BELGIAN ADVISORY COMMITTEE ON Bioethics

Opinion no. 53 of 14 May 2012 on the refusal of medical care by a pregnant woman impacting on the foetus

Content of the opinion

The question put to the Committee

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In a letter dated 29 December 2008 from Pr. Dr R. Rubens, chairman of the medical ethics commission at Ghent teaching hospital, the following question was put to the Advisory Committee on Bioethics: "What is the position of the Advisory Committee on Bioethics in the high unusual situation in which an HIV seropositive pregnant woman refuses all treatment during the pregnancy and at the delivery?".
On 8 March 2010, the Committee decided to consider this request and asked commission 2010/2 to look more generally at the ethical questions raised by the issue of refusing care or treatment with consequences for third parties.

After having studied the question, it was finally decided to choose the title above: "Opinion on the refusal of medical care by a pregnant woman impacting on the foetus. For the purposes of this opinion, the Committee understands "foetus" to mean the product of conception, from this point until birth.

I. Introduction

A. Description of the question

The Committee extended the initial question, which was confined to seropositive pregnant women, to include other pathologies as long as they had consequences for the foetus or the unborn child. The emphasis is placed on the possible negative consequences for the foetus of the refusal, by the pregnant woman – whether or not she herself is in good health – to follow treatment or health advice. By doing so, she deprives her foetus of a major health benefit and thus risks placing it in a situation that may prove fatal.
Our discussion concerns exclusively the refusal, by the pregnant woman, of common, necessary treatments that are proposed and not, for instance, the refusal of exceptional interventions or experimental surgery on the foetus. Nor do we discuss the refusal to follow general health advice, such as not smoking or limiting the consumption of alcohol, but the refusal of individual medical treatments offered, that relate directly to the pregnancy, which implies a danger for the foetus.

B. Content of the opinion

In order to clarify question initially asked about seropositive women, Chapter II, "Medical aspects", takes stock of current medical and scientific knowledge in this field. Chapter III contains a detailed description of the legal framework of the refusal of medical care with consequences for others, paying particular attention to the legal position of the embryo and the foetus.
Chapter IV deals with ethical considerations and comprises two parts.
The first part (A) concerns the examination and discussion of actual cases taken from three different sources: ten cases of pregnant women admitted to Belgian hospital units, three cases published in the context of the Unesco Chair in Bioethics at the University of Haifa, and a few cases that reflect the approach adopted by North American jurisprudence.
The second part (B) is devoted to the in-depth analysis of ethical aspects, in particular the concept of autonomy as seen respectively by the German philosopher I. Kant and the Anglo-Saxon utilitarian philosopher, J. S. Mill.
This is followed by Chapter V containing the conclusions and Chapter VI setting out the recommendations made.

II. Medical aspects

In this chapter, we will be presenting a number of medical aspects of HIV (human immunodeficiency virus) relating to the prevention of the transmission of HIV from the mother to the foetus during pregnancy, delivery and the neonatal period[1].

In Belgium, an official report dated 31 December 2009 indicates that around 23,000 people contaminated with HIV have been diagnosed since 1986; assuming that approximately half of them still live in this country, that 35 % of them are women and that 90 % of these women are aged between 15 and 50 years old, Belgium has between 1,750 and 3,000 seropositive women of child-bearing age.
HIV can be transmitted to the foetus during pregnancy, delivery and post-partum period. Belgian statistics indicate that during the period from 1984 to 31 December 2009, this transmission occurred in 395 of the 22,234 recorded cases (1.8 %)[2].

In the United States, where the population stands at about 300 million, 7,000 seropositive pregnant women are recorded every year who, without specific measures, would give birth to around 3,500 babies contaminated by HIV.
A great many factors influence the risk of mother-foetus HIV transmission. These include the number of viral particles in the maternal blood, the stage of the disease and the immunological resistance (number of CD4 lymphocytes), the existence or otherwise of co-infections (sexually transmitted diseases, tuberculosis, toxoplasmosis), nicotine addiction and the use of intravenous drugs. Obstetric factors also play a role: the moment when the amniotic sac breaks, contamination of this membrane, the mode of delivery and whether or not the mother has an episiotomy. A shorter pregnancy, low birth weight and the presence of cracks in the breasts are other elements that increase the risk.

If measures are not taken and treatment is not given, the level of transmission is high. At world level, the figures vary between 10 and 80 %, with an average of about 30 % of recorded cases. In 5 to 10 % of seropositive pregnant women, contamination occurs *in utero* by the absorption of infected amniotic fluid. This form of transmission is rare with pregnancies of 24 to 28 weeks and with normal pregnancies. Ten to 20 % of foetuses are infected just before or during delivery by mother-foetus transfusion and contact with the amniotic fluid, vaginal secretions and maternal blood. Finally, 10 to 20 % of new-born babies are contaminated by breastfeeding.

However, vertical transmission can be prevented, on the basis of *counselling*, the use of intensive antiretroviral therapy (HAART: highly active antiretroviral therapy), the use of a suitable mode of delivery and by avoiding breastfeeding. The American guideline[3], regularly adapted, is taken as a basis for numerous recommendations.
Effective treatment of the seropositive pregnant woman requires the cooperation of a multidisciplinary team, ideally made up of at least medical and paramedical HIV specialists who also treat her when not pregnant, the obstetrician and the woman herself. Particular attention is paid to the continuation of the treatment by the patient and discussion with the latter of the known and less well known advantages and disadvantages of the therapy.

Antiretroviral therapy aims to treat the maternal HIV infection (if necessary) and to reduce vertical transmission. Pregnancy is not a reason not to start the necessary therapy and the

[1] Report from Dr B. Spitz, 2 November 2010 on the medical aspects of HIV (human immunodeficiency virus) in relation to the prevention of mother-child transmission during pregnancy, childbirth and the neonatal period.

[2] WIV-IPS (Scientific Institute of Public Health; Operational Directorate Public Health and Surveillance/College of AIDS reference laboratories. HIV/AIDS in Belgium; situation as at 31 December 2009. Half-yearly report No 70, available for consultation on line: http://www.wiv.isp.be/pdf/vihsida_sem_70_EN.pdf.

[3] *Panel on Treatment of HIV-Infected Pregnant Women and Prevention of Perinatal Transmission. Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States*. 24 May 2010; pp 1-117. Available for consultation on line: http://aidsinfo.nih.gov/ContentFiles/PerinatalGL.pdf.

antiretroviral treatment has to be personalised. If the pregnant woman has not yet been treated and does not yet need treatment for her own health, no HAART will be administered during the first trimester, but this will start at the latest from the 20th to the 28th week. During delivery, zidovudine is administered by drip, the principle being that zidovudine crosses the placenta and thus serves as post-exposure prophylaxis (PEP) for the foetus. After the pregnancy, the treatment can be stopped for the mother. If the mother needs HAART for her own health, then if possible this treatment will be postponed until the 14th week of amenorrhea. The perpartal treatment also consists of zidovudine, but in this case it will usually be necessary to treat the mother after the delivery. If there is an active wish for a child or if a woman falls pregnant while under HAART, then in any case the aim will be to avoid teratogenic molecules such as efavirenz during the first trimester. The previous plan will then be resumed. With pregnant women whose follow-up begins only at an advanced stage of the pregnancy or who are already in labour, HAART will be started together with perpartal treatment with zidovudine. In these cases, however, there can be no certainty that the viral charge in the maternal blood has been rendered negative.

Generally speaking, given that we have less experience with the various combined antiretroviral treatments during pregnancy, more intensive follow-up is advised. Usually, the CD4 cell levels and the viral charge will be determined in the mother every three to four months in order to identify the need to start or adapt the prophylaxis and the treatment. A dose of protease inhibitors is usually recommended because their plasmatic concentration declines during pregnancy and may become subtherapeutic. Efavirenz is inadvisable during the first trimester for teratogenic reasons. In addition, attention will be paid to the potentially greater risk compared with non-pregnant women of hyperglycaemia with the administration of protease, acidosis and hepatic steatosis inhibitors in the event of nucleoside analogue reverse transcriptase inhibitors and cutaneous lesions and hepatic disorder in the event of nevirapine. As regards the foetus, an ultrasound scan is advisable in the first trimester to confirm the duration of the pregnancy, assess any medical contraindications and if need be plan the necessary antiretroviral treatments. Given the uncertainties that persist concern all the possible effects of combined therapies on the foetus, most experts advise an ultrasound morphological examination of the foetus as well as careful follow-up of the well-being of the foetus by biophysical profile.

As regards the means of delivery, an elective Caesarean is advised around the 38th week of amenorrhea if the viral charge is above 400-1000 copies/ml. The same applies if no combined therapy can be started or if the viral charge is unknown. When scheduling the Caesarean before labour begins, materno-foetal microtransfusions are planned, which may accompany the contractions of the cervix. This intervention is also intended to reduce contact with infected secretions and the blood in the perineum. A zidovudine drip must be started three hours before the intervention. Post-operative infectious morbidity seems to be slightly higher among HIV patients owing to the decline in their resistance; consequently, antibioprophylaxis is also advisable.

If the viral charge is undetectable or very slight (< 400-1000 copies/ml), the benefits of an elective Caesarean seem to be marginal, or even non-existent, so this is no longer recommended. The artificial rupturing of the amniotic sac and invasive procedures such as the fitting of cranial electrodes that break the cutaneous barrier of the foetus should be avoided with a vaginal delivery. The same applies, where possible for artificial childbirth procedures and episiotomies. Here again, the administration of zidovudine by drip should be started from the onset of labour and in general, ongoing oral antiretroviral treatment should be taken for as long as possible during childbirth. The newborn baby should be washed before blood is taken, injections are given or other invasive procedures are carried out. Moreover, prophylaxis, usually consisting of zidovudine, is advisable for the newborn baby for four to six weeks and the need to prevent pneumocystis pneumonia should be assessed in consultation with a specialised paediatrician.

In order to prevent the postnatal transmission of HIV through breast milk, breastfeeding is not advisable. The same applies for mothers undergoing treatment. Existing studies do not

provide absolute proof of the efficacy of antiretroviral therapy in the prevention of postnatal transmission and the possible harmful effects of exposure to antiretroviral agents through breast milk are still insufficiently known.

To sum up, targeted attention and *counselling* together with rigorous but no longer exceptional treatment plans can reduce the rate of vertical transmission of HIV by around 30 % to less than 1 %. The most effective preventive interventions, as documented in the Netherlands[4] can even reduce transmission to virtually zero (0 % between 2000 and 2008 out of 689 cases).

III. Legal framework

Introduction

The refusal of care is an acute problem in medical law, as it requires a delicate balance between the autonomy of the patient capable of assessing his or her interests and the personal duty of the doctor to provide assistance[5]. It should be pointed out straight away that this conflict may, if necessary, be resolved by means of recourse to the general criminal-law concept of *state of necessity*, which authorises committing an offence – or, more generally, infringing a value protected by law – when this is the only means of preserving another value deemed to be more important and more worthy of protection. For instance, a doctor who treats a patient whose life is in danger in an emergency, without having the time or the possibility of obtaining the patient's consent or that of his representative, can invoke the state of necessity: saving the life of a person at risk of dying is a higher value than the preservation of the decision-making autonomy of this individual.

It should be pointed out that in the context of this opinion, we are confining ourselves to considering the refusal of medical care by a pregnant woman and the consequences of this refusal for the health of the unborn child[6]. This may cover two cases:

- the mother is not ill herself, but refuses treatment that would be beneficial for the foetus;
- the mother is ill and the treatment being considered is intended (solely) to prevent the baby from being contaminated by the HIV virus which the mother carries; her own treatment could be deferred but if she refuses to be treated, the risk of contamination of the foetus is significantly increased (this is the specific hypothesis set out in the question put before the Committee).

From the legal point of view, these two cases do not seem to call for different treatment. In fact, medical law does not question the *grounds for the refusal of care as such,* but rather endeavours to gauge the relevance of the refusal in terms of its potential consequences; whether the mother is or is not ill herself is therefore of little consequence, since this is not directly about her. On the other hand, the main question that arises in both cases is that the future mother is at the very least responsible for decisions concerning the foetus which she is carrying and in this instance, this could, in either case, withdraw the benefit of the treatment considered (which, incidentally, explains why the law on patients' rights applies in

[4] *Stichting HIV Monitoring, Academisch Medisch Centrum, University of Amsterdam.* http://www.mst.nl/hivbehandelcentrum/meer_informatie/shm.doc/

[5] The following developments are taken from the work by G. GENICOT, *Droit médical et biomédical*, Brussels, Larcier, collection of the Faculty of Law at the University of Liège, 2010, spec. 129-140 (basic law on informed consent and refusal to consent), 190-196 (representation of under-age patients), 546-561 (interruption of pregnancy and harm done to the unborn child or the child being born), 583-587 (legal status of the embryo and of the foetus) and 724-729 (refusal of blood transfusion on grounds of philosophical or religious conviction and refusal of transfusion for a child).

[6] The hypothesis of risky behaviour by the pregnant woman, independent of any pathology and any medical context, will therefore not be covered, in any case not in the legal part.

both cases). The question is therefore whether it is legitimate for the pregnant woman to refuse this benefit for the unborn child.

Judges called upon to settle disputes in which the issue being debated here is at the forefront would not lack tools and support for their arguments, which will necessarily be conducted *in concreto* on the basis of all the circumstances of the case in point and the parameters surrounding the decision taken. For all that, there is no clear response in principle to the question put to the Committee, either in law or in jurisprudence, and this matter does not appear to have been explored by doctrine, probably owing to its specific nature and the rarity with which it occurs in practice. Consequently, the considerations set out below make no claim to resolve the issue as such, but simple set out the legal parameters within which it lies and which clarify it.

In fact, medical law regulates – more or less completely – various questions *related* to that which is the subject of this opinion. The refusal of care is regulated fairly meticulously, whether it comes from a patient who is of age and capable or from the representative of an under-age child; for example, this may concern the refusal to have a blood transfusion, coming from (parents who are) Jehovah's Witnesses. There is no doubt that the unborn child is protected by criminal law and labour law; but beyond that, the embryo and the foetus have no legal qualification. They remain *pars viscerum matris* and the mother – or the parents together – exert extensive powers in their place, which may go as far as destruction pure and simple. For instance, while in principle it remains punishable, abortion is decriminalised under certain circumstances and is widely allied with the discretionary freedom of the woman; the fate of superfluous embryos in the event of medically assisted procreation – which will not be raised here – also attests to this power. However, while medical law confirms that pregnant women have the "power" to take medical decisions *that affect the health* – and even the life – of their future child, it does not contain any specific instructions concerning the *measure* of this power and its possible weighting against other potentially concurrent values.

1. Refusal of care in medical law

A. Requirement for consent and the right of patients who are of age and capable to refuse care

The right in principle of patients who are of age and capable to refuse the care offered to them is a direct corollary of the cardinal importance of the consent of the patient in medical law. This undisputed requirement is laid down in various texts and in particular the law on patients' rights, which states that the latter is entitled to consent freely to *all* interventions by the professional practitioner, subject to prior information (Article 8, § 1er) and details the information that must be provided for the patient with a view to expressing this consent (Article 8, § 2). Following on from this, the law states that the patient is *always free to refuse or withdraw their consent to an intervention* (Article 8, § 4), but also that in the event of an emergency and when "there is uncertainty as to the existence or otherwise of a will expressed beforehand by the patient or his representative", "any necessary intervention is undertaken immediately by the professional practitioner in the interests of the patient" (Article 8, § 5). The requirement imposed upon the doctor to obtain the free and informed consent of the patient before undertaking the intervention he recommends[7] constitutes

[7] Which implies for the doctor the obligation to inform the patient about the intervention in question (Cass., 14 December 2001, *Pas.*, 2001, 2129, concl. DU JARDIN, *J.L.M.B.*, 2002, 532, note LELEU and GENICOT, *J.T.*, 2002, 261, note TROUET, *R.G.A.R.*, 2002, No 13.494, *R.G.D.C.*, 2002, 328, concl. DU JARDIN, note TROUET, *Rev. dr. santé*, 2001-2002, 239, note FAGNART). Similarly, in France, since acts No 2002-303 of 4 March 2002 on patients' rights and the quality of the health system and No 2005-370 of 22 April 2005 on patients' rights and the end of life, no medical act or treatment may be carried out without the free and informed consent of the person; this consent may be withdrawn at any time. The doctor must respect the will of the person after having informed him of the consequences of his choices. If the wish of the person to refuse or interrupt any treatment puts his life in danger, the doctor must do everything possible to convince him to accept the essential care. He can call upon another

imperative protection of the patient, which the latter can only relinquish in *full knowledge of the facts,* i.e. duly informed – to the extent that he so wishes – of the consequences of his choice.

