected. He quoted a recent judgement of the court of cassation, that established that a doctor is criminally liable for coercion if he treats a patient who is competent, informed and of age and has explicitly and voluntarily refused the life-saving treatment performed.

The debate

The case attracted the attention of the media, which called the woman ‘Maria’, and generated a rather chaotic debate. The media constantly suggested that ‘Maria’ could be

1 See Corriere della sera, 31 Jan., 1 Feb., 2 Feb., 3 Feb. and 19 Feb. 2004
2 We are referring to article 32. 2 of the constitution and article 32. 1 of the code of medical ethics, as interpreted by the Court of Appeal of Milan in the Englaro case and by the Court of Cassation in the case quoted by the prosecutor. For details see SOFIA MORATTI, ‘The Englaro case’, MBPSL Newsletter 7.
3 Court of Cassation, first criminal chamber, 11 July 2002, nr. 2646.
4 A crime under article 610 of the Italian Criminal Code.
forced to undergo the proposed treatment against her will, through an ‘obligatory health treatment order’. Such an order is an extraordinary measure, that can be issued by the Mayor on the advice of the treating doctor only if the patient’s pathology endangers society, e.g., in the case of psychiatric patients who become violent due to their illness. This had nothing to do with the woman’s case. Nevertheless, this idea found a few important supporters: for instance, one of the town councillors of Milan and an advocate of a well-known consumers’ association. However, in an open letter, the Mayor of Milan made clear that the law did not give him any power of intervention in this case. Furthermore, the Minister of Health, the president of the College of Physicians, and the secretary of the Tribunal of the Rights of the Ill all intervened, stating that the will of a competent patient must always be respected.

‘Maria’ did not receive the operation, and died at home on 11 February 2004.

Conclusions

Although Italian law recognizes the patient’s right to refuse a life-saving treatment, this right seems still to some extent socially controversial. However, recent judicial decisions show that informed consent has become a recognized principle of Italian law. In this specific case, the media apparently tried to attract public interest by presenting the case as more problematic than it actually was. A few similar cases were later reported in the media, but they did not attract as much attention.

Transplantation and organs shortage:
should we abandon the gift paradigm?

GRACIELA NOWENSTEIN

Since transplantation became a normal therapeutic tool in the 1970s the problem of the shortage of organs and tissues has emerged as an important public health issue in those countries where it became an established practice. The constant improvement of surgical techniques and of biological knowledge have extended the spectrum of possibilities of transplantation, and hence the number of potential candidates. The problem of shortage has thereby become more acute, waiting lists longer, and the number of patients


6 One example is a recent judgement of the tribunal of Pavia. The S. Matteo hospital of Pavia was ordered to pay € 300.000 to the family of a patient who died after heart-surgery, because the medical team had not adequately informed the patient about the risks of the operation. Thus, the patient was not able to express an informed consent. [See La provincia pavese, 21 Feb. 2004].


RSPMB RESEARCH GROUP - UNIVERSITY OF GRONINGEN, THE NETHERLANDS
dying for lack of an available organ greater.1

Most organs for transplantation presently come from bodies in a state of brain death.2 Living bodies, although for obvious reasons not all of them, can also be a source of organs; it is only for kidneys that this source is statistically significant. Worldwide, the extraction of organs from both these sources is only legally allowed in so far as it results from an act of donation, markets of organs or compulsory extraction having until now being excluded by law and policymakers.

Within this context of human-to-human donation of organs, legislative and policy efforts have so far proven unable to supply enough organs to treat all the patients transplantation surgeons could operate on. As a consequence, thousands of patients die every year after a painful wait for a gift-of-life.3 After the first years of euphoria, when transplantation appeared as a technical and medical wonder rendered possible by the conjunction of biomedical progress and human generosity, disenchanted voices have gained strength, calling for revisions of the existing systems of donation and consent. Some of these voices argue that to deal with the shortage of organs it is necessary to abandon the exclusivity of the gift-paradigm, and to switch to regulated markets4 and/or to systems where consent would no longer be required or requested.

