### **REVIEW ARTICLE**

# Involuntary euthanasia of severely ill newborns: is the Groningen Protocol really dangerous?

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#### **Abstract**

Advances in medicine can reduce active euthanasia of newborns with severe anomalies or unusual prematurity, but they cannot eliminate it. In the Netherlands, voluntary active euthanasia among adults and adolescents has been allowed since 2002, when the so-called Groningen Protocol (GP) was formulated as an extension of the law on extremely premature and severely ill newborns. It is maintained that, at bioethical level, it serves the principle of beneficence. Other European countries do not accept the GP, including Belgium. Admissibility of active euthanasia is a necessary, though inadequate, condition for acceptance of the GP. Greece generally prohibits euthanasia, although the legal doctrine considers some of the forms of euthanasia permissible, but not active or involuntary euthanasia. The wide acceptance of passive newborns euthanasia, especially when the gestational age of the newborns is 22-25 weeks ("grey zone"), admissibility of practices within the limits between active and passive euthanasia (e.g., withholding/withdrawing), of "indirect active euthanasia" and abortion of the late fetus, the tendency to accept after-birth-abortion (infanticide) in the bioethical theory, the lower threshold for application of withdrawing in neonatal intensive care units compared with pediatric intensive care units, all the above advocate wider acceptance of the GP. However, the GP paves the way for a wide application of involuntary (or pseudo-voluntary) euthanasia (slippery slope) and contains some ambiguous concepts and requirements (e.g., "unbearable suffering"). It is suggested that the approach to the sensitive and controversial ethical dilemmas concerning the severely ill newborns is done not through the GP, but rather, through a combination of virtue bioethics (especially in the countries of the so-called "Mediterranean bioethical zone") and of the principles of principlism which is enriched, however, with the "principle of mutuality" (enhancement of all values and principles, especially with the principles of "beneficence" and "justice"), in order to achieve the "maximal" bioethical approach, along with the establishment of circumstances and alternatives that minimize or eliminate the relevant bioethical dilemmas and conflicts between the fundamental principles. Thus, the most appropriate/fairest choices are made (by trained parents and physicians), considering all interests involved as much as possible. Hippokratia 2014; 18 (3): 196-203.

**Keywords:** Active euthanasia, newborn, neonatal, Groningen Protocol, bioethics, virtue ethics, principlism, beneficence, withholding, withdrawing

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## 1. "Early" active euthanasia and the Groningen Protocol

Advances in fetal and neonatal medicine [especially advances in neonatal intensive care units (NICUs)] have resulted in newborns with congenital defects previous considered non-viable surviving<sup>1,2</sup>; however, they often remain dependent on medical care or are neurologically devastated. Life-sustaining intervention, may itself induce chronic diseases or disabilities to the infant ("products of the NICU")<sup>3</sup>. Despite the progress made, modern anesthesiology cannot ensure the elimination of "unbearable suffering" of the newborn by palliative means (e.g. in conditions such as "osteogenesis imperfecta")<sup>4</sup>.

As the German theory<sup>5</sup> rightly observes, it is very difficult to detect a prevailing view from an ethical and legal

aspect on the issue of the so-called "early" euthanasia of severely ill newborns.

In the Netherlands, active euthanasia (voluntary) is permissible and constitutes a medical procedure<sup>6</sup> (with well-defined requirements) among adults and adolescents with limited life expectancy, and severe and persistent suffering (starting from 12 years of age, whereas up to 16 years of age full parent consent is required), following a voluntary, carefully considered, repeated request. A sequence and extension of this Dutch "death culture" is the Groningen Protocol (GP), which allows non-voluntary euthanasia among severely ill neonates with congenital anomalies in order to "give relief to" some newborns with stable physiology, hopeless prognosis, no prediction of a good quality of life, from "unbearable suffer-