In terms of principles, it may be deduced from the combination of several fundamental guarantees enshrined in the European Convention for the Protection of Human Rights (Articles 3, 8 et 9) that the patient has grounds for refusing treatment, for instance, because it goes against his culture or his convictions. Although he is authorised to attempt to persuade the patient to accept the care which is in his interest, the doctor does not have any right scrutinise the grounds for such a decision. As a rule, he is not authorised to ignore a refusal from a patient who is of age, capable and fully informed. These imperatives are confirmed by the law on patients' rights, which guarantees the patient the right to "respect for his human dignity and his autonomy" and prohibits any distinction in this respect (Article 5). For instance, the practitioner is obliged, in particular, to respect the moral and cultural values of the person consulting him, as well as his religious and philosophical convictions. However, this has to be reconciled with the personal and autonomous duty of assistance which he bears, both from an ethical point of view[8] and in legal terms (non-assistance of a person in danger, Article 422*bis* of the Criminal Code), which is likely to oblige him to perform an act that is essential for the survival of the patient.

The patient must be scrupulously *informed by the doctor of the possible consequences of his decision* (Article 8, § 2, of the law) and the serious risks which may be incurred in the event of opposition to the recommended treatment, so as to be put in a position to be able to give *informed* consent or refusal to the medical acts considered. There is no doubt as to the solution: the refusal of consent, just like consent to the treatment, must be based on the patient being *fully informed* of the implications of the decision taken, and the risks that this is likely to entail. For instance, if the doctor believes that the choice made by the patient will adversely affect his health, he must warn the patient of this and endeavour to convince him; if need be, he has to offer possible alternative treatments, checking the proportionality of the risk they involve and their anticipated effectiveness. This having been done, if the patient persists in refusing *all treatment*, the doctor will have no option but to *refrain from intervening* and put an end to the contract of care, making sure that the patient is not abandoned to his fate.

Only *urgency or necessity* can temper this rule, in which case the doctor has an obligation to assist a patient in danger. In such a situation, there are, as usual, certain exemptions from the principles; the immediate safeguarding of the health, or even the life of individual cannot be hampered by prevarication. So in the context of an emergency, the doctor himself can decided to intervene on his own initiative; if a serious danger threatens the patient, he will provide the necessary care without delay, in the event of uncertainty regarding the existence of a wish freely expressed previously by the patient[9].
In fact, by not taking any action, the practitioner becomes guilty of failing to assist a person in danger; in this case, the state of necessary in which he finds himself legitimises his action[10].

While the patient's wish to refuse the care offered must be dealt with cautiously, as a general rule it must be respected; *it takes precedence over the legal (and ethical) duty of the doctor to lend him assistance*. The debate on the existence of fault in such as context is, however,

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member of the medical corps. In any case, the patient must reiterate his decision after a reasonable period; this is recorded in his medical dossier.

[8] Articles 3, 6 and 29 of the Code of Ethics: "the doctor take care, in all circumstances, of the health of individuals and of the community"; he "must, whatever his function or specialist field, provide emergency assistance to a patient in immediate danger" and "endeavour to inform his patient of the reasons for any diagnostic or therapeutic measure proposed".

[9] See Article 8, § 5 of the law on patients' rights; G. SCHAMPS, "La nouvelle réglementation relative aux droits du patient et son incidence pour les proches", *Ethica Clinica*, 2005, pp. 41 and 42; G.SCHAMPS, "L'information et le consentement du patient au regard de la loi du 22 août 2002 relative aux droits du patient", in *Droits du patient et responsabilité médicale*, Diegem, Kluwer, 2003, pp. 50 ff., spec. pp. 66-67.

[10] We should also mention the specific issue of forced hospitalisation, which can lead to forced treatment; see on this point the opinion of the Committee No 21 of 10 March 2003.

by definition delicate. The law even goes further than this, as it lends binding force to the *advance refusal to undergo an intervention* validly expressed by a patient, before he becomes incapable of exercising his rights. Given such an advance declaration of refusal of a *specific* intervention, backed up by the required guarantees, the practitioner has to give way even if the life of the patient is at stake.

The provision of Article 8, § 4, of the law is general and refers to *all* interventions which the patient does not wish to undergo, even if this is vital; the right of the patient to refuse treatment, the essential corollary of self-determination, lends concrete form to the higher principle of the *free disposal of one's own body*[11].

B. Representation of children by their parents in medical matters

Under the terms of Article 12 of the law on patients' rights, if the patient is under age then his rights are exercised by the parents exercising authority over him (or, where appropriate, his guardian). Depending on his age and his maturity, the patient is *associated* with the exercising of his rights. He can go as far as to exercise them *alone, autonomously,* if he may be deemed capable of reasonably assessing his interests. The fact that under-age children are represented by their parents is of course logical; involving the child in the exercising of his rights, and the possibility offered to adolescents (mainly) of exercising them alone if they are sufficiently mature, are innovative legal provisions. This is a matter of parental authority, the permanent feature of which is that this must be exercised *in the interest of the child;* this is a "right of function", a *finalised* prerogative with a view to this interest[12].

If a child is in *urgent* need of a medical intervention and if the doctor comes up against the refusal of the parents or does not have the possibility of obtaining their consent, whereas the life or the integrity of the child is in danger, he must nevertheless intervene; the principles set out above apply. The law on patients' rights expressly states that the representation of the patient is *finalised and defined*: his representative must take as a basis the presumed will of the patient himself or, if this is not known, his best interest. Article 15, § 2 of the law therefore includes a very important provision: it opportunely grants the practitioner the power to consider that the decision taken by the parents is not *in line with the interest of the child* – the cornerstone of all parental authority – or even constitutes a *threat to his life* or risks causing *serious harm to his health*. In such cases, he is expressly authorised to *depart from the law* (if necessary acting in a context of multidisciplinary consultation, and always including a written justification in the dossier). Before the law, if there is no emergency and if the parents refuse an intervention deemed *necessary* by the doctor, in the final instance the latter can always bring the matter before the public prosecutor, asking the juvenile court to force the parents, in the interest of the child, to allow the child to undergo the medical act in question (Article 387*bis* C.civ.). He could also act directly, by applying the state of necessity.

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[11] See on this point Y.-H. LELEU and G. GENICOT, La maîtrise de son corps par la personne, *J.T.*, 1999, 589; by the same authors, Le statut juridique du corps humain. Belgian report, in *Le droit de la santé: aspects nouveaux*, Swiss Days 2009 of the Association Henri Capitant, to be published, available on the website http://www.henricapitant.org; Y.-H. LELEU, G. GENICOT and E. LANGENAKEN, La maîtrise de son corps par la personne. Concept et applications, in *Les droits de la personnalité*, J.-L. RENCHON (dir.), Brussels, Bruylant, Famille & Droit collection, 2009, 23-118. See also, for a synopsis, *La libre disposition de son corps*, J.-M. LARRALDE (dir.), Brussels, Bruylant/Nemesis, Droit & Justice, 2009.

[12] In extreme cases, a parent may be deprived of his or her authority by the juvenile court, and the request either of the other parent, or of the public prosecutor. This loss of authority may be ordered if "the father or the mother (…), through bad treatment, abuse of authority, notorious loose living or serious negligence, endangers the health, the safety or the morality of their child" (Article 32, al. 1er, 2°, of the law of 8 April 1965 on the protection of juveniles, in the version taken from the law of 31 March 1987). The case may, if need be, be brought before the public prosecutor by the doctor having witnessed such events. It should be added that if parental authority is exercised exclusively by one of the parents, this parent may incur liability in respect of the other parent in the event of negligence.

C. *Refusal of blood transfusion out of philosophical or religious conviction*

Some people refuse all blood transfusions for religious reasons; this, as is known, is the stance taken by Jehovah's Witnesses. This refusal to accept transfusions, however vital, constitutes the purely hypothetical case of the refusal of care[13]. In application of the principles set out above (right to respect for privacy and freedom of conviction, protection of bodily integrity and, more widely, autonomist logic of patients' rights), every individual is free to agree or not to give his own blood or accept a transfusion of foreign blood, and may refuse this, even though it be at the peril of his life. Nevertheless, the doctor is subject to a *duty of imperative care*, legally and ethically; the question therefore arises as to whether he can decide to carry out a transfusion that is *absolutely necessary*, bearing in mind the condition of the patient, even against the wishes of the latter. The application, in such a case, of the precepts laid down in Article 8, §§ 4 and 5 of the law on patients' rights is difficult; this does not appear to have given rise to illustrations in Belgian jurisprudence, although it has done so in France[14].
Everything will depend, of course, on the context: the path that can be used to justify the doctor's attitude differs depending on whether he has ignored consent to save the life, or conversely whether he has respected the patient's wish, at the cost of his life. It seems that, provided that the circumstances of the case offer the necessary support, both attitudes may be understood; moreover, this complex issue reveals the *very archetype* of the delicate balance of concurrent values and interests which (bio)medical law often imposes on the practitioner, and sometimes on the judge. It seems that, necessarily, the starting point for the debate lies in the *absolute right of the patient* to refuse to undergo an intervention – however vital and therefore even if this is at the cost of his death – which, in our legal architecture, in principle takes precedence over the obligation to lend assistance to a person in danger, as we saw above.

The problem become more acute – and different – when *parents refuse to allow their under-age child to undergo a transfusion*[15]. The freedom of conscience and of religion of adults can be limited when it goes against *the interest of the child*, the natural role of the law being to protect the weakest. To our knowledge there is no other Belgian jurisprudence on this point, but the principles of medical law and the law on patients' rights provide tools that can be used to resolve this particularly complex arbitration procedure: what if the parents refuse to allow their under-age child to undergo a blood transfusion which is necessary for his survival? If he did not act, the practitioner would be guilty of failing to assist a person in danger; he will be able to assert the state of necessity if, considering the act to be medically necessary, he carries it out *as an emergency* in the interest of the child. When the child's very life is in danger, the doctor has the authority to act.

If there is no emergency, as we have seen the child and in particular the adolescent already have control over their own body and decision-making autonomy in medical matters (natural

[13] Refer in this respect to the Committee opinion No 16 of 25 March 2002 on the refusal of blood transfusions by Jehovah's Witnesses.
[14] The French Council of State admits that preference should be given to the obligation to protect the life of the patient, even against their will. According to a ruling of 26 October 2001, this is not a matter of generally giving precedence to the obligation of the doctor to save life over that to respect the will of the patient, but of noting that, bearing in mind the extreme situation in which the patient is, blood transfusions are required as the *only treatment likely to save his life* and that the doctors opt, solely with a view to trying to save him, to perform an *act essential to his survival and proportionate to his state*; in these conditions, and moreover, whatever their obligation to respect his will based on his religious convictions, they have not committed an error. Even since the law of 4 March 2002 – which seems to argue the contrary (Article L. 1111-4 C. santé publ.) – the Council of State considers that doctors do not commit a serious and clearly illegal attack on the basic freedom of the patient, of age, when in a condition to express this, to give his consent to medical treatment when, after having done everything possible to convince a patient to accept the essential care, with a view to trying to save him, they perform an act that is essential for his survival, proportionate to his state and carried out with a view to saving him (ruling of 16 August 2002).
[15] See the aforementioned opinion of Committee No 16 of 25 March 2002, pp. 21-27.

capacity)[16]. On the other hand, if he is confronted with a child who is not yet sufficiently mature to exercise his rights alone, the doctor cannot, as a general rule, ignore the refusal to accept a transfusion expressed by the parents. Before the law on patients' rights, the only possibility open to the medical team was to call upon the public prosecutor in order to ask the juvenile court to *order* the parents to accept the transfusion, on the basis of Article 387*bis* of the Civil Code (which authorises this tribunal to order or to modify any provision regarding parent authority, in the interest of the child, at the request of the father and mother, one of them or the public prosecutor)[17]. This roundabout procedure did not fit in well with the necessities of medical treatment; what is more, it is not the role of the public prosecutor's office to advise the doctor. Since the advent of the law on patients' rights, which was innovative here, it has been accepted that although the patient who is of age and capable decides *freely for himself*, the same does not apply to the *representative* of a patient who is incapable, the representation in medical matters being *finalised* in the interest of the person protected. On the basis of Article 15, § 2, of the law, nursing staff have the power to impose their views on recalcitrant parents; while this provision is undeniably useful, it should nevertheless be used sparingly and as a very last resort, giving preference, before reaching this position, to education.

2. The legal position of the embryo and the foetus

A. Medically assisted procreation and interruption of pregnancy

The law of 6 July 2007 on medically assisted procreation fully backs the idea of the autonomy of the individual and the couple and hence control over begetting, as well as over the gametes and embryos at the heart of the process. The legislator interferes very little in the autonomy of people and the in freedom of decision of centres as to whether or not to grant the request and gives precedence at every stage to the c*onsensualist* model, the process permanently being *contractual*[18]. The fate of surplus gametes and embryos, which is without any doubt the central aspect of this matter, does not escape this principle: the way in which they are used is decided *by the requesting parties in the agreement and by them alone*, and this must always be respected. This illustrates the idea that control over the body extends to these highly symbolic elements and is permanent, with consent having a special character[19].

This control over the result of conception is even more pronounced in the regulations on the *interruption of pregnancy* resulting from the law of 3 April 1990. If confirms that, in legal terms, the foetus is *pars viscerum matris* until the start of labour; it fall under the mother's

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[16] See not. G. GENICOT, *Droit médical et biomédical*, Brussels, Larcier, collection of the Faculty of Law at the University of Liège, 2010, pp.190-201; N. COLETTE-BASECQZ, S. DEMARCH and M.-N. VERHAEGEN, *L'enfant mineur d'âge dans le contexte de l'activité médicale,* Rev. dr. santé, 1997-1998, p. 166; N. GALLUS, *La capacité des mineurs face aux soins de santé*, *in*: Actualités de droit familial et de droit médical. *Les droits des personnes les plus faibles*, E. THIRY (dir.), Brussels, Bruylant, 2007, p. 3.

[17] Provision introduced by the law of 13 April 1995 on the joint exercising of parental authority and amended by the law of 18 July 2006 tending to give preference to equal custody of the child whose parents are separated and regulating forced implementation as regards custody of the child. See not. Y.-H. LELEU, *Droit des personnes et des familles*, Brussels, Larcier, 2e éd., 2010, pp. 713-729; N. MASSAGER, *Droit familial de l'enfance. Filiation, authorité parentale, hébergement. Nouvelles lois, nouvelles jurisprudences*, Brussels, Bruylant, 2009, pp. 269 ff. (decisions relating to parental authority) and pp. 545 ff. (parent practising a religion). Published in France, Articles 375 ff. of the Civil Code on educational assistance, most recently amended by law No 2007-293 of 5 March 2007 reforming the protection of childhood. See for example T.G.I. Besançon, 29 May 1998, Gaz. Pal., 1998, p. 85, note PANSIER.