In January 2004 the MBPSL programme organised jointly with Groningen University Hospital a colloquium on ‘Bottlenecks in transplantation medicine. The importance and limitations of law in the functioning of a donation system. ’ Professor John Harris from the University of Manchester presented a paper5 where, in light of the apparent failure of donation systems to meet transplantation needs, he stressed the ethical justification of regulated markets for organs, as well as the right of the community to disposition of corpses.6

As to the market option, which Harris limited to organs from living bodies, he defended the idea of establishing ‘ethical markets’ in order to avoid the risk of exploitation of the poor. He suggested (a) regulated markets should be established within limited geopolitical areas that would exclude the import of organs from low-income countries; (b) the acquisition and allocation of organs should be under the exclusive control of unique public authorities, so that no direct transaction between the seller and the receiver would take place.


2 Brain death occurs when the brain has been irreversibly destroyed by massive brain injury caused by brain haemorrhage, drowning, smoke inhalation, etc. The body of the brain dead patient is kept functioning thanks to drugs and an artificial ventilator until the organs can be extracted.


5 “Transplantation and the Duty to Others”.

6 Govert den Hartogh reacted to Harris’ ideas, but in this report I limit myself to Harris.
Professor Harris also argued for reconsideration of the necessity of consent from potential donors and/or their close relatives. He raised the question whether the sacrifices community interests can demand of on individuals cannot include the disposal of useable organs after death. He noted that although it may be understandable that individuals might prefer not to have their organs removed after death, and that those who have lost a beloved relative might also prefer to have her body intact, the effects that respect for these preferences will have on those in need of an organ must also be taken into account. For a patient in need of an organ, death can be at issue, he stressed, if no organ is found on time. It is in his view the saving of lives that should prevail when it comes to balancing the preferences of these two groups of actors. Furthermore, he added, this opting for the interests of community would not be a complete legal novelty, as shows the case of legally-mandated autopsy where the law has long since accepted the priority of community interests (discovery of crime, prevention of spread of disease) over the private interest in the inviolability of a corpse.

Both options defended by Professor Harris as possibilities for dealing with the shortage of organs for transplantation lead to discussions with the audience about their ethicality, the possibilities of implementation by policymakers, and their socio-political acceptability. For different reasons both options seemed to be intuitively rejected by part of the audience. As to ‘ethical markets’ for organs, some participants were more than sceptical about the possibilities of excluding exploitation, even if the markets were limited as he suggested to rich geopolitical areas, for even these areas have their poor. Some were uneasy at the very idea of commodification of body parts.

As to obviating the requirement of consent in cases of brain death, the main question raised was that of the socio-political feasibility of the option. In fact, systems of presumed consent to organ donation, that formally are pretty close to Professor Harris’ idea, exist in some European countries since the mid 1970s, and they have not proved effective. Their practical implementation is problematic for two reasons: it seems to be difficult for the relatives of a brain dead patient to accept the extraction of organs and it is difficult for doctors, even with the full backing of the law, to impose this upon them. One of the reasons for the difficulty of implementing presumed consent legislation may be the lack of public campaigns to inform the general population about the existence of a legal presumption of consent to organ donation. Professor Harris stressed that legislation creating a right of the community to disposition over corpses would have to be accompanied by ‘educational campaign’. Only on this condition might the implementation of a policy of public ownership of corpses for purposes of transplantation be socially acceptable.

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On 6-8 April 2004 several members of the MBPSL research group (Heleen Weyers, Donald van Tol, Cristiano Vezzoni and Kim Goossens) gave presentations at the annual conference of the Socio-Legal Studies Association (SLSA) in Glasgow.

Heleen Weyers argued that sociology of law exist two – at first sight opposite – propositions in relation to the emergence of law: law emerges in situations of strong social norms versus law varies indirectly with social control. She applied these two propositions to three phenomena that are often suggested to have given an impulse to the debate on euthanasia: individualization which leads to a call for autonomy, the diminishing taboo on death and changes in medical practice. Heleen reached the following conclusion: the strong informal norm of patient’s right to self-determination played a role in Dutch euthanasia law but the law itself is not properly characterized by calling it the enactment of patient’s autonomy; the change in law concerning euthanasia shows that more social control goes hand in hand with more governmental control instead of a replacement of one by the other.