ings", and also reduce implementation of this practice in the clandestinity<sup>7</sup>, lend transparency<sup>8</sup>, so that any abuses are limited (even those done with a good intention), and this practice is carried out only in extreme and hopeless situations. It is reported that, in the Netherlands, one in 200 newborns dies within the first year of their life. Sixty per cent of these deaths are preceded by an end-of-life decision<sup>7</sup>. A study (EURONIC) has shown that, at least in France, Belgium and the Netherlands, clandestine neonatal euthanasia is a fact9. Seventy-three per cent of neonatologists in France and 68 per cent of pediatricians in Flanders have made decisions to perform active euthanasia among newborns who were terminally suffering, which is in contrast with their colleagues in other countries (Italy 2%, Spain 2%, Germany 4%, UK 4%, and Sweden 2%)7. According to the EURONIC project, 45%-85% of neonatologists have administered drugs to accelerate death<sup>10,11</sup>. In Greece, euthanasia is totally prohibited, both by the Code of Medical Ethics (article 29) and the Penal Code (articles 299, 300, and 301). The Greek legal doctrine<sup>12</sup> has suggested that the possibility of leaving direct active euthanasia unpunished in extreme situations be enacted (de lege ferenda), and through the construction of the existing provisions of the law (de lege lata) they accept the admissibility of certain forms of euthanasia, especially passive and indirect active euthanasia (while rejecting the admissibility of direct active and involuntary euthanasia) and recommend the possibility of interrupting (or not applying) a newborn's life support, even against the will of the parents in cases where the newborn is not a "potential person", along with a significant lack of autonomy<sup>13</sup>. However, there is no clear legal immunity of the physician. In the overwhelming majority of legal doctrines, early active euthanasia is surrounded by the same disdain as active (direct) adult euthanasia12,14,15. An impressive exception at an international level is the so-called "Protocol at the Dutch city of Groningen".

In accordance with the Protocol, the requirements for performing early euthanasia are: "unbearable suffering" and hopeless prognosis; informed consent by both parents; no alternative solutions; assent by at least one doctor who is independent of the incident; and carrying out the termination of life in a medically appropriate way.

The GP refers to three groups of severely ill newborns<sup>7</sup>: a) those who will die shortly despite the medical intensive care applied (e.g. severe lung hypoplasia); b) those with a very poor prognosis, dependent on intensive care (e.g. holoprosencephaly); and c) those with a hopeless prognosis, physiologically stable, unbearable suffering that cannot be alleviated (including epidermolysis bullosa, Hallopeau - Siemens type). The GP is mostly concerned with this case.

The GP was drafted by doctors, in collaboration with the Public Prosecutor's Office, which appears to play a very significant part in the Netherlands. Following the publication of the GP in 2002, it was justifiably criticised in the international literature<sup>6</sup>. The proponents behind the protocol's creation published an article in 2005 that advocated on its behalf, which protested against the erroneous widespread interpretation and its mission being misunderstood<sup>7</sup>.

The physician's immunity is not absolutely guaranteed by the GP. In the Netherlands, in case of abnormal death, the doctor informs the Coroner, then the Public Prosecutor, the Council of Public Prosecutors, and finally, the Minister of Justice who is influenced by the GP, but he/she is not bound in his/her judgment<sup>7</sup>. No doctor has been prosecuted until now. During the seven-year period 1997-2004, 22 cases have been reported<sup>16</sup> to the authorities (three on average per year), while it is estimated that there have been 15 cases per year, approximately, in the Netherlands<sup>7</sup>. The 22 cases where the law was applied (while the number of clandestine cases of active newborns euthanasia is estimated to be much larger) referred to cases of spina bifida [myelomeningocele (MMC)]<sup>17</sup> during the seven years of its application. Although it is reported<sup>18</sup> that the admissibility of active (adults) euthanasia in the Netherlands has resulted in a slippery slope and in a large increase in (illicit) cases of non-voluntary active euthanasia, five years after application of the GP it was established that there were neither any abuses (slippery slope) seen, nor any increase in transparency<sup>19</sup>.