[18] For more details, see M.-N. DERÈSE and G. WILLEMS, *La loi du 6 juillet 2007 relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gamètes*, Rev. trim. dr. fam., 2008, p. 279; G. GENICOT, *La maîtrise du début de la vie: la loi du 6 juillet 2007 relative à la procréation médicalement assistée*, J.T., 2009, p. 17; H. NYS and T. WUYTS, *De wet betreffende de medisch begeleide voortplanting en de bestemming van de overtallige embryo's en de gameten*, R.W., 2007-2008, p. 76; more generally and prior to the law, N. SCHIFFINO and F. VARONE (dir.), *Procréation médicalement assistée: régulation publique et enjeux bioéthiques*, Brussels, Bruylant, 2003. On the contractual model in Bioethics, see not. F. BELLILIFER and C. NOIVILLE, *Contrats et vivant. Le droit de la circulation des ressources biologiques*, Paris, L.G.D.J., 2006.

[19] See J.-C. GALLOUX, *L'utilisation des matériels biologiques humains: vers un droit de destination?,* D., 1999, chr. 13. This rule is also included in the law of 19 December 2008 on human bodily material.

control over her body, enshrined in law, which protects it as a *human entity* but not yet a person in the legal sense (see below).

In principle, abortion is a criminal offence. Article 348 of the Criminal Code punishes the perpetrator of an abortion undertaken without the consent of the woman; Article 349 refers to abortion caused by deliberate violence, but unintentionally (for instance, blows and injuries or the murder of a pregnant woman without knowledge of her condition); Article 350, paragraph 1, makes abortions undertaken with the consent of the woman a criminal offence as a matter of principle; Article 351 punishes the woman who has deliberately had an abortion carried out other than under the conditions provided for by law; finally, Article 352 imposes a heavier penalty when the means employed to bring about the abortion have caused the death of the woman, making a distinction depending on whether or not the woman consented. Generally speaking, both the doctor – or any other person taking action – and the woman are liable for criminal penalties. In this general context, the law of 3 April 1990 introduced a *partial decriminalisation* of the voluntary interruption of pregnancy when this is practised on a *consenting* woman, either during the first twelve weeks of pregnancy or, after this period, for therapeutic reasons. The conditions imposed are strict, in particular as regards the prior information to be given to the woman; they are laid down in Article 350, paragraph 2, of the Criminal Code.
For a voluntary interruption of pregnancy carried out before the end of the twelfth week after conception not to be liable to punishment, it must mainly concern a pregnant woman "whose condition places her in a situation of distress", a concept that the law does not define but that is described in parliamentary works as the "result of an acute moral conflict moral linked to the profound refusal of the woman to allow her pregnancy to continue". The reasons put forward by the woman to refuse to allow her pregnancy to continue are personal and she is not asked to *justify* them: her motives are assessed first and foremost by her, as it is difficult for them to be judged by a third party, given the lack of objective criteria. The doctor consulted is however *associated* with the assessment of the existence of a state of distress and the determination of the patient: his task – based on his experience and his psychological intuition, more than on his professional knowledge - is to *assure himself* of this determination, which is closely linked to the *conviction* of the woman, whose state of distress results in a profound and persistent refusal to allow her pregnancy to continue, which the doctor consulted has to *note*. To simplify matters, the law judiciously states that the assessment of the determination and the state of distress of the pregnant woman, leading the doctor to agree to intervene, is *sovereign* when the conditions laid down in Article 350 are respected. It should be pointed out that, from an autonomist point of view, the voluntary interruption of pregnancy is accessible to minors without the consent of their parents[20], as well as to women living as part of a couple without the consent of their husband or partner: the legal provisions do not grant him any right of veto[21].

B. Harm done to the unborn child or the child during birth

Lawsuits for compensation originating in the life given to a child are thorny issues that are

[20]The law of 3 April 1990 does not make any particular provision in this respect, but this results from Article 12, § 2, of the law on patient's rights. See C. arb., 19 December 1991, ruling No 39/91, J.T., 1992, p. 362, note COENRAETS, and the obs. of S. VAN DROOGHENBROECK *in*: *Droit international des droits de l'homme devant le juge national*, Brussels, Larcier, 1999, p. 61 (the principle of the equality of Belgians before the law does not require an under-age child who is pregnant and wishes for an abortion to consult her parents beforehand, or permit these to bring the matter before a court). See M.-N. VEYS, *Abortus bij minderjarige en wilsonbekwame patiënten*: *de rol van de Wet Patiëntenrechten en de noodtoestand*, note under Corr. Bruges, 7 February 2006, Rev. dr. santé, 2006-2007, p.153.

[21]C.E.H.R, *Boso v. Italy*, No 50490/99, decision on admissibility of 5 September 2002: the interpretation of the right of the potential father to respect for his privacy and his family life must, above all, take account of the rights of the mother who intends to abort, since she is primarily concerned by the pregnancy, the continuation or the interruption of this pregnancy; once the abortion has been performed in accordance with the law and pursing the objective of safeguarding the health of the mother, any interference in this right of the father is justified as being necessary to the protection of the rights of others. This also results, *mutatis mutandis*, from the ruling of the Court of Cassation of 14 December 2001 quoted above, pronounced on the subject of sterilisation (note LELEU and GENICOT, *J.L.M.B.*, 2002, p. 532); see also Ghent, 8 August 1992, note BALTHAZAR (consent of the unmarried partner), *R.W.*, 1992-1993, p.366.

difficult to decipher. The law (both criminal and civil) faces three separate but related issues in this respect: the harm done either to the foetus *in utero*, or to a child during birth; liability consecutive upon the birth itself, when this occurs further to failed sterilisation or interruption of pregnancy; and that resulting from the medical condition of the child, if the latter is born with a serious handicap that was not detected during ultrasound scans or prenatal diagnosis. There does not seem to be any need to look at these last two questions here; the extremely complex issue of lawsuits involving civil liability consequent upon the birth of an unwanted or serious disabled child[22] bears very little relation to the question being analysed. Similarly, in terms of civil law, the harm done to the unborn child or the child during birth does not really pose any particular problem: when the cause of this lies in an error, it gives rise to a claim for compensation, as with any other injury caused by fault, in this case in favour of the parents, both personally and as representatives of the child whose bodily integrity has been harmed.

It is more relevant to take a closer look at the way in which the protection of the foetus *in utero* and of the child at the time of birth is assured under criminal law; in this respect, the situation is more complex, as can be seen from the relative duality of the analyses of the French and Belgian Courts of Cassation. Criminal law, as modelled by basic rights, protects *human life.* In the view of the Belgian Court of Cassation, the right to life, within the meaning of Article 2 of the European Convention on Human Rights, "refers only to the right to physical life in the usual meaning of the term and not to what could, according to an individual's own subjective opinion, be considered to constitute or not constitute life worthy of being lived" and this provision "includes the protection of the life of the child from before its birth"[23]. As a sign of the conceptual autonomy of criminal law, there is no need, when making a statement like this, to consider the unborn child as a *person*; this civil-law concept refers to the insertion of a human being into a lineage, with a view to making it more capable of benefiting from the prerogatives of familial patrimonial law, which is totally different.

As regards *criminal liability in the event of damage caused to the foetus before or during childbirth*, it is important to remember that the murder of a child at the time of its birth or immediately afterwards is classified as *infanticide* (Article 396 Criminal Code). For this infringement to be established, the child must be alive at the moment when it is committed, but it does not have to be viable. *Involuntary* infanticide is not punished as such by the Criminal Code but in a famous ruling dated 11 February 1987[24], the Court of Cassation decided that the *manslaughter of a child during delivery is liable for punishment*. This confirms that the criteria of civil law, to recognise the right to a legal personality, are foreign to criminal law: this law protects the child *during birth*, even though it has not experienced life outside the womb, against any deliberate or unintentional act leading to its death or directly causing injuries. The deduction is that the doctor – and indeed anyone else – who, owing to a lack of foresight or precaution, causes the death of a child during birth, commits *manslaughter* even though the child in question has not yet experienced life outside the womb, if this death was caused by his fault or his negligence.

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[22] On this matter, see G. GENICOT, *Droit médical et biomédical*, Brussels, Larcier, collection of the Faculty of Law at the University of Liège, 2010, pp. 561-580; G. GENICOT, *Le dommage constitué par la naissance d'un child handicapé, R.G.D.C.*, 2002, pp. 79-98; G. GENICOT, *L'indemnisation de la perte d'une chance consécutive à un manquement au devoir d'information du médecin*, *J.L.M.B.*, 2009, pp.1165-1182.

[23] Cass., 22 December 1992, *Pas.*, 1992, I, p. 1402, *J.D.J.*, 1994, p. 31, *R.D.P.*, 1993, p. 650, *R.W.*, 1993-1994, p. 464, note WOUTERS; however, this is not a ruling of principle.

[24] Cass., 11 February 1987, *Pas.*, 1987, I, p. 694, concl. JANSSENS DE BISTHOVEN, *J.L.*, 1987, 630, note PREUMONT, *R.D.P.*, 1987, 812, concl. JANSSENS DE BISTHOVEN, note HENNAU-HUBLET, *T. Gez.*, 1987-1988, p. 41, note ANDRÉ, *J.T.*, 1987, p. 738 and the note of F. KÉFER, *La protection pénale de l'enfant à naître.*
A doctor was prosecuted for having committed an error during the hours prior to the delivery of a lady who had given birth to two children, one of which was stillborn, the other born alive but not viable, and died the following day. The court of appeal in Liège had, in a ruling of 25 June 1986 (*J.L.*, 1986, 674), considered that this doctor had omitted "with culpable obstinacy, to take the elementary measures necessary for a successful delivery" and "that his successive errors engendered the death of the twins". The doctor sentenced appealed to the Court of Cassation against this decision establishing against him the accusation of manslaughter and culpable abstention because these infringements concerned babies that were stillborn or born alive but not viable. He maintained that such children could not be defined as a person, as this definition is only applicable to a human being born alive and viable. This argument was rejected.

The major ruling, approved by doctrine, means that the protection provided by Article 396 of the Criminal Code[25] is broad: it begins *from the onset of labour* and therefore concerns a human being who, although already alive, *is not yet a person within the meaning of civil law.* Pursuant to the principle of the *autonomy of criminal law*, the criminal concept of the human person is therefore not the same as the civil concept; criminal law protects human life, rather than the legal person, the crime of murder or manslaughter can refer to a child *who is not yet born but is on the point of being born*.

Can Article 422*bis* of the Criminal Code, which punishes the failure to assist or obtain assistance for an individual exposed to a grave danger also be applied to an unborn child, whether or not it is viable? The answer to this question is, in principle negative: subject to the above, the child not yet born cannot, in legal terms, be described as a person and in theory is therefore not eligible to be hold rights, even in the criminal sense. While criminal law is conceptually autonomous, it is also, and above all, *to be strictly interpreted* as regards the accusations it contains. It should be noted that, in the case that led to the ruling from the Court of Cassation of 11 February 1987, the Court of Appeal in Liège had judged the doctor guilty of *non-assistance to an unborn child exposed to a grave danger* and had sentenced him for failing to assist a person in danger, deeming that Article 422*bis* of the Criminal Code also applies by analogy to the child not yet born; the Court of Cassation did not have to pronounce judgement on this issue, as the appeal did not request this.

What is the situation when involuntary injuries are inflicted upon the foetus *before delivery*, for example during a medical intervention, and cause its death *in utero*? This hypothesis may be compared to the situation in which a therapeutic abortion is rendered necessary by negligence on the part of the doctor. "Involuntary" abortion is not punished as such by the Criminal Code; the scope of the aforementioned ruling of 11 February 1987 must be limited to the harm – deliberate or not – done while the child is "being born". There cannot therefore be any question of murder or manslaughter when the act is *prior to delivery*; the protection conferred by Article 396 of the Criminal Code does not extend back to conception[26].
In France, involuntary harm done to the life of the unborn child does not, in the eyes of the Court of Cassation, constitute *manslaughter*: the principle of the legality of offences and punishments, which requires a strict interpretation of criminal law, prevents this accusation being extended to the case of the child that is not born alive, for which the legal system falls under specific texts on the embryo and the foetus[27]. So there is only scope for the accusation of *blows and injuries* inflicted on the future mother, with, in terms of civil law, reparation (basically moral) for the particular harm thus caused to her. As the foetus is therefore not considered to be a human person with criminal-law protection under French law, a grievance was brought before the Court in Strasbourg concerning an infringement of Article 2 of the European Convention on Human Rights, which gave rise to the ruling of 8 July 2004, *Vo v.*

[25] As, moreover, by Articles 418 C.P. (referring to manslaughter) and 420 C.P. (referring to blows and injuries due to a lack of foresight and precaution).
[26] In this regard: Ghent, 26 March 1997, *A.J.T.*, 1997-1998, p. 463, note COUDRON. See also, in jurisprudence, Corr. Antwerp, 24 November 2000, *R.W.*, 2000-2001, p. 1423, notes DESMET and NYS, *J.D.J.*, 2001, No 206, p. 45 (Articles 418 and 419 of the Criminal Code, which punish unintentional injuries, protect the person only as of birth – the life to be born being protected more precisely as of the commencement of childbirth, but not as regards unintentional injuries against errors committed *before the* commencement of childbirth; on the other hand, the threat of losing the unborn child undeniably constitutes, *for the pregnant mother,* a situation of serious danger within the meaning of Article 422*bis* of the Criminal Code); Corr. Hasselt, 24 December 1999, *Rev. dr. santé*, 2001-2002, p. 167 (a doctor cannot be sentenced for manslaughter if the proof of the causal link between the error and the death of the child is not sufficiently established, notably when the child, from birth, presented serious, pre-existing and irreversible injuries, but on the other hand he is guilty of failing to provide assistance to an unborn child who is in serious danger when, despite a telephone call from a midwife, he fails to go to the hospital to check on the state of the patient); Pol. Turnhout, 30 September 2003, *Bull. ass.*, 2004, p. 326, note MUYLDERMANS, *R.W.*, 2004-2005, p. 1073 (a 14-week foetus cannot, as an unviable being, be considered to be a *weak user* having been the victim of a road accident to which applies Article 29*bis* of the law of 21 November 1989 on mandatory liability insurance for motor vehicles). See also Liège, Chapter 8 corr., 22 November 2007, unpublished, notice No 2007/CO/84; Mons, 24 April 2003, *R.G.A.R.*, 2004, No 13.870 (compensation for moral harm, necessarily individual, suffered by the parents in the event of the loss of a stillborn child, taking account, by analogy, of the "applicable jurisprudential standards in the case of the loss of a child").
[27] Rulings of the criminal chamber of 30 June 1999 and 25 June 2002, and the plenary assembly of 29 June 2001. These decisions, which have been very widely commented on, caused great emotion and criticism of doctrine.

France, to be referred to below.

C. Legal status of the embryo and the foetus

This is a bottomless pit of bioethical literature which appears, if not insoluble, then at least unlikely to give rise to a single, consensual response; this thorny issue has already been broached by the Committee in previous opinions[28] and it does not seem advisable to open up again, in the context of the question examined in this opinion, the debate on the *nature* and *status* of the embryo. This question, which is often included in philosophical, not to say metaphysical analyses, when posed from a strictly legal point of view and in terms of *legal definition*, appears to be a delicate one to resolve, particularly since this quest must always involve ethics. These days, it is wise to "give concrete form" to the issues involved by including them in the subject matter of research into *in vitro* embryos, pre-implantation diagnosis and more generally all aspects of medically assisted procreation, as currently governed, in Belgium, by the laws of 11 May 2003 and 6 July 2007.