Donald van Tol’s presentation dealt with the considerable differences in interpretation of legal classifications of medical end-of-life decisions between legal professionals and doctors. These differences in classification have a profound influence on the effectiveness of the reporting procedure, which requires doctors to apply several legal classifications to their own behaviour. He discussed the findings of his survey and in-depth interviews among Dutch general practitioners, coroners and public prosecutors and suggested several explanations for the found differences based on psychological theories on classification.

Cristiano Vezzoni presented the results of his surveys about the practice of advance directives among nursing home doctors and family doctors in the Netherlands. He argued that the right of autonomy for incompetent patients is not fully ensured, because of on one side lack of information on advance directives for potential users and on the other hand the reluctance of doctors to extend the principle of autonomy to incompetent patients as they prefer to base their decisions on medical assessment of the patient’s condition and on the wishes of the family.

Kim Goossens gave a presentation on the divergent legal development in England and the Netherlands regarding medical end-of-life decisions. The talk focused on possibilities of justification of voluntary euthanasia and physician-assisted suicide by the defence of necessity and contained an analysis of the outcomes of judicial decisions in both countries, which pointed at differences in the balancing of individual and community interests, the degree of judicial activism and the nature of the euthanasia debate.

The participation to the conference also proved to be an opportunity to establish ties with members of the department of medical law at the University of Glasgow.
News, activities and visiting scholars

A bill to legalize euthanasia in the United Kingdom has been reintroduced in this session of Parliament by Lord Joffe (see MBPSL Newsletter no. 8 for Griffiths’ presentation to an informal briefing at the House of Lords in connection with last year’s bill). John Griffiths made a written submission to the House of Lords select committee – based on his lecture at the Giessen conference, (see above HELEEN WEYERS, Report on the international symposium on Physician-assisted suicide held in Giessen, Germany), and his contribution to Euthanasie. Knelpunten in een voortgezette discussie (see below, publications) – on the difference in practice and in legal treatment between euthanasia and physician-assisted suicide, arguing that there should be a (gentle) legal preference for the latter.

On 8-9 June 2004, John Griffiths attended an international conference on medical ethics hosted by the Evangelical Academy Arnoldshain and devoted to the role of the family in medical decision making and in particular the tension between individualistic ‘informed consent’ and the claims of family solidarity and responsibility. The conference was organized by Dr. Kurt Schmidt of the Zentrum für Ethik in der Medizin, Frankfurt, and prof. Gabriele Wolfslast of the University of Giessen.

The opening lecture, ‘Conflicting views of the “family” and its proper role in medical decision making,’ was delivered by the well-known medical ethicist H. Tristram Engelhardt. Among other interesting presentations, particularly intriguing was the discussion between prof. Ruiping Fan and prof. Julia Tao, both of the City University of Hong Kong, on the differences between Western (American) individualistic ethics, traditional Confucian ethics in mainland China, and the in-between position of Hong Kong. The ethics of informed consent require that a dying patient be informed that he is dying and participate directly in decisions concerning treatment. Confucian ethics require the head of the family (and not the patient) be informed and be responsible for decision making on the patient’s behalf. And in Hong Kong, the head of the family is informed first, but is expected to inform the patient, and if he fails to do so the doctors must do so themselves. See Journal of Medicine and Philosophy (vol. 29 nr. 2, April 2004) for presentations of the research findings of professors Fan and Tao.

Mirjan van Heffen-Oude Vrielink presented us her research at self-regulation in home-care organizations (‘thuiszorg’). Van Heffen-Oude Vrielink is sociologist of law at the University of Twente. In the article we discussed, she uses the theoretical framework of the social working approach developed by John Griffiths.