### 2. Circumstances for adoption of the Groningen Protocol

Circumstances advocating the adoption of the GP (and also favored by its adoption) include the following:

- a) The tendency of the legal doctrine to smooth out the value difference between active and passive euthanasia¹²,¹⁴,²₀ and acceptance in some countries (including Belgium and the Netherlands) of (voluntary) active euthanasia among competent adult persons (and also persons ≥ 12 years old, as in the Netherlands), who have limited life expectancy and experience severe and persistent suffering. The European Court of Human Rights (ECtHR) has accepted that the "right to die" may result, not from article 2 of the European Convention on Human Rights (ECHR) (case of Pretty vs UK, no. 2346/2002), but rather, from article 8 ECHR (privacy), on the vague condition, however, that the individual "is able to freely form his or her will on this and act accordingly" (case of Haas vs Switzerland, 2011).
- b) Early passive euthanasia is much more widely accepted compared with the corresponding passive adults euthanasia<sup>21,22</sup>. The admissibility of withholding/withdrawing of the intensive care, which is performed through a certain act, so that the doctor is basically equally responsible for the patient's death, either this was caused by withdrawing or by active euthanasia. Withdrawing is considered (admissible) passive euthanasia, which is done in the best interest of the newborn (beneficial to it); it raises strong ethical dilemmas to the neonatologist who evaluates the quality of the patient's remaining life (mostly the quality of future life, rather than the quality of the patient's current life)<sup>23</sup>. Although withholding is considered morally equivalent to withdrawing (e.g.

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Nuffield Committee of Bioethics)<sup>24</sup>, in practice there are certain differences, since the threshold for withdrawing is higher than the threshold for withholding, and two thirds of European neonatologists -rightly- believe that they are not the same thing in terms of moral demerit<sup>25,26</sup>. In addition, withdrawing has an active character, which is also due to the fact that it cannot be performed by any other person apart from the physician<sup>27</sup>. The method of withholding/withdrawing is a more common cause of death in NICU<sup>9</sup>.

Evaluation of the quality-of-life (QOL) is inevitable when the physician decides to perform (marginally active) withholding/withdrawing. Therefore, it is much more inevitable when active involuntary euthanasia is performed. It often concerns the future<sup>23</sup>. When suffering of the non-terminal newborn is not taken into account, an unacceptable qualitative evaluation of life is clearly concealed. A highly problematic case is that of a newborn of the so-called "grey zone": i.e. a newborn with a gestational age of 22-25 weeks<sup>2,28</sup>. In addition, it is to be noted that the gestational age can hardly be estimated precisely. In 22 weeks' time, it is considered that continuation of the treatment constitutes a futility. It is difficult to establish such futility when it is not quantitative (i.e. the intensive care does not work) but is rather qualitative (i.e. the treatment is useless and non-application or interruption thereof is considered a "good medical practice"<sup>27</sup>. In 25 weeks' gestational age, provision of intensive care is characterized as beneficial. The time interval between 23 and 24 weeks of gestation, which is considered a grey zone, weighing of the benefits and burdens for the newborn is rather difficult<sup>2,25,28,29</sup>. Application of supportive care is examined by the doctor and the parents. In other countries, depending on the degree of protection recognized in the fetus, people consider that there is futility in the 25<sup>th</sup> week (e.g. in the Netherlands)<sup>30</sup>, or in the 22<sup>nd</sup> week (e.g. in Italy)31. Fontana et al32, note that despite any theoretical recommendations (e.g. Nuffield Committee of Bioethics)<sup>24</sup>, the threshold for application or continuation of the application of a life support treatment for the NICUs is lower than that of the pediatric intensive care units (PICUs), where respect for the child's life is greater than respect for the newborn's life. Thus, there is withdrawing of the life-sustaining treatment for children with unstable physiology in the PICUs, while there is withdrawing of the life-sustaining treatment for newborns with (yet) stable physiology in the NICUs. The ethical dilemmas neonatologists are faced within the NICUs are strong, especially when they have to deal with a nonterminal newborn, with stable physiology and hopeless prognosis11.