The fundamental right to respect for life is granted to every person[29]. Does this presuppose the prior recognition of the existence of the person in legal, biological or anthropological terms? Can the embryo be described, *in legal terms*, as a "person"? The question of the status of the 'embryo and foetus, placed at the centre of this question, has repercussions in the fields of the voluntary interruption of pregnancy, medically assisted procreation and civil liability (medical or not) in the event of damage caused to the unborn child, a matter (in)directly concerned by the question examined in this opinion.

According to the ruling of the European Court of Human Rights of 8 July 2004, *Vo v. France*, the embryo is not as such the holder of the right to life protected by Article 2 of the Convention; the respect due to it results from a coherent body of rules, which provide it with sufficient protection[30]. More specifically, the Court considers "that it is neither desirable nor even possible, at the moment, to give an abstract response to the question of whether the unborn child is a “person” within the meaning of Article 2 of the Convention", after having noted that the unborn child does not have a clear legal status, nor is there any European consensus on the status of the embryo. So it does not settle the question of principle – for which it was criticised – but notes that, as the dispute in question concerns an involuntary fatal attack on the unborn child, against the wishes of the mother and at the cost of particular suffering for the latter, the interest of the foetus (in this case aged 20 to 21 weeks, and therefore not viable) and of the mother merged.

Briefly, the ethical progress which, according to some people, is said to be marked by granting the embryo or the foetus the quality of a *person* within the means of this provision,

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[28] See in particular the opinion No 18 of 16 September 2002 on research on the human embryo *in vitro*, in which the Committee noted the impossibility of reaching a consensus and noted several insurmountable currents of thought among its members: "gradualist", "fixist", "scientific positivist" and "intentionalist".

[29] Pursuant to Article 2 of the European Convention on Human Rights, "Everyone’s right to life shall be protected by law".

[30] E.C.H.R., 8 July 2004, *Vo v. France*, J.C.P., 2004, II, p. 10158. This concerned a virtual homonymy between two Vietnamese patients who came to a hospital in Lyon at the same time, one for a medical visit in the sixth month of her pregnancy, the other to have an IUD removed. The doctor performed the procedure to remove the IUD on the first patient, piercing the amniotic sac, which led to the therapeutic interruption of the pregnancy. After a long legal process, the French Court of Cassation decided that the "error of imprudence and negligence, which presents a certain causal link with the death of the child borne by the patient", is not equated to the "fact of causing, (…) by clumsiness, imprudence, inattention, negligence of failure to fulfil an obligation of safety or prudence imposed by the law or the regulations, the death of another". Before the European Court, the plaintiff claimed in particular the infringement of Article 2 of the Convention, the reason being that the charge of manslaughter had not been brought against the doctor responsible for the death of her child *in utero*. In its ruling, the Strasbourg court examined the case from the point of view of the adequate nature of existing means of appeal in French law, in other words, it assessed the protection granted to the mother to assert the liability of the doctor in the loss of her child *in utero* and to obtain reparation for the forced interruption of her pregnancy; once the mother had the possibility of taking action for liability owing to the error committed by the doctor, the Court held – even supposing that Article 2 applies in this case – that this action could constitute effective recourse at her disposal, such that Article 2 had not been infringed.

is said to be offset by the risk of overturning the balances achieved in terms of the bodily integrity of the pregnant woman[31]. In fact, if the embryo is considered to be a person in legal terms, its *right to life* will be guaranteed, and this creates at least an apparent contradiction with the legislation on the voluntary interruption of pregnancy; to escape from this impasse, it would be necessary to consider that, in conditions laid down by law, the voluntary interruption of pregnancy constitutes *excusable homicide*, by analogy with legitimate defence or the state of necessity, and weigh the interests against those of the mother on a case by case basis.

From a purely *legal* point of view, it is preferable *not to consider the embryo as a person*. In this sometimes heated debate, involving the moral, ethical, philosophical and "convictional" views of each individual, sight is often lost of the fact that the concept of the person is *plural* and that, when used in the field of legal regulations – particularly put to the test here – it has a precise and "technical" meaning from which it would be hazardous to depart. The unborn child benefits from obvious protection; this concern, which involves guarantees offered to the pregnant woman, is clearly present in our legal texts[32]. It would not be advisable, with a view to optimising the legal system applicable to it, to call into question the civil-law rules governing the insertion of an individual into a lineage and the various consequences of acquiring a legal personality.

The embryo has now been given a legal definition: the laws of 11 May 2003 and 6 July 2007 describe it as a "cell or organic set of cells likely to develop into a human being", the embryo being *in vitro* when it "lies outside the female body" and surplus if it "has been constituted in the context of medically assisted procreation but has not been implanted in the woman". Within the meaning of the law of 19 December 2008 on obtaining and using human bodily material intended for human medical applications or for the purpose of scientific research, the embryo is "the cell or functional set of cells of an age between fertilisation and eight weeks of development and likely to develop into a human person", whereas the term foetus refers to "the functional set of cells aged older than eight weeks of development and likely to develop into a human person".

These definitions are devoid of any real ontological effect on the further debate: they are purely "functional" descriptions aimed at defining the scope of application of the texts that contain them[33]. They do, however, indicate that the normative system thus implemented assumes a distinction between the embryo and the person: without a body and its own individuality, *pars viscerum matris*, the embryo is not yet a legal person, although this does not, of course, mean that it is not worthy of protection. When developing this, the law must take care to safeguard a number of imperatives: not to hamper scientific and technical progress, which is very largely beneficial and which, whether we like it or not, involves "harming" the embryo; not asserting one system of moral values above another in a pluralist

[31] See, in this respect, Y.-H. LELEU et G. GENICOT, *La maîtrise de son corps par la personne*, *J.T.*, 1999, p. 597, No 38-39; Y.-H. LELEU and E. LANGENAKEN, *Quel statut pour l'embryon et le fœtus dans le champ juridique belge?*, *J.T.*, 2002, p. 658, No 5.

[32] As an example, the royal decree of *2 May 1995 concerning the protection of maternity* (Belgian official journal of 18 May 1995) aims to detect risks in the context of employment relations and prevent pregnant women being exposed to them; Annex 2 refers to the human immunodeficiency virus (HIV) among the banned biological agents referred to in Article 7, paragraph 2, of the royal decree, and that would entail the immediate application of one of the measures provided for by the labour law of 16 March 1971 if the pregnant or breastfeeding employee performed an activity which, upon assessment, revealed the risk of exposure and which endangered the safety or the health of the employee or her child. Article 20.1.1.3, paragraphs 2 and 3, of the *royal decree of 20 July 2001 containing general regulations on the protection of the population, workers and the environment against the danger of ionising radiation* (Belgian official journal of 30 August 2001) states that "the protection of the unborn child may not be less than that offered to members of the public. As a result, as of the declaration of pregnancy, the conditions to which the pregnant woman is subject in the context of her employment must be such that the dose received by the unborn child is as low as it is reasonably possible to obtain and must be less than 1 millisievert throughout the pregnancy. If this dose is already exceeded at the time of declaration of pregnancy, the pregnant woman will be removed for all work stations exposing her to the risk of ionising radiation. No woman who is breastfeeding and no pregnant woman after the declaration of pregnancy may be allocated to a work station comprising a professional risk of bodily radioactive contamination".

[33] In this respect, Y.-H. LELEU, *La loi du 11 mai 2003 relative à la recherche sur les embryons in vitro*, *Rev. trim. dr. fam.*, 2003, p. 718, No 6; N. GALLUS, *La procréation médicalement assistée et les droits de l'homme*, *Rev. trim. dr. h.*, 2008, p. 886, note 12.

society; guaranteeing the people from whom the embryo comes – whether or not it is part of a plan to become parents – a constant right of scrutiny, control over the use made of it; finally, provide ethical barriers to accompany this use (research, experiments, development of assisted procreation techniques), set all the more firmly and followed all the more naturally if they are not devised abusively and overly severely, in the interests of respect for the *humanity* of the embryo and hence of human dignity.

By referring to a set of cells likely to develop into a human person, the Belgian legislator appears to be adopting the famous definition of the *Comité consultatif national d'éthique français* (CCNE – French national advisory committee on ethics), which at a very early stage (opinions of 23 May 1984 and 15 December 1986) described the embryo and the foetus as "potential human persons". This is a *human being*, in the biological sense of the term – what is more, in the *continuum* of the start of life, biology cannot be used to distinguish between the embryo and the foetus – but which is *not yet individualised as a human person*. This description can be used to stress the necessary protection due to the person which the embryo is *destined to become*, but also indicates that the legal system to which it is subject has to take account of the imperatives of scientific progress and the autonomy granted to people *who exist at present*, foremost among whom is the mother. This explains why abortion is permitted, while being subject to certain conditions.

It is true that legal logic finds it difficult to escape from the persons/things duality. While *biological* man is a *continuum*, from fertilisation to death, *legal* man is characterised by discontinuity or dichotomy: each stage defined by law risks being tinged with arbitrariness, as scientific knowledge progresses[34]. This is why – and the legal definitions given above confirm this – while it is not relevant, and is even totally inadequate, to describe the embryo as a person *in legal terms*, it is, nevertheless, certainly advisable to model the system to which it should be subject on its *nature as a human being*. Biological existence, human nature: the distinction is not pure quibbling[35]. Moreover, it seems futile to want to add anything at all to an endless debate; the law does not close its eyes nor yield anything if it confines itself to providing adequate protection for the embryo, which is already a being and becoming a person[36].

IV. Ethical considerations

A. Case study

In the ethical treatment of the question submitted to the Committee, the case study seems to be a particularly instructive method for at least two reasons.

The first relates to the fact that, given the diversity of contexts in which it arises, it does not seem possible to deal with this question adequately in ethical terms using a deductive method, that is by the systematic application of a few major principles to all the situations encountered. The second reason results from the very way in which the experts invited by the select commission tackled this issue. They all started from their own professional experience, situations that they had seen themselves or of which they had been told.

Thinking about ethical aspects on the basis of cases implies taking a few precautions. The cases that are to enable us to clarify the question before us and examine the solutions

[34] Hence, in the pluralist context that characterises our society, the plurality of the aforementioned Committee opinion No 18 of 16 September 2002 on research on human embryos *in vitro*.
[35] P. MURAT, *Réflexions sur la distinction être humain / person juridique*, *Dr. Fam.*, 1997, chr. No 9.
[36] "Thus it appears that this human being cannot be reduced to a classification that at the same time seems to be outdated, because it is inappropriate" (M. GOBERT, v° Biologie et droit, *in: Dictionnaire de la culture juridique*, D. ALLAND and S. RIALS (dir.), Paris, P.U.F., Quadrige, 2003, p. 141); see also and compare C. M. MAZZONI, v° Embryon, *in*: *Dictionnaire du corps*, M. MARZANO (dir.), Paris, P.U.F., Quadrige, 2007, p. 330.

chosen by the experts consulted from an ethical point of view come from three sources. The first is that of oral testimonies from the experts heard by the select commission, the second is UNESCO and the third is the jurisprudence of the United States of America.

The status of these three sources and the objectives that they pursue in presenting and analysing the cases differ from one another. The narration of a case reflects these various ultimate aims and the position of the narrator[37]: in the choice of elements of the situation deemed to be sufficiently important to be related, in the way of introducing the various points of view or of not including them all in the narration, in the way of naming the protagonists (their capacity), in the way the solution found is explained, etc.
As part of this ethical discussion, case analysis will simply set out the elements that seem to play a major role in the treatment of the question involved, without giving exhaustive details of all its dimensions.

1. Cases having arisen in Belgian hospital units

The unit heads of the obstetrics or neonatal departments of the teaching hospitals attached to the KUL, the ULg and the ULB have witnessed various examples in their units linked the question raised (see *in fine* "invited experts").

Ten patient cases were selected and classified on the basis of the main reason given for the refusal: A/ religious and cultural grounds, B/ personal reason or comfort, C/ fear of social exclusion, D/ negligence due to the psychopathology of the pregnant woman.
The experts recounted the cases in varying degrees of detail. The cases for which the narratives were most extensive concerned categories A, C and D. Category B cases were usually explained in just a few sentences, no doubt because the experts consider them to be illustrations of the pure and simple expression of the will of the pregnant woman. We shall see that the ethical assessment of this expression of the will of the pregnant woman is more complex that it appears at first glance.

A. Religious and cultural grounds

A.1. Case of a woman who is a Jehovah's Witness and who, owing to her religious convictions, refused an intra-uterine blood transfusion via the umbilical cord

The presence of antibodies corresponding to a rhesus negative factor incompatible with that of the blood of the foetus is detected in the blood of the mother. She is at 31 weeks and has been experiencing cardiac problems for a week, such that if there is any further delay in taking action, cardiac decompensation, cerebral anoxia and the rapid death of the foetus are to be feared. An in utero transfusion via the umbilical cord is technically possible and proves medically necessary. If action is taken in time, the prognosis is favourable (three blood transfusions are usually sufficient to enable the foetus to develop normally and be born at full term). However the mother, who is perfectly aware of the risks owing to her professional training, refuses the treatment owing to her religious convictions.
After intensive discussions, the pregnant woman still refuses to agree to the principle of an intra-uterine blood transfusion but agrees to an induced delivery at 32 weeks (eight weeks before term). In advance, the team did not rule out the possibility of a transfusion on the child born before term were its haemoglobin level to be less than 7 g/100 ml. The mother accepts this possibility, going along with the argument that her baby – once born – has individuality and its own autonomy (and as such is

[37] See on the subject of the construction of cases in bioethics, the work by Tod Chambers, *The fiction of bioethics. Cases as literary texts*, New York and London, Routledge, 1999.

protected by the law).

The team decides to induce the birth at 32 weeks, one the one hand to limit the risks just to the consequences of a premature delivery and place the baby on artificial respiration, and on the other hand to be able to carry out a blood transfusion on the baby. The baby recovers quickly. The nurses have huge difficulties in giving their consent; in fact, they are in the front line when it comes to seeing to the respiration and care of the premature infant, whereas this could have been avoided. Moreover, during the discussions, the argument was often put forward that it would have been possible to avoid two or three weeks of intensive care (costly in terms of equipment and staff).

In this case, the pregnant woman refused to accept the treatment on a duly informed basis, since due to her profession she is capable of considering, in full knowledge of the facts, the consequences of her refusal for the health of her foetus.
Although this woman bases her refusal on religious convictions, this does not mean that she is closed to discussion, and hence to compromise. This was indeed what happened. What this case clearly shows is that the compromise was reached with difficulty both on the part of the patient and on the part of the medical team, in particular the nurses. Both parties had the interest of the foetus at heart, but referred to different existential categories. The woman wished to comply with a religious ban (blood transfusion) so as not to encumber the life of her future child with a spiritual, personal and social weight deemed to be intolerable. The medical team wanted to act in the interest of the foetus by applying the rules of good clinical practice which would enable the child to live in good health. Both protagonists agreed to make major concessions, as can be seen from the heat of the discussion: the mother acknowledged that upon the birth of the child, religious and cultural precepts would take second place and that as a legally protected person, he would be able to receive a blood transfusion; the nursing team agreed to give up on the solution that was the most obvious in medical terms (an intra-uterine blood transfusion) and the least costly in economic terms[38].

A2. *Case of a Muslim woman refusing a Caesarean and for whom an imam was called in*

A pregnant Muslim woman presented arterial hypertension giving rise to chronic foetal suffering and a significant retardation in the development of the foetus. In the interest of the health of the child, the medical team favoured a premature delivery to prevent irreversible lesions. The language and cultural barrier prompted a refusal, by the pregnant women, to undergo the Caesarean birth suggested. She gave no credit to the diagnosis or to the proposed treatment, something which is more common among new immigrants who have not yet had the time to become familiar with our culture and with the advantages that our health-care system has to offer. The reasons put forward to justify the refusal included a combination of the following arguments: "this is not a normal way of giving birth", "I have a friend whom they wanted to force to have a Caesarean, who refused and who eventually gave birth normally, and everything went well" and "I think the Koran forbids it".