Penny Lewis (King’s College London) came to Groningen in order to do research at the documentation center of the MBPSL-group. Lewis is a lawyer and is specialized in the legal aspects concerning euthanasia and other medical behavior that shortens life. A lunch meeting was organized wherein she talked about her research at the regulation of euthanasia in France and the special elements of the French law.
Marjon Siebelink, who works as a ‘donation-officer’ at the academic hospital in Groningen, came to talk about her research plans. Siebelink prepares a research at organ-donation in the case of young children. She is going to investigate for example how parents come to the decision to agree or disagree with donation of the organs of their deceased child. During the meeting her research proposal was discussed.

The sociologist of law Richard Abel, who wrote several books about the legal profession and the role of lawyers in society, was invited for a yearly course for PhD-students on the interdisciplinary study of law, organized by John Griffiths. Also a brown-bag lunch was organized wherein Abel discussed a case study he is going to use for new writings on the ethics of the legal profession.

Margo Trappenburg, political scientist from the university of Utrecht, came to discuss her article that was published in the book Euthanasie. Nieuwe knelpunten in een voorgezette discussie, edited by Adams, Griffiths and Den Hartogh (see below, publications). In the article, Darwin in de medische ethiek (Darwin in medical ethics), Trappenburg explores what an evolutionary approach has to offer if one wants to do research at public debates concerning issues in medical ethics.

Publications

In cooperation with the University Library of the University of Groningen, plans are well advanced for the launching of a new, open-access digital journal dealing in a broad, interdisciplinary and international/comparative way with problems of regulating socially-problematic medical behavior. The journal, tentatively entitled Journal of Medicine, Ethics and Law, will be published by the RSPMB group. It will have a strong, international editorial board and will publish only peer-reviewed and carefully edited articles. In keeping with the new possibilities of digital publishing, there will be no distinct ‘issues’, but articles will be added to the web-site as soon as they are ready for publication.

A number of important developments have taken place since the first edition of Euthanasia and Law in the Netherlands (J. Griffiths, A. Bood and H. Weyers) was published in 1998. Recently we have agreed with Amsterdam University Press to publish a substantially revised edition, to be entitled Euthanasia and Law in the Netherlands and Belgium. The authors will be John Griffiths and Heleen Weyers, joined by Maurice Adams of the University of Antwerp. Publication is expected in 2006.

As the title indicates, the scope of the new edition will include Belgium, where euthanasia was made legal by legislation in 2002. Legal developments in the Netherlands since 1998 will be exhaustively covered (including the euthanasia law of 2002, the establishment and later the formalization of the Regional Assessment Committees and their functioning in practice, and important new case law such as the Brongersma case, rejecting the availability of physician-assisted suicide for a person whose suffering is not ‘medical’ in nature). In addition, the data from a large number of empirical studies in the two countries will receive full treatment.
In 1987, when the public debate over legalization of euthanasia was just getting up steam, G. A. van der Wal edited a collection of essays on the difficult issues emerging in the discussion. With the enactment of a euthanasia law in 2002, after more than 20 years of vigorous national debate and more than 15 years after legalization had already been accomplished in the case law, the time seemed ripe for examination of some of the new issues that a legal practice of euthanasia has brought to the fore. Furthermore, since euthanasia has in the meantime been legalized in Belgium – where the political history of legalization and the nature of the public debate were very different – it was decided to treat the issues discussed in a comparative way. The title of this publication is *Euthanasie. Knelpunten in een voortgezette discussie* (Kampen: Kok 2003). The editors are Maurice Adams (legal philosophy, Antwerp), John Griffiths (sociology of law, Groningen) and Govert den Hartogh (ethics, Amsterdam).

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2. H. Weyers, *How can legalization in the Netherlands and in Belgium (and nowhere else) be explained?*
4. B. Broeckaert, *Are euthanasia and palliative care alternatives?*
5. B. Chabot, *Ending one’s life without doctor’s help, a descriptive study.*
6. H. van Delden, *Medical-ethical aspects of the choice of the right time for euthanasia.*
13. J. van Gerwen, *The ‘Drion pill’ [with which elderly people can end their lives at a moment and for reasons of their own choosing] as an instrument of self-determination.*
16. H. Wijbsk, *Is ‘unbearable suffering’ too subjective a criterion for doctors to use in deciding on requests for euthanasia?*