c) Admissibility of the administration of palliative care in cases of acute pain, since this is justified by the sophisticated and rather intuitive "principle of double effect". According to this principle, it is considered that there is a moral distinction between intending a bad foreseen outcome and just foreseeing it (not intending it), while the good outcome is the intended one; therefore, it is excus-

able. Pain treatment is usually administered, combined with withdrawing of the treatment (for providing relief from the suffering caused by it). A highly controversial issue, however, is admissibility of the administration of muscle relaxants<sup>2,25</sup>. It is to be noted that anti-pain treatment is generally underused in neonatology<sup>28</sup>.

d) Admissibility of the abortion of a late fetus<sup>33</sup> (beyond the limits of viability which may be shifted to an earlier phase due to advances in medicine), as is the case in the Netherlands<sup>30</sup> and in other countries, including Greece<sup>14</sup> and the most conservative country favoring the protection of the fetus, Italy<sup>31</sup>, by covering the avoidance of causing damage -even psychological damage- to the pregnant woman. It is possible that this is, in fact, eugenic abortion.

e) Review of modern literature (A.Giubillini/F.Minerva, 2013)34, which considers that the newborn may be admissibly killed provided that there is abortion of a late fetus, since a late fetus and a newborn infant are morally equivalent ("potential persons"), so that killing of the newborn is acceptable (even under certain conditions), thus blurring the line between abortion and infanticide, which is called after-birth (post-partum) abortion (PPA). This view has rightfully received much dispute. It constitutes a more "advanced" form of the GP. In the context of acceptance of PPA, it is maintained that the newborn has no intrinsic human value, dignity, or inalienable human rights. Adopting the utilitarian bioethical approach of "actual personism"35, it is claimed that there is no fully protected "person", since the newborn does not either possess certain capacities, including rationality, communication skills, minimal self-consciousness, or render himself/herself a (minimal) value, being unable to make any plans for the future, so that, if the newborn loses these capacities, he/she can experience such loss as harm. Others consider the ability to experience pain as a criterion. Others ground the low moral status of the newborn on the different social status: the newborn is considered a "social person", who has only rights to rise and protection (as weakest member of society)<sup>36</sup>. However, PPA is governed by arbitrariness and moral inconsistencies<sup>35</sup>. It is unjustly discriminatory and counterintuitive. It is argued<sup>37</sup>, however, that there are also inconsistencies in favor of the admissibility of PPA: 1) It is maintained that it is unacceptable to make a distinction between a viable fetus (who may undergo an abortion) and a premature infant (who may not undergo infanticide, according to the common belief) only using the location in or out of the maternal body. The fetus' viability is shifted to an earlier point in time because of the advances in medicine. It is difficult to define viability, at least based only on the newborn's weight and gestational age (22-24 weeks of gestation, at the borderline of viability)<sup>29</sup>; 2) The American Medical Association thinks that one may extract organs from the anencephalic infant for transplantation purposes, prior to brain death<sup>37</sup>. For genetic reasons, there are human fetuses and infants who are unable to develop any cognitive abilities higher than those of a chimpanzee

(lack of potential); 3) Fontana et al 32 observe that in practice, a lower moral status is intuitively (and culturally) attributed to the newborns in the NICUs compared with the children in the pediatric ICUs (PICUs). However, Fontana et al, do not provide a clear definition of the terms "QOL" and "certain prognosis"38. As mentioned above, some people attribute such discrimination against infants compared with children to certain intrinsic characteristics, and others to social characteristics (acquisition of social membership in a community<sup>39,40</sup> or attachment that the physicians and parents feel towards children<sup>28</sup>); 4) Kuhse and Singer<sup>41</sup> think that any "consistency"<sup>32</sup> in the decisions made for newborns and older children would result in consistency in the decisions made for newborns and fetuses. However, from a cultural, social (since they have acquired social membership in a community), and intuitive point of view, a newborn is a "person", not a "potential person" since, for transition from the status of a newborn to that of a child, there are no substantial changes in the outer world (as in the case of childbirth).