So an imam was called in. With the Koran in his hand, he found the right arguments to have the mother agree to the Caesarean. Imams are sometimes included in the discussions as mediators, persons of trust, culturally acceptable intermediaries, to build a bridge with our system of reference; they are often proud of being able to fulfil this role.
The expert notes that with immigrants from eastern European countries, he is confronted with this type of case less frequently because these people are more

[38] For a more precise analysis of the ethical problems raised by the refusal of blood transfusions by Jehovah's Witnesses, we refer to the Committee opinion No16 of 25 March 2002 on the *refusal of blood transfusions by Jehovah's Witnesses*.

familiar with our system of reference when it comes to health care.

It should be pointed out that two of the arguments put forward by the pregnant woman are not specific to any particular culture. The first argument is based on the fact that delivery by Caesarean is not normal, i.e. not natural. The wish for a natural pregnancy and delivery without or with a minimum of technical, medical intervention is a trend that can be found among the Belgian population and in Western society. The second argument also has no specific cultural resonance. Relying on accounts of medical diagnoses that proved to be incorrect, the pregnant woman doubts the need for a Caesarean. Her behaviour reflects that of a number of people who see medicine as knowledge and practice based on certainties. So if the medical discourse fails to correspond to reality, this is interpreted as incompetence on the part of the doctor and can give rise to suspicion with regard to medicine in general, or even a rejection of medicine, pure and simple. Now, medical knowledge is based on certainties, but also on assertions that include a variable degree of probability. The line from cause to effect is rarely clear and definite; it often includes dotted segments, revealing the limits of medical knowledge.

The narration of the case hardly gave rise to any discussion of these two arguments by the pregnant woman and the medical team. The language barrier was put forward as an excuse and could not be overcome by calling upon a family member, a member of the medical staff speaking the same language, an external translator, etc.
While the medical team does not appear to have managed to establish the legitimacy of its argument and its practices with the pregnant woman, this lack of a decision-making body that was legitimate in the eyes of the pregnant woman was to be overcome by the intervention of the imam. In fact, the imam is seen by the pregnant woman as a figure of trust, whose argument is credible and whose decision is not open to appeal. He is also seen positively by the medical team. The narrator states that this mediation role is a matter of pride for the imam.

Does this mean that in this case, the woman was convinced of the benefit of the Caesarean and was therefore persuaded that the recommended intervention was valid? This is not certain: she may simply have accepted the opinion of the imam, a religious leader in whom she places more trust than medicine as practised in Europe. And ultimately, it does not really matter: what matters is that the child was delivered safely.

Contrary to what this narration seems to indicate, mediation between two points of view – one religious, the other scientific – does not really seem to have occurred, in that the imam did not make the link between the two, or cause the transition from the one to the other. On the contrary, the doctors, representatives of the scientific point of view, called upon the religious point of view, represented by the imam, to obtain the patient's consent. Far from being a triumph of "science" over "faith", "faith" represented by religious authority, finally won the woman over.
This case raises the question of the ultimate aim of the intervention of a third party, in this case a confessional third party, in an exchange between the patient and the medical team. We will return to this issue in the next case.

A3. *Case of a Muslim woman who refuses a Caesarean without having the prior consent of her husband.*

A young woman, originally from North Africa who has recently arrived in the country, with an extremely limited knowledge of French, was 34 weeks pregnant and was taken in for an endoscopy of her digestive system owing to very severe abdominal pains. The endoscopy, carried out as an emergency, revealed the presence of a gallbladder stone that had become lodged in the peritoneal cavity and had not only led to a chemical inflammation of the peritoneum but was also causing critical if not fatal problems for the foetus. An emergency Caesarean section was therefore proposed but the woman, panic-struck, refused to allow a laparotomy to be performed until her husband had been asked for his opinion. The woman had great difficulty in expressing herself in

French, but it was nevertheless clear that she was aware of the critical nature of the situation and the need to intervene as the only solution to the medical problem. Nevertheless, she persisted in her refusal on religious and cultural grounds. The urgency of the situation rendered impossible any long discussion or negotiation with an intermediary or a cultural mediator with a view to finding a solution. Contacted by telephone, the husband arrived too late. The foetus' heart had already stopped beating. The following day, a laparotomy proved necessary in any case, in order to carry out the intervention.

Unlike in the previous narration (A2), the function of decision-maker recognised by the pregnant woman is held by her husband.

This case highlights a threefold difficulty. The first concerns the conflict, as regards the patient, between her perception of the serious and urgent nature of the medical situation and the impossibility, in her eyes, of taking a decision alone, without ensuring that this was in line with her husband's opinion. In this respect, on the basis of medical experience in Palestine, one of the experts consulted told us that ordinarily, pregnant women do not give their own opinion but express the wish of the head of the family. It is necessary to negotiate firmly and with authority with this person in order to succeed in imposing a decision. We will return to the implications of this decision-making by a third party for the concept of autonomy.

The second difficulty, already mentioned in the previous case, is that of communication hampered by the language barrier.

The third one relates to urgency in decision-making. The narrator implies that the rapid intervention of an intermediary and the possibility of holding a longer discussion would perhaps have led the pregnant woman to accept the intervention, even without the consent of her husband. This would have created a situation similar to that of case A2 in which an imam intervened. Without an intermediary who is rapidly available and in an emergency, the medical team nevertheless took the decision to respect the patient's request, by attempting to discover the opinion of her husband and agreed to take the risk of not being able to save the foetus, a risk that unfortunately materialised.

B. Reasons of advisability

B1. A *pregnant woman refuses to give up her holiday planned in a far-off country despite her advanced pregnancy and a less-than-reassuring health-care infrastructure*

B2. A *pregnant woman refuses to give up her winter sports holiday despite the risks of serious compilations* (*placenta praevia*[39])

These first two cases refer to the expression of the will of the pregnant woman as a major reason for her refusal to follow medical advice in the interests of caution. Unlike the category A cases, the ethical problem is not linked to the heteronomy of the will, that is the fact that the pregnant woman leaves it up to an external party (family, religious figure) to take a decision that concerns her, but to the autonomy of the person.
From a legal point of view, we have seen that the expression of the will of the patient, her informed and free consent or refusal, must be respected by the medical team.
As regards ethics, some members of the Committee uphold the same attitude: irrespective of the reason given by the pregnant woman for the refusal, even if this reason may seem trivial (holidays) or even if no reason is given for the refusal, this absolutely must be

[39] Definition of *placenta praevia*: abnormal insertion of the placenta in the lower uterine segment, *in*: *Dictionnaire abrégé des termes de médicine*, J. Delamare, Maloine, 2006.

respected, because the pregnant woman is the only one who can decide on an intervention on her own body. The medical team must confine themselves to passing on the information to her, giving her advice and establishing a dialogue to dry and reverse her refusal. Other members – and we will return to this point of view in more detail in Part IV B 2.3., believe that there is a major inconsistency in wanting to give birth to a child in good health and not doing everything possible to attain this objective, that is, if need be, not giving up secondary sources of satisfaction such as holidays.

B3. A primiparous pregnant woman aged 39 refuses to stop engaging in a violent sport (kick-boxing) because she wants to carry on at least with "light" training, despite the warnings of her gynaecologist about the risks of abdominal traumatisms. And indeed, she suffers a blow to her stomach and miscarries in the sports hall.

This case illustrates the difficulty of defining the often complex context in which a person takes a decision, all the more so when this decision potentially has consequences for the foetus. In fact, while engaging in a violent sport does indeed mean taking a serious risk with regard to the health or the survival of the foetus, the decision to practise this sport may be based as much on a simple wish to continue an enjoyable activity as on the psychological, social or economic need for the pregnant woman to continue to train. The distinction between these contexts of refusal leads us to make a distinction between personal reasons and reasons of pure convenience. The expression of the person's will is not necessarily – far from it – the expression of a egotistical point of view preoccupied with the satisfaction of trivial or irresponsible desires (reason of convenience).

Once again, some members see respect as such of the will of the pregnant woman as an attitude that is justifiable in ethical terms, while others require that the force of the justification put forward should be assessed before a judgement is pronounced on its ethical nature.

B4. An aerobics teacher is pregnant and her gynaecologist asks her at least not to jump any more. However, she refuses to listen because she has to earn her living and finally gives birth to a stillborn child in the gymnasium

This case could meet the demand made by some members (see above, the comments on case B3) for a strong justification in ethical terms. In fact, the pregnant woman may not have a choice about whether or not to give up her work. This situation is frequently encountered among women who exercise a liberal profession, at home, among those without job security or those who fear that their employer will take advantage of this interruption in their work to delay promotions to which they could lay claim in the same way as their male colleagues.
This case again shows that the refusal of the pregnant woman may be motivated not by egotistical reasons but by the interest of the foetus, ore more accurately the interest of the child that this foetus will become. The pregnant woman may, if necessary, take a risk for the foetus in order to be able to welcome the child into the world in good material conditions.

B5. A woman pregnant with twins who is giving birth prematurely refuses to take tocolytics[40] to delay delivery. She refuses to take the drugs because of the side effects that they could have and because they are seen as toxic.

The grounds for refusal put forward in this case are similar to those in case A2 in that they call into question the reliability of the medical argument: the pregnant woman fears that she is being made to take toxic substances or substances with serious side effects. The only difference compared with case A2 is that here the pregnant woman takes a decision herself and this decision is apparently not linked to any particular religious or cultural context.

[40] "Taking medical care of the threat of premature delivery aims in particular to prevent contractions of the womb (tocolysis). Although tocolytics do not usually make it possible to prevent the premature delivery, short-term tocolysis can, nevertheless, improve the perinatal prognosis..." see the website of *Folia Pharmacotherapeutica* available at http://www.chu-rouen.fr/ssf/prod/tocolytiques.html.

C. Reason based on the fear of social exclusion

A Dutch woman originally from Surinam, on the point of giving birth, comes in for an examination on an impromptu basis. As the results of the serological examination provided indicate that she is seronegative, she gives birth by Caesarean section. However, subsequent blood tests reveal that she had concealed the fact that she is seropositive. The gynaecologist has issued the prescription but the blood test had been done in another unit and the patient had provided a sample that was not her own. By doing this, the mother deliberately put her foetus and the care providers in danger. She had also concealed the fact her therapeutic relations with her GP in the Netherlands were difficult and that custody of her first two children had been taken away from her by a Dutch judge. By coming to have her child in Belgium, she wanted to escape the coercive measures that had been imposed on her in her own country.

Negotiations took place with the obstetricians and the nursing staff of the team, who were fairly annoyed about this deception, to enable her to return nevertheless with her child and to benefit, along with her baby daughter, from antiviral treatment, which she agreed to do.

This case demonstrates the social difficulties encountered by those who are seropositive and the harmful effects of these for the health of the foetus and the pregnant woman. The Committee has already covered the issue of the fear of stigmatisation in its opinion No 17 of 10 June 2002 *on the ethical aspects of self-screening tests for the human immunodeficiency virus (HIV).*

In the case in point, the refusal took the form of withholding information by the pregnant woman and deception as regards the hospital units, likely to have health implications for the nursing staff. In this context, therefore the risk taken for the health of the foetus is replaced by a more global risk, since it concerns the health of the pregnant woman and that of the medical team.
Added to this are problems of communication and the transmission of information between medical services, between doctors practising in different countries and between social services. The question of the gradual creation of a single medical dossier and the possibility of this being available for consultation by the various medical protagonists is raised here. In the case described here, the lack of such consultation made it possible to withhold information and practice a deception which resulted in the failure to provide adequate care.

The interest of this case lies in the fact that it presents a new means of refusing care. This is no longer an expressed refusal (which this is expressed by the pregnant woman (case B) or by the pregnant woman in line with the opinion of a third person (case A)), but a refusal not expressed to the medical team, and even a refusal made possible by lying to the medical team. So the anger of this team as expressed in the narration is understandable: anger at having been duped, anger at having been put in danger (risk of transmission of the virus), anger at not having been able to provide appropriate care in time.
This type of unexpressed refusal is the consequence of more or less explicit social discrimination in respect of those who are seropositive, but also of socio-medical decisions taken previously. The attitude of the pregnant woman is linked in the narration to her flight from the various constraints imposed in the Netherlands. This may indicate a lack of dialogue between the pregnant woman and the decision-making bodies, and gaps in her understanding of the socio-medical provisions imposed.
In the situation recounted, if the nursing team had been informed that the pregnant woman was seropositive, they would have observed medical confidentiality, leaving it up to the patient whether or not to disclose her state of health and the risks incurred by her foetus to third parties.

D. Reason linked to psychopathology

> *A young girl aged 16, a drug addict and pregnant, seeks escape and refuses to take any medication or undergo any prenatal examinations. She has no wish to become a parent and cares nothing for the life of her foetus. When she gives birth at 36 weeks, the baby is in the breech position. She gives birth alone, in terrible conditions, in a squat. The child becomes blocked in the pelvis and does not survive. The juvenile protection service placed the young girl in an enclosed institution.*

In the account given of the situation, the pregnant woman did not decide to abort the baby or abandon it at birth, but she does not take care of herself or her foetus.
Some members of the Committee stress the social misery that very often gives rise to and goes hand in hand with the various types of addiction and the need to take the necessary measures to put an end to this.
Addiction (alcohol, drugs, etc.) affects the capacity of the individual to give a free and informed consent or refusal.
Some members believe that it is important to draw attention to the fact that massive and chronic cerebral intoxication by toxic substances in fact significantly alters the cognitive functions of drug addicts and gives rise to doubts about their capacity to take a decision (whether positive or negative). Both the 'yes' and the 'no' of patients who are drug addicts when treatment is proposed are of little value, but the 'yes' does make it possible to intervene in the interest of the person and her foetus. On the other hand, a 'no' does not allow any intervention, even if this 'no' is in fact devoid of any value.
Other members, meanwhile, want to emphasise the fact that doubt as to the truly free nature of the expression is not linked here to the more or less proven presumption of their dependence on the will of another individual (case A), but this doubt arises from the observation that this person is subject to one or more substances that are particularly harmful for her and for her foetus.

As in case C, caring for the health of the woman is a major objective of the medical team. KULeuven reports numerous cases (10 to 15 a year) of pregnant women who are dependent on drugs or alcohol and for whom the use of narcotics risks causing cerebral damage to the foetus (microcephalia, mental backwardness, withdrawal symptoms suffered by the baby upon birth). During the pregnancy, meetings are organised to overcome the drug addiction or the consumption of alcohol. This usually proves to be a difficult task.

2. Presentation of the analysis of three cases by the UNESCO Chair in Bioethics at the University of Haifa (Israel)

The Office of the UNESCO Chair in Bioethics[41] has published cases studies complied under the title *Medical Ethics in Reproductive Health*[42]. Three of the situations described are of particular interest to us, and one of them corresponds precisely to the question initially submitted to the Committee.
We will set out these three cases briefly, together with the comments made by the authors, and then we will draw lessons from them.

First situation[43]

> *A seropositive woman who is four months pregnant and whose condition does not require antiretroviral treatment for herself refuses this treatment during the third trimester of her pregnancy, treatment intended to prevent the transmission of the*

[41] Under the aegis of the International Centre of Law, Health and Ethics, Faculty of Law, University of Haifa, Israel.
[42] Signed by professors Bernard M. Dickens, Rebecca J. Cook, Eszter Kismodi and Jean F. Martin, reference available on http://unesdoc.unesco.org/images/0014/001499/149913f.pdf.
[43] This situation corresponds to case No14 in the UNESCO publication.

virus to the foetus. She claims that she does not like taking medication and could develop a resistance to substances that could, in the future, prove vitally important for her.

The authors analyse the situation as follows:
"Generally speaking, the ethical rights of patients to self-determination in respect of their own body, including those of pregnant woman, take precedence over their ethical duty to protect the life of another person, including children who are not yet born. Consequently, the professionals who are treating S.M. cannot, ethically, compel her to take medication which she does not wish to take. They can state that they will only continue to follow her if she takes the antiretroviral medication, but they cannot stop treating her without giving her adequate time and without making arrangements for her care to be continued. S.M. was informed of the implications of her refusal for the health and long-term survival of her child, but her fear of developing a resistance to medication that may become essential for her own treatment is ethically relevant. The ethical principle of respect for people also demands that she not be treated as an egotistical person or someone who is indifferent to the well-being of her foetus and her future child."

They add that the only way of forcing the woman to accept treatment would be to obtain a court order, which is possible under Canadian law but not in Belgium.

Second situation[44]

A pregnant woman, convinced that she will benefit from divine intervention and will give birth to a baby in good health, refuses a Caesarean section, even though the doctor has diagnosed placenta praevia[45] *and deduced that with a natural delivery, the foetus and the mother would run a serious risk.*

In their analysis, the authors point out that, in the absence of any ethical or legal authority enabling them to unilaterally impose their decision, doctors have to respect the will of the pregnant woman, draw the attention of the couple to the fact that a diagnosis is not a certainty, inform the pregnant woman and her husband of the serious consequences of the refusal for the health and survival of the foetus and provide the necessary medical facilities for a high-risk natural birth. The authors stress the need to consider in advance with the parents the decisions that will have to be taken during delivery should things go wrong for the foetus and/or for the mother.
"*If the couple persist in their denial and refuse to take a decision, the doctor will indicate what will be the priority in this case and ask for their response. He can also inform them that, depending on the ethical and legal principles applicable in cases of emergency, if a vaginal delivery proves impossible, if the foetus is condemned to be stillborn and if the life of Ms T.P. is seriously threatened, a non-elective Caesarean section will be performed if this seems to the only way to save the mother."*
"(…) Dr R.R. will however, if this is relevant, be able to consider the option of presenting the situation to a court and asking this court for authorisation to carry out an elective Caesarean. It is important to note, however, that international experience in the field of Caesareans ordered by courts is mixed to say the least, as can be seen from a famous case that ended disastrously both for the child and for woman, in which the court authorisation was stated on the death certificate of the mother as the cause of death. This provides food for thought about turning to the courts. If Dr R.R. were nevertheless to follow this path, he will act in enough time to enable the two parties to gather relevant information, including expert opinions."

[44] This situation corresponds to case No10 in the UNESCO publication.
[45] For a definition, see *supra* note 40.

Third situation[46]

> *A woman is in labour in the delivery room, with her husband at her side; the foetal heartbeat is slowing seriously and recurrently, probably due to compression of the umbilical cord and asphyxia. The doctors suggest a Caesarean; the woman and her husband refuse, stating that in their culture, the woman has to give birth naturally and that the scar from the Caesarean would put the health of the woman in danger should they return to their country of origin. Here, the legislation of the State does not allow the patient to be compelled to undergo a surgical intervention, but it is legally possible to do this in an emergency situation.*

The analysis of the authors, here again, is in favour of abstention. They focus their discussion on the concept of the patient. They point out that the woman alone is the patient and that her will takes precedence over that of her husband. They also stress that "*the foetus is not a real patient in legal terms, but only a patient "by analogy*" and that "*the fact of giving the patient an anaesthetic and operating without her consent would be a serious attack on her integrity. Accepting her refusal is therefore ethically justifiable and in line with the current legislation. The lawyer consulted points out that a Caesarean under anaesthetic would, however, be approved, given that the court would probably believe that it involved an urgent and therefore excusable intervention. The legal defence when a surgical intervention gives rise to a complaint lodged for the violation of bodily integrity is to cite the state of necessity. In general, this means the necessity of saving the life of a patient, but the argument whereby the intervention was intended to avoid the loss of a viable foetal life can be admitted before the courts – depending on the ethics of professional obstetrics practice. Moreover, although in principle ethics requires observance of the law, the liability incurred in such a case for legal offence could be minimal, unless the court decides to be strict and condemn a medical intervention which it sees as paternalistic, since the parents do not usually obtain any significant compensation for attacks on integrity intended to save the life of viable foetuses.*
The probability that the couple concerned may return to their country of origin and that the woman may be in danger because of the existence of a Caesarean scar will have some weight in the assessment, but as an ex post facto consideration in a choice dictated by ethics."

The striking point, no doubt, in the accounts of these cases and in the way in which they were dealt with is their "judiciarisation": in the first two cases, it is suggested that the ethical question be settled not by the nursing team but by a judge who authorises or does not authorise the necessary intervention against the will of the woman; even if, in the third case, the legislation of the State does not permit recourse to a judge, a lawyer was consulted and the approach was determined on the basis of his response.

Another surprising subject: in these three cases, the attitude of the woman may seem, at first sight, to be somewhat casual *("I don't like taking medication"*), gullible ("*I will benefit from divine intervention"*), or naive ("*delivery must be natural"*), such that some members of the Committee believe that it would be totally justified to ignore their opinion in order to safeguard the interest of the unborn child – and moreover, that of the parturient herself. In addition, it will be noted that the last two cases refer to an emergency situation, and hence the possibility of acting in a state of necessity[47].

3. Presentation of cases from United States jurisprudence

[46] This situation corresponds to case No13 in the UNESCO publication.
[47] Because urgency is not sufficient from a legal point of view: Article 8, § 5, of the law of 22 August 2002 on patients' rights in fact states that: "When, in an emergency, there is uncertainty as to the existence or otherwise of a will expressed previously by the patient or his representative referred to in Chapter IV, any necessary intervention is performed immediately by the professional practitioner in the interest of the patient"; now, in the cases we are considering here, the will of the patient has been expressed, in that the patient has refused.

Finally, in order to shed light on the ethical debate, it seems relevant – even though the legal system in the United States is very different from our own, and the questions which are the subject of this opinion are presented there in another light – to examine briefly certain decisions that illustrate the way in which American jurisprudence tackles them.
The British decisions and analyses, although less numerous, follow the same lines[48].

In a *McFall v. Shimp* judgement dating back to 1978, the *Pennsylvania District and County Court* decided that it did not have the authority to compel a person who is of age and capable to undergo medical treatment for the benefit of a third party (this involved taking a bone marrow sample). The court clearly stated that "*For a society, which respects the rights of one individual, to sink its teeth into the jugular vein (...) of one of its members and suck from it sustenance for another member is revolting to our hard-wrought concept of jurisprudence"*[49], and concluded – while expressing its wish to be able condemn the refusal of the prospective donor for moral reasons – that "*in law, a person who is of age and capable cannot be forced to undergo a medical procedure for the benefit of a third party*[50]*"*.

In the article quoted, the author notes that the unequivocal protection of the right of a capable person to safeguard their bodily integrity, despite the needs of a third party, was reflected in the "provocative context" of the *rights of the foetus against those of its mother*. She cites a ruling of 1994 from the *Appellate Court of Illinois*, *In re Baby Doe*, which refuses to compel a woman to undergo a Caesarean for the benefit of her unborn child. According to this decision, which is particularly clear and firm, *the rights of a viable foetus do not have to be weighed against that of a capable woman to refuse a Caesarean, even if respect for the refusal of the woman is likely to harm the foetus.* In the case in point, the Caesarean was medically necessary, as the baby's oxygen supply was impeded by a placental dysfunction, but the woman refused it, partly on religious grounds, stating that her faith in the healing powers of God obliged her to await a natural birth. The court of appeal noted that: (1) the foetus would be viable outside the womb without medical assistance; (2) the foetus' chances of survival with a natural birth were virtually nil; (3) the risk that the mother may die during the Caesarean was approximately one in 10,000.

Drawing a parallel with the removal of an organ from a live donor[51], the *In re Baby Doe* ruling clearly states that *the only decisive factor in such a case is the decision of the woman, and not the interest of the foetus, and that it would be inconceivable for a mother to be forced to undergo a Caesarean to save her viable foetus*. The court stresses that compelling a capable adult to undergo a medical procedure is a practical radically contrary to a fundamental value of our society; it believes not only that the right of the woman to autonomy and the protection of her bodily integrity must be safeguarded, but that *the interest of a third party (in this case, the foetus) should not even be included in the analysis*[52].

Three years later, in the *In re Brown* ruling which dates from 1997, the *Supreme Court of Illinois* confirmed and extended this jurisprudence, considering that the interest of preserving the life of a viable foetus is also insufficient to *compel a pregnant woman to undergo medical treatment* "on behalf of this foetus". This case concerned the refusal of the mother, on religious grounds, to *accept a blood transfusion*. The first judges had appointed a guardian *ad litem* to represent the foetus, and ordered that the transfusion be carried out

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[48] See J.K. MASON and G.T. LAURIE, *Law and Medical Ethics*, Oxford University Press, 8th ed., 2011, pp. 92-96, No 4.69-4.79, "*Refusal of treatment in late pregnancy*"; S.D. PATTINSON, *Medical Law and Ethics*, Sweet & Maxwell / Thomson Reuters, 2nd ed., 2009, pp. 136-143, Ch. 4.5 and 4.6; J. HERRING, *Medical Law and Ethics,* Oxford University Press, 3rd ed., 2010, pp. 333-338, Ch. 6.16 and 6.17.
[49] Taken from the transcript of the case.
[50] Decision quoted by C. CHEYETTE, "*Organ harvests from the legally incompetent: an argument against compelled altruism*", *Boston Coll. L. Rev.*, 2000, 41, pp. 465-515, here pp. 494-495.
[51] Regarding which the Committee refers to its opinion No 50 of 9 May 2011 on certain ethical aspects of the modifications made by the law of 25 February 2007 to the law of 13 June 1986 *concerning organ removal and transplantation*.
[52] C. CHEYETTE, *op. cit.*, pp. 495-496.

despite the objections of the mother; they were censured in appeal[53].

In an opinion published in 2005, the *American College of Obstetricians and Gynecologists* (ACOG)[54] confirmed that, according to majority jurisprudence, the decisions of the pregnant woman regarding the medical treatment that she wishes to receive take precedence, irrespective of the presumed consequences for the foetus. Thus in a ruling of 1990, a court of appeal in the *District of Columbia* quashed the decision of the lower court – which had ordered that a Caesarean be carried out against her will on a serious ill woman at 26 weeks of pregnancy – pointing out that "*in virtually every case, the question of what should be done must be settled by the patient – the pregnant woman – on her behalf and on behalf of the foetus*", and that it did not see any situation "*extremely rare and truly exceptional*" in which the State would have a sufficiently peremptory interest in circumventing the wish of a pregnant patient[55]. The ACOG notes in this respect that within a sometimes heated debate, most ethicists also believe that the informed refusal to undergo a medical intervention by a pregnant woman should take precedence, provided she has the capacity to take medical decisions[56].

The opinion referred to above reports on four cases (between 1999 and 2004) of criminal proceedings motivated by conflicts of interests between the unborn child and the woman carrying it, who adopts dangerous behaviour or takes an inappropriate decision: in Utah, charge of murder brought against a woman, a cocaine addict, who had refused a Caesarean and had given birth to a daughter who tested positive for cocaine and a son who was stillborn (changed into endangering children, to which the woman pleaded guilty); in Pennsylvania, a hospital obtained a court injunction to carry out a Caesarean on a pregnant woman who refused this, owing to a suspicion of macrosomia[57] and for custody of the child to be granted to the hospital before and after the delivery (the parents fled to another hospital, where the woman was reported to have given birth naturally to a baby in good health); in the State of New York, charge brought against a young woman whose baby had tested positive for alcohol at birth, for endangering the child by having "deliberately nourished it with blood containing alcohol, via the umbilical cord" (sentence quashed on appeal); finally, in South Carolina, sentencing of a homeless woman and cocaine addict who had given birth to a stillborn child, for maltreatment of a child owing to the behaviour she adopted during her pregnancy (12 years in prison, sentence confirmed in appeal; higher appeal rejected before the Supreme Court).

The ACOG is critical of these coercive or punitive approaches; on the base of ethical arguments and highlighting the basic rights of the woman to privacy and bodily integrity (right to take decisions about the medical interventions she undergoes), it considers that the use of rules and legal proceedings specifically to protect the foetus as a separate entity from the mother to compel her or punish her *a posteriori* is not justified.

B. Specific analysis of a number of ethical aspects

[53] C. CHEYETTE, *op. cit.*, p. 495, note 202, and the reference quoted in the article by John J. PARIS, "*Planning on a miracle: The case of mother versus foetus*".
[54] ACOG Committee Opinion, "*Maternal Decision Making, Ethics, and the Law*", Obstet. Gynecol., No 321, 2005, pp. 1127-1137.
[55] *In re A.C.*, 573 A.2d 1235 (D.C. 1990).
[56] ACOG Committee Opinion, *op. cit.*, p. 1128 and the references quoted in notes 3 and 4. See also H. MINKOFF and L.M. PALTROW, "*The Rights of 'Unborn Children' and the Value of Pregnant Women*", *Hastings Center Report* 36, No 2 (2006), pp. 26-28.
[57] Foetal macrosomia refers at birth to a baby whose birth weight exceeds 4 kg and, during pregnancy (thanks to ultrasound scans), a baby whose size exceeds the maximum normal values; see http://www.vulgaris-medical.com/encyclopedie/macrosomie-f-tale-9343.html.

The experts consulted unanimously noted that it is very rare for a woman to refuse a medical opinion or treatment deemed necessary in the interest of the foetus. The question before the Committee therefore only very seldom arises: in Belgium, the rate of transmission of the HIV virus from mother to foetus is just 1.8 %, and this rate is even lower for neonatal transmission thanks to the effectiveness of antiretroviral treatments[58] and in general, the docility of patients. On the other hand, Caesareans are still sometimes refused, justified by religious grounds, by fatalism, by a lack of trust in Western medicine or a lack of understanding that doctors can diagnose the suffering of the foetus and the need to induce birth before term.

Moreover, there are cases in which an *in utero* blood transfusion to the foetus, although essential, is refused on religious grounds. Another difficulty may be that of persuading a pregnant woman in good health to stay in bed for a prolonged period of time and follow treatment intended to improve the well-being of the foetus owing to an asymptomatic risk of premature delivery[59].

1. The issues of power and conflicts of interest

The situation described in the question put to the Committee is a situation of issues of power (power of the doctors over the woman, of the husband over his wife or of a social group over one of its members), conflicting principles (respect for the bodily integrity of the mother against protection of the foetus) or intentions (parental plan against the need for care), and conflict between:
- the will of the woman and the interests of her foetus;
- what the woman thinks is her interest and what she things is that of her foetus;
- and the interest of the woman as she conceives it and that which the family concerned and society may have in limiting the risk that a child may be born carrying a serious, incurable and transmissible disease.

For some members of the Committee, the objective nature of the first conflict is obvious and must guide the discussion and therefore the solution to be put forward.
For other members, the objective nature of the first conflict is only apparent: we analyse it and seek to resolve it on the basis of our own values, that is the cultural, social and ethical values that form the basis of the society in which we live. This attitude is legitimate and even consistent; but to a certain extent, our ethical values also include tolerance of the values governing other societies and the attention paid to those imbued with these values, which does not mean that we should accept them – we can even be indignant about them – but, if we have to fight them, this can only be done through persuasion.

The foundation for the second conflict of interests as regards the woman seems to be subjective and poses a problem for those who see it from the outside, with a critical attitude, imbued with our western culture with its confidence in science and medicine, because it brings into play the cultural, social and possibly religious values of the woman.

2. The autonomy of the pregnant woman and respect for her bodily integrity

One of the basic values of our way of understanding society is respect for the integrity of others: bodily integrity, admittedly, but also intellectual and moral integrity. The ethical problem raised therefore comes down to this question: can the nursing team looking after a woman who refuses treatment and thereby puts her foetus in danger compel this woman to give way? None of the experts heard by the select commission responded to this with an

[58] Indications given by Prof. B. Spitz, head of obstetrics department at UZ Leuven.
[59] Indication given by Prof. J.M. Foidart, head of obstetrics department at the Hôpital de la Citadelle in Liège.

unequivocal yes.

The extent of the autonomy of the pregnant woman lies at the heart of the problem submitted to the Committee and it would be instructive to recall some of the historical and conceptual dimensions of this concept.

First of all (2.1.), we will briefly set out one of the two conceptions of autonomy most frequently raised in bioethics, that of I. Kant. The second is that of J.S. Mill, which will be covered in part two (2.2.).

A. A Kantian approach to the concept of autonomy

The expansion of the circle of people involved in the decision that we noted in the analyses of cases A2 and A3 (under the heading: "religious and cultural grounds") prompts us to rethink the place and meaning of the concept of autonomy. This concept is one of the ethical pillars of European and North American culture. Autonomy lies at the centre of the 18th-century philosophy known as "des Lumières" in France (the "Encyclopaedists" Diderot, Voltaire, Rousseau, d'Holbach, Condillac and others…), the Enlightenment in Great Britain John Locke, David Hume and others) and the "Aufklärung" in Germany (Immanuel Kant and others). This humanist movement upholds the idea that knowledge of the world and the conducting of human affairs must be based on *natural enlightenment* – the human faculty of knowledge – and not on *supernatural enlightenment*, that lavishly dispensed by religions, the Church or Revelations.

One of the most well-know definitions of the movement was provided by I. Kant:
Enlightenment is man's emergence from his self-imposed nonage. Nonage is the inability to use one's own mind without another's guidance. (…) *Sapere aude !* (Dare to know) Have the courage to use your own understanding is therefore the motto of the Enlightenment."[60]

One of the main tasks of the Enlightenment philosophers will therefore be to study the human faculty of knowledge[61]: Are we capable of knowing everything? Is direct and immediate knowledge of reality possible? Kant is to give reason an active role in the knowledge process: to perceive the details of experience is not purely to receive them, but to give them form. The reverse of this activity of the mind is that the totality of reality to be known is not understood by the structures of reason. So human beings cannot know everything. This awareness makes it possible to trace a boundary between legitimate knowledge – that acquired on the basis of the limits of human reason – and illegitimate knowledge (metaphysics) and beliefs. This division between knowledge and belief, content and structure of knowledge, reality and knowledge of reality is characteristic of what Is known as "the Kantian critique" or the "critical philosophy" of Kant.

So the promotion of reason goes hand in hand, in a single movement, with awareness of the limits of this reason in the faculty of knowing. When Kant talks about autonomy, he keeps this epistemological limitation in mind. For him, the human being is a being of reason, will, and sensitivity. As a being of reason, he is capable of producing rules that he wants to obey; as a being of will, he has the faculty of determining freely for himself to act in accordance with the representation of the law provided by his reason; as a sensitive being, he is subject to physical laws and causal determination. The human being is therefore both autonomous through the activity of his reason and the application of his will but he is also heteronymous in his submission to external laws that hamper his free and informed will.

In ethical terms, the autonomy of an individual finds expression in their faculty to conceive a

[60] *Vers la paix perpétuelle. Qu'est-ce que les Lumières ? Que signifie s'orienter dans la pensée ?*, translated into French by E. Proust and J.-E- Poirier, Paris, Flammarion, 1991. (English translation: Mary C. Smith)
[61] In the 17th and 18th centuries, the titles of the various treaties included the words "human understanding" bearing witness to the attention paid to the human being and his knowledge process: J. LOCKE, *An Essay Concerning Human Understanding* (1690); D. HUME, *An Enquiry Concerning Human Understanding* (1748); J. Le ROND D'ALEMBERT *Essai sur les éléments de philosophie ou Sur les principes des connaissances humaines* (1759), etc.

moral law that will be rational, universal and formal (since it has to be valid irrespective of the situation to be assessed morally). Such a law is known as an injunction, a mandatory provision. For instance, one of the formulations of one of the mandatory provisions (the categorical mandatory provision) states: “Act such that you treat humanity both in your person and in the person of others always at the same time as an end, and never simply as a means”. The humanity of the human being is the fact that he is a being of reason and of freedom, capable of conceiving ends and pursuing them voluntarily. To respect one’s own humanity or that of other is to refuse to relate to oneself or to others as to an object that is available and subject to external intentions. “Never simply as a means”, Kant specifies lucidly. The promotion of reason and freedom is an aim towards which all human action should tend, bearing in mind that the human being is also marked by heteronomy.

Seen in this way, autonomy therefore presumes that the person uses his reason in awareness of its limits (the division between knowing and believing, metaphysics), that he applies his will to respect the rules and laws supplied by his reason (the voluntary pursuit of the conceived aims), and that he takes into account the heteronomy resulting from the impossibility of escaping the physical laws that govern his body and the material world. Autonomy is essential to the humanity of the person, since it consists in being able to live as a being capable of setting himself ends and wanting to pursue them. As soon as the opinion of another is imposed on the person, that is as soon as the person sees himself compelled to fulfil ends that he has not set himself rationally and that he has no will to apply, this person is dehumanised. As Kant says, he regresses to the state of nonage.

In the cases we have considered here, each time the pregnant woman is incapable of conceiving the rule that could dictate her conduct (when she has to call upon a third party to state the rule) or when she does not recognise the limits of reason in her faculty to know (each time she places knowledge based on experience and rationality, and beliefs or metaphysical statements on the same plane), each time she gives up wanting to apply a rule herself (when she asks a third party to decide in her place), and finally each time she does not take into consideration the physical constraints of her body (when she believes that things will eventually sort themselves out naturally or supernaturally), she is not acting as an autonomous being in the Kantian sense.

B. A utilitarian interpretation of the concept of autonomy and the question of wrong

In his *Essay on Liberty* (1859)[62], the English philosopher John Stuart Mill (1806-1873), a leading figure in utilitarianism, sets out a principle intended to settle the dealings of society with the individual in the way of compulsion and control. According to this principle, "*the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant".* Mill concedes that the acts of mankind are admittedly *"good reasons for remonstrating with him, or reasoning with him, or persuading or entreating him, but not for compelling him or visiting him with any evil, in case he do otherwise"*. The only part of the conduct of anyone, for which he is amenable to society, is that which "*concerns others*". In the part "*which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign"*. According to the "minimalist" ethics of Mill, as summarised by Ruwen Ogien, "*the self-self relationship is therefore morally indifferent"*. And the fact of *just harming oneself* cannot lead to the deprivation of freedom or of autonomy for the purpose of care as long, a condition *sine qua non* for Mill, as this individual act does not harm the interests of others. In the opposite case, Mill was also clear: harming someone else may authorise the deprivation of freedom or of autonomy.

However, unlike Mill – whom some people tax with egotistical indifference – paternalist ethics will, on the contrary, consider the *sole self-harm* of an isolated individual to be a "state of necessity". And this will not take account of the *consent* of the autonomous subject to care. A close relation, family or the doctor therefore treat another person – the subject (patient) – in accordance with what they themselves believe to be the good of this other person. Under this condition, care and non-respect for the autonomy of the subject prove, on specific occasions and temporarily, compatible in respect of an isolated individual. Care which must, of course, ultimately prove beneficial. Which justifies *a posteriori* the choice of the paternalist option.

Some people will, however, point out to these (benevolent) paternalists that, in the case of "marginal" acts with *purely* individual consequences, their intervention may be similar to a "police-based moral code". The paternalists will reply that there are sometimes real "states of necessity" further to "marginal" acts by the individual concerned alone. This, in fact, is the question of the *consent of an autonomous subject to a self-inflicted "wrong" without consequences for others*. Should we respond with the "minimalist" ethics of Mill: reason, persuade, entreat but not compel – in other words, respect the autonomy of the subject – or, conversely, with benevolent paternalist interventionism? In reality, the issue is broader: it covers, as above, (1) self-inflicted wrong (or damage) with consent; but also (2) self-inflicted wrong (or damage) with consent and with (medical) assistance; and (3) excludes, as this is condemned by definition, wrong (or damage) inflicted on others *without consent.*

In itself, an ethical stance inspired by Mill – according to which the self-self relationship is morally indifferent – authorises each one of us to engage in the practices of our choice, provided that these do not harm others. This being so, according to the way in which Alex Mauron[63] interprets it, this liberal philosophy does not, nevertheless, became "liberalism" pure and simple, or "relative radicalism". In fact, "minimalist" ethics, as Mauron sees it, maintains that the concepts of damage, wrong and ("serious") anomaly can, within certain limits, be given an *objective* definition if these anomalies are related to *rational* choices which render these *abnormal situations* objectively undesirable.

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[62] See John STUART MILL, *On Liberty*, translated into French by Laurence Lenglet, Paris Gallimard, Folio/Essai, 1990, pp. 205-220.

[63] See A. MAURON, "*Homo faber sui*: *quelques questions d'éthique démiurgique"*, in J.-N. MISSA & L. PERBAL (coord. sc.), "*Enhancement". Ethique et philosophie de la médecine d'amélioration*, Paris, Vrin, 2010, pp. 205-220.

On this basis, (1) inflicting objective damage upon oneself, *without assistance*, to which one *consents*[64] – in other words, putting oneself deliberately in an *abnormal situation* – cannot be condemned from the point of view of a libertarian code of ethics which upholds an integral right to ownership of one's own body and the inalienable freedom of every individual in this respect. However, (2) in the eyes of a third party (paternalist), this action can be *judged to be* aberrant and denounced in view of the *irrationality* of inflicting "serious" objective damage, in short, wrong. Thus (3) self-inflicted objective damage with consent which requires *assistance* can be refused by the (medical) assistant – principle of non-harm – in view of the irrational nature of a request to inflict "serious" objective damage, even with consent.

Nevertheless, (4) faced with attempts as self-inflicted harm without assistance with catastrophic consequences, without denying the aberrant nature of the act, persisting in throwing the patient back solely on his own resources may seem "as absurd as it is cruel" to the medical assistant. Which, according to Mauron, can lead to thinking about the self-infliction of damage in terms of "shared responsibility".

In the specific case of a "refusal of care by a pregnant woman having an effect on a foetus", does applying Mill's principle whereby the *self-self relationship is morally indifferent* and the related principle of *non-harm to others* not imply being, *firstly*, attentive in terms of the consequences to the (very) strong or the (very) slight probability of inflicting damage[65] on the foetus? But, *secondly*, would not the fundamental complexity of the case lie in the fact that there is not one but *two parties* having "interests" – mother and foetus – who have the joint particularity of being *spatially united (in one and the same body) at different temporal stages?*

In other words, approaching the case of a "refusal of care by a pregnant woman having an effect on a foetus" from the point of view dear to Mill of the fundamental respect for individual freedom provided that this does not harm anyone else would therefore imply (1) finding out about the slight or strong probability of consequently inflicting harm on the foetus. (2) Informing the mother of this. (3) If the probability is strong, attempting, as Mill said, to reason, persuade, even entreat her to accept the care.

If she nevertheless persists in her refusal, it is then necessary to decide, in this period of *spatial indistinction* between a *present subject* and a *potential other individual within the subject*, (4) not to compel the subject who is physically present? That is, imperatively to respect the autonomy of a free and *unique* subject who is, however, "*double"* in spatial and temporal terms in that she bears within her a *potential other individual*? Or is it necessary (5) to opt for paternalist interventionism and – this is another question – within what limits?

With option (4), the autonomy of the present subject is respected at the cost, with a strong or slight probability, of damage to a potential other individual. With option (5), the autonomy of the present subject is not respected and this may therefore involve a (minor or major) intervention on this subject in order to avoid, with a strong or slight probability, damage to a *an internal potential other individual* whose *spatial indistinction with the present subject* and *own development over time* (and hence the appearance of the capacity to feel) poses a problem for a philosophy inspired by Mill which upholds that in themselves the relations of a (unique) subject with himself are morally indifferent as long as these individual relations do not harm the interests of others apart from himself.

[64] Inflicting objective damage on another *non-consenting* person is, by definition, excluded.
[65] Likewise, the nature of the "care" (major-minor) refused must be determined.

C. A critical approach to the autonomy of the pregnant woman

First position

Some members of the Committee think that the foetus should be granted a *status* which, if not recognised and organised by law, must at the very least be *moral*[66]; it follows that it must be able to be cared for as such, irrespective of the will of its mother. They believe that the argument that the pregnant woman is the sole patient and that she can therefore decide on the basis of her individual interests alone contradicts the intuition, share by them and by others (including in countries where the law decriminalises the voluntary interruption of pregnancy subject to certain conditions), that the woman puts at stake something other than "part of her internal organs", if not a *person*, or in any case a *being* that is developing in her, thanks to her, even though this being does not have a legal personality, particularly if the pregnancy is voluntarily continued.

Among these members, some refuse to accept – irrespective of any philosophical or religious stance – that in ethical debate, only the being legally described as a person – the child born – is taken into account and intend to take account of the existence of the foetus at a certain stage of its development, that of a real being, sensorial, capable, according to the most recent data of neurobiology and human ethology, of a relationship with others from the final months of pregnancy – a relationship which, in their eyes, constitutes the essence of the human being and as such confers upon him a status worthy of protection. In accordance with the ethical principle of beneficence, associated with that of proportionality, they believe that it would be a serious moral or ethical error to abandon this almost new-born baby to its probable fate of a future disabled individual or, worse, let it die for want of appropriate care.

This status, which they describe as *moral* to distinguish it from the *legal* status of the woman or the child once born, implies that the autonomy of the woman can be assessed in the light of the vital interests of the foetus she is carrying and wishes to bring into the world or for which, at least, she has not requested an abortion up to this stage in its development.

Given these situations in which a woman plans to become a parent and continues her pregnancy, these members are indignant: how it is possible to tolerate a contradiction between this plan and the possibility of not treating well, or even maltreating the foetus, or even of behaviour having harmful effects, either directly or indirectly, on the foetus? In these cases where the woman knows that a child will be born and she accepts and wishes for this birth, it seems to them that such cases fall under protection by criminal law and a reasonable obligation to protect the foetus is vital. This reasonable obligation should no doubt not be the subject of a law – but not at all for the sole reason that these cases are very rare: they would at the very least like this to be the subject of a strong ethical statement.

In this spirit, these members would like the medical team in charge of ensuring a successful delivery to have a margin of freedom of action faced with a refusal of case that they may consider unreasonable. They intend to see the right of nursing professionals to exercise their share of collegial responsibility recognised and respected. To this end, the balance of interests involved should be established together with a scale of priorities in the values to be upheld, even though this may differ from that set by the woman. They should be able to do this in line with the ethics of their profession, without facing the threat at any time of possible prosecution for having infringed the autonomy of the woman established as a virtually absolute law. In this context, they believe that the doctor, in his soul and conscience and in the interest of the child, can oppose the will of the mother when he judges that the

[66] See the work by M. A. WARREN, *Moral Status – Obligations to Persons and Other Living Things*, Oxford University Press, 2000. See also, for an analysis of this paper and beliefs relating more specifically to the embryo *in vitro*, in the context of the political deliberation prompted by the bioethical debate, the recent thesis by D. SMADJA, *Bioéthique, aux sources des controverses sur the embryo*, Paris, Dalloz, Nouvelle Bibliothèque de Thèses de Science politique, 2009.

(physical or moral) aggression of the treatment is proportionally less than the benefit for the foetus. In this respect, they point out that in its opinion No 87 of 14 April 2005, *Refusal of treatment and autonomy of the person*[67], the French national advisory committee on ethics recommends "*agreeing to ignore a refusal of treatment in exceptional situations, while maintaining an attitude of modesty and humility likely to attenuate the tensions and lead to dialogue. Even if it is impossible to set the criteria, situations can be envisaged in which it would be permissible to commit such an infringement, when time constraints jeopardise the life or health of a third party. For instance, […] an emergency delivery jeopardising the life of an unborn child. In this field, ethics must not act as a screen for a false good conscience that respects an excess of autonomy*".

As one of the experts heard by the select commission suggested, the difficulty brought up by the principle of autonomy could be summarised as follows: either we accept the principle of the autonomy of the will of the woman and provide the means for good mediation while accepting the eventuality that this will fail, or we decide to ignore it, citing the superior interest of the foetus.
To justify this exemption from the principle of the will of the patient in the interest of the foetus, some members put forward the argument of the principle of proportionality. This principle aims to measure the correlation of an act or an event with the context (for instance, the means used, the ends sought and the effects actually obtained). To the extent that it regulates a certain "balance" between these elements, it sometimes results in some "limitation" of an act which produces effects considered to be positive or negative. Thus the principle of proportionality plays a role in the ethical justifications of a refusal of care likely to be exercised in various situations. These may include, in particular, 1) refusal of care with negative effects virtually exclusively for the person who has refused the care, 2) refusal involving minor negative effects, also or solely for other people, third parties in the general sense, 3) refusal entailing serious negative effects for these third parties, 4) in the particular case of the parental plan, refusal involving slight or serious negative effects for the unborn child.

No doubt less well known and far less widely studied than other principles of bioethics, the principle of proportionality is, however, neither less determined nor more debatable than the others[68]. In fact, just as autonomy or benevolence have to be precisely defined depending on the situations and have hardly any concrete meaning without this contextual information, proportionality can only be exercised in a real-life situation, in sight of and weighing the actual elements of this situation. This is certainly the case in various areas in which the principle is applied on a relatively standard basis: the right to wage war (with, in particular, the concept of the "just war"), the right to taxes, "partial" rights for "partial ethical agents"[69], regulations on self-defence[70], etc. Traditionally, the principle of proportionality has been applied to assess the ethical value of so-called dual-effect acts, where the act will be morally accepted provided that the unsought negative effect remains "limited" compared with the positive effect sought, in a "proportion" which will be judged to be acceptable and which it will be decided to accept. The question, of course, is whether it is actually possible to "calculate" the positive and negative effects and draw an objective conclusion[71].

The "rebirth" of the principle of proportionality in the debates on recent models and definition of justice, where the concept of "reasonable" is linked to the concept of

[67] C.C.N.E., opinion No 87 of 14 April 2005, 'Refus de traitement et autonomie de la personne', Les Cahiers du C.C.N.E. No 44, 2005, p.21 (on line: http://www.ccne-ethique.fr/docs/fr/opinion087.pdf , pp.33-34).
[68] For a different opinion on this point, see G. **HEMERÉN**, "The principle of proportionality revisited: interpretations and applications" in *Med Health Care and Philos*. 2011, pp.1-10.
[69] Certain theoretical models on the allocation of rights in a given community envisage the existence of partial agents (for example children, deficient adults or mental patients, foetuses, animals, etc.) and hence a proportioned allocation of rights to these beings, depending on the degree to which they resemble the full agent. Ancient and Medieval analogies inevitably spring to mind.
[70] It will be noted that some authors discuss the morality of the interruption of pregnancy, comparing this debate to that of self-defence: see for example the inaugural article of N. DOPINION, "Abortion and Self-Defence"» in *Philosophy and Public Affairs*, 13, 1984, pp. 175-207.
[71] On this and with regard to the debate on the "just war", see the in-depth analysis of Th. HURKA, "Proportionality in Morality and in War" in *Philosophy and Public Affairs*, 33, 2005, pp. 34-66.

"proportionality", will not be discussed here. Reasonable conduct is adequate, adapted to the various parameters of the situation. This character makes it possible to introduce the necessary compromises between the various social conceptions of good, of what must be done or not done. So the reasonable demarcates a field of the rational where certain balances are safeguarded, at the expense of elements that are deliberately pushed to the back (the "concessions" made by each party), and consequently, the reasonable implies setting aside certain aspects of the autonomy of individuals.

These members believe that, when applied to situations in which care is refused, and in particular the situation in which the refusal implies negative effects that are considered serious for the unborn child whereas the parental plan is conscious and voluntarily maintained until term, the principle of proportionality will highlight a "disproportion" between individual freedom and specifically the refusal of care for personal reasons on the one hand and on the other hand the harmful, perhaps even fatal effects for the unborn child. This does not call into question the consensus on the fact that the refusal of care is a recognised right when it only affects the person who, fully aware (because duly informed) and freely[72] suffers the negative consequences of this refusal. When a third party is directly affected by the negative effects of the refusal of care, and particularly in the case of the foetus participating in a parental plan (*i.e. where no decision has been taken to interrupt the pregnancy*), the refusal of care will be considered to be "more or less acceptable", depending on how serious the negative effects are for this third party. In the case in point, according to current medical data on the quantification of the risk, these negative effects of the refusal of care may be reasonably described as serious and therefore not acceptable.

Second position

Other members point out that this first position only compares positive and negative effects for the foetus, without taking into consideration those that concern the woman. They add that all the difficulty, from an ethical point of view, comes from the fact that, to care for the foetus borne by a woman who refuses this care, violence must be done to this woman or it will be necessary to act by ruse. They believe that the expression *status* can only be used in a legal sense and that, while it is reasonable to admit that the foetus is a distinct entity from the woman who bears it, this entity is not a separate patient from this woman: to reach the foetus, it is necessary to *go through the body* of the woman, and the woman has control over body.

From a legal point of view, the will of the patient as regards the interventions that she could undergo (free and informed consent or refusal) must be respected, given the respect due to her bodily integrity. It is therefore forbidden to intervene in any way in the body of the pregnant woman when she has freely expressed her informed refusal. The law of 22 August 2002 on patients' rights does not really allow the doctor to deviate from the expressly formulated will of the woman, since Article 8, § 4 of this law states that the patient *is always free to refuse or withdraw her consent to an intervention.* Now, in the case covered in this opinion, the patient is the woman and not the foetus she is carrying, whatever the stage of the pregnancy; and even should it be admitted that the patient is the foetus, it is nevertheless represented by its mother, who refuses the necessary care. Nor does it seem to be possible to apply Article 15, § 2, of the law by analogy, since the child has not yet been born and therefore does not have a legal individuality. This is the code of ethics adopted by the legislator. Only a situation of emergency and of necessity, in which the life of the person is in danger and in which the person has not been able to express their will, permits any proportionate deviation from this ban. On the other hand, once the child is born, it is legally protected against parental decisions that would not be in its best interest.

It may, however, be pointed out that the conception whereby the autonomy of the patient is

[72] The only reservations concerning patients' rights refer to the state of awareness of the latter, or the alteration of his free will due, for instance, to a deterioration in his cognitive faculties.

the rule is not shared throughout the world and is very recent in the history of western societies. In societies facing serious public health issues – in Belgium par example, until the Second World War, syphilis and tuberculosis or, a few years later poliomyelitis – there is an urgent need to ensure that care and prevention take precedence over the concern to respect the will of the patient, or even of a healthy person. In these situations, it will be deemed ethical to intervene to care for the foetus, if necessary against the will of the woman, in order to prevent the greater evil of the risk of contamination that the child would pose if born carrying the virus. In our society, we believe we can triumph over disease; but this belief is fragile and at the mercy of fear of an epidemic[73].

Some members point out that even if the ethical discussions centred around autonomy in western countries currently differ from those in other countries in the world in which solidarity is a condition of survival and where our principle of autonomy is perceived as an "egotistical" conception of life, there nevertheless remains a trace of this solidarity among most women who accept the care offered, even when this is invasive, in a spirit of solidarity with the unborn child: they refuse to take responsibility for giving birth to a child with a disability owing to a lack of solidarity with the child's fate. Given the consequences of the refusal for the foetus, it would not be possible simply to invoke the right of the patient "for herself". At the least, this is a situation that involves a third party, with an aggravating condition of dependence or vulnerability.

Others, however, wonder about the possible link between this conception of solidarity and that which is found in our contemporary western societies, where solidarity may possibly concern not only the women themselves, their partner and their family, but also their community (through the foetus). They doubt *a priori* the extent to which those surrounding the patient, the medical team would give themselves the authority to intervene, in a spirit of solidarity, in a decision that concerns an individual whereas the latter can, moreover, benefit from a social security system that is not without means and which brings into play mechanisms of solidarity. This is why some people nevertheless see a problem of collective solidarity requested from society when this will be requested to deal with the disability of the child once it is born.

3. The need for full information given to the pregnant woman and possible recourse to intermediaries

All the members of the Committee believe that it would not be ethically admissible for the pregnant woman to take a decision to refuse treatment without having been fully informed by the medical team of the risks involved in this decision. This requirement for the patient to be fully informed so that her decision can be considered to be validly expressed is, moreover, also contained in Article 8 of the law on patients' rights. In this, the members of Committee align themselves with the opinion of the French advisory committee, which judiciously states that "respect for autonomy of thought is reflected in practice, for the doctor, in the duty to ensure that the individual who is refusing care has perfectly understood the information given to her and the foreseeable consequences of her refusal and that in this field he exercises freedom with regard to a third party or a society"[74]. To fulfil this essential condition, recourse to religious and cultural intermediaries is recommended, even though it should be stressed that their intervention sometimes means that the woman

[73] Reference could be made in this respect to Opinion No 48 of 30 March 2009 on the Belgian "influenza pandemic" operational plan.

[74] C.C.N.E., opinion No 87 of 14 April 2005, *op.cit.*, p. 24. In this regard, according to G. Moutel, "in any case, the determining factor will be the degree of autonomy of thought of the patient, the real criteria for classifying his capacity to develop a coherent and considered argument. In practical terms, this is a matter of saying whether the patient is capable of taking part in a discussion, backed up by the acquisition of sufficient knowledge concerning his illness. The autonomous subject is the subject who is capable of understanding medical information and exercising his critical mind". (G. MOUTEL, *Médecins et Patients. L'exercice de la démocratie sanitaire*, Paris, L'Harmattan, coll. L'Éthique en mouvement, 2009, p. 102).

concerned dares even less to move away from her religious and cultural convictions.

On this point, it is worth noting that in the aforementioned opinion, the C.C.N.E. advises, "*as always in a crisis situation", "not only to seek a second opinion, but also to engage in a mediation process or undertake the function of mediator, in order that the doctor and the patient, or the doctor and a family are not left alone facing one another. It is in this respect that third parties make the patient and the doctor aware of the recognition that they can have for one another, and what that implies. The concept of the person of trust laid down in the law (of 4) March 2002 takes on its full significance here. The importance of psychologists, or even psychiatrists, and of the nursing staff can only be emphasised. The objective, in fact, is not only to accept a word of refusal as truly significant, but also to judge the degree of possible alienation. And yet, it is not a matter of handing the responsibility for taking the decision to a third party, but of helping the person to decide for him- or herself."*[75]. Some members of the Committee stress the need for the medical team to be trained in understanding other ways of thinking and behaving, and to learn to transpose scientific language into the cultural language of the patient, and vice versa. This capacity for acculturation would enable the medical team to manage certain conflicts with the patient and the family itself, which would strengthen the patient's confidence in the team. This would also make it possible to act in an emergency situation, when calling in an intermediary is not an option.

V. Conclusions and recommendations

The members of the Committee stress the importance of maintaining a dialogue with the pregnant woman while at the same time, if necessary, opening up the discussion to linguistic or cultural mediators. They think, however, that the ultimate aim of opening up the discussion in this way should always be to restore the dialogue, that may temporarily become difficult or be interrupted, with the pregnant woman and to encourage her to express her own will in the decision that she takes. In the context of this dialogue, the Committee believes that every attempt must be made to persuade the pregnant woman to take the reasonable decision recommended by the nursing staff.
In fact, it would be ethically inadmissible for the hospital to become a place where the subjection of the woman to any authority at all (marital, religious, community, etc.), that adversely affect harms the emancipation of the woman, would be admitted, or even encouraged.

Some members believe that if the pregnant woman persists in her refusal despite all the attempts made to persuade her, then this refusal absolutely has to be respected in ethical terms, whatever her motives and the consequences that this is likely to have, in the name of the patient's right to respect for her privacy and her bodily integrity. They give pride of place to the principle of autonomy and assess the other ethical principles – of beneficence, avoidance of evil, justice – in the light of this. The infrequency of the occurrence in medical practice of cases similar to the question submitted prompts them to recommend that the legislator does not intervene.

Other members consider it to be logically inconsistent and ethically unacceptable for a women wishing for a child not to do everything possible to safeguard its health, or even its survival. From an ethical point of view, they uphold the idea that the medical team has a duty to intervene to the best of medical knowledge, to give the foetus a chance to live and to live in good health. While they admit that legally, the doctor cannot compel the pregnant woman (and for instance perform a Caesarean if she has expressly refused this), these members believe that, from and ethical point of view, it may be desirable, or even essential, to intervene, if need be against the will of the woman, if this is necessary to safeguard the

[75] C.C.N.E., opinion No 87 of 14 April 2005, *op.cit*., pp. 33-34.

health or even the life of the foetus.

With a view to protecting the child close to birth, these members would like the medical team in charge of ensuring a successful delivery to be able to use its freedom of conscience when faced with a persistent decision to refuse care which they may consider unreasonable. They believe, in fact, that it would not be admissible to compel the practitioner to become an accomplice to unreasonable decisions that endanger the life of the weakest. They intend to see acknowledged and respected the right of the medical team to intervene, after having assessed the degree of urgency of the situation together, weighed up the interests involved and discussed the best measure to be taken, in accordance with the ethics of their profession.

Some believe that the argument of the rarity of the cases put forward by some to recommend a status quo to the legislator must not cancel out this reasonable obligation to protect the foetus and they would like this at least to be the subject of a strong ethical statement.

The members of the Committee stress the importance of giving the pregnant woman full and repeated information about the consequences of her refusal, for her own health and that of her foetus.

They stress the need to put in place appropriate means to overcome the various difficulties of understanding between the patient and the medical team, in order to enable this team to better convince her of the validity of a health care plan. In this respect, the Committee cannot recommend too strongly that hospital staff involved in taking the decision should call upon the mechanisms of information and mediation that are available and request the opinion of the local ethics committee.

The members of the Committee would like to point out that both society and the various players and care providers must to everything possible to ensure that weakened and vulnerable people do not suffer any medical or social discrimination in the care they are given and that all these people benefit from appropriate multidisciplinary medical, psychological and social support.

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The opinion was prepared in the select commission 2010/2, consisting of:

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	J. Messinne	M. Dumont	
	M.-G. Pinsart	M. Eisenhuth	
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Prof. G. Naulaerts, head of the neonatology department, UZ KULeuven

The working documents of the select commission 2010/2 – request for opinion, personal contributions of the members, minutes of the meetings, documents consulted – are stored as Annexes / at the Committee's documentation centre, where there may be consulted and copied.

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This opinion is available at **www.health.belgium.be/bioeth**, under the heading "Opinion".