- f) There are certain situations where absolute protection of the human life gives way (legal defense, war)<sup>12</sup>, especially in medical practice (depending on the age of the patient, his/her possibilities of survival, futility of the treatment, and distributive justice and allocation of resources, especially in terms of the patient's access to ultramodern medical methods).
- g) Certain trends in theory in favor of the admissibility of some loose forms of assisted suicide (plain facilitation) and delimitation of the medical duty to support life which inevitably falls into decline at a point in time earlier than those proposed by theory<sup>12,14</sup>.
- h) There is a tendency to accept certain non-voluntary forms of euthanasia (e.g. unilateral delimitation of medical duty and interruption of any artificial life support means, Baby Doe case, etc.)<sup>14</sup>. Acceptance of non-voluntary (or involuntary) active euthanasia presupposes the acceptance of voluntary active euthanasia<sup>42</sup>.

### 3. Reasons against the adoption of the Groningen Protocol

The GP is rightfully one of the most controversial and important issues of modern bioethics. At legal level, it violates certain articles (e.g. article 3) of the United Nations' "Universal Declaration of Human Rights" 17,35, certain articles (e.g. article 2) of the "European Convention on Human Rights"35 (ECHR), articles (e.g. article 6§1) of the Convention on the Rights of the Child<sup>35</sup>, etc. At bioethical level, it is in conflict with the universal principles established after World War II26, including: "there is no human life not deserving to live". It conflicts the equal dignity principle<sup>35</sup>, the bioethical principle of "no harm"17 and the principle of autonomy: This is nonvoluntary (involuntary) euthanasia. There is neither any real or presumed consent of the newborn, nor can it be substituted by the parents; besides, the parents have inadequate information and true serving of the newborn's best interest is doubtful. It is also in conflict with the principle of justice, since there may be discrimination against newborns belonging to poorer families; thus, more modern palliative means cannot be applied to prevent their "unbearable suffering" <sup>12</sup>. In addition, the GP may favor certain slippery slopes, thus enhancing any trends seeking a limitation in the protection of human life in certain phases, with the risk of turning euthanasia of newborns into "large-scale" euthanasia against vulnerable groups of the population (newborns). The GP may also favor a slippery slope from voluntary to involuntary (which has been occurring in the Netherlands for many years now) <sup>18,26</sup> and from non-voluntary to involuntary euthanasia<sup>35</sup>. As cited above, the same trends favor the adoption of the GP.

The Nuffield Council of Bioethics states the active euthanasia of newborn should not be done "no matter how serious the condition of the baby"<sup>8</sup>.

The GP has "imprecise terminology and vagueness" 17,42-44 and certain conditions which are difficult to ascertain whether they are satisfied in practice. Chervenak<sup>44</sup> notes that the GP presents some "clinical and ethical imprecision". Thus:

a) The concept of "unbearable suffering" is vague (individual perception) and hard to be conceptualized and objectively estimated45, since it has a subjective character<sup>6,42</sup>. Neonatal pain is difficult to assess and quantify<sup>46</sup>. Suffering is a "wholly subjective" experience<sup>42</sup>. The term "suffering" is associated with the ability to form wishes, hope for the future and goals. "Immeasurable" 47 suffering must be quantified, so that the GP may serve the principle of beneficence, as argued. For death to constitute a benefit, in order to serve the best interest of the newborn, there must be some certainty when weighing the burdens and benefits<sup>42</sup>. The view that the physicians can accurately determine if the newborn suffers unbearably is erroneous, especially when it comes to newborns of an extremely low gestational age, including neurologically devastated newborns, newborns weighing less than 800gr<sup>46</sup>, and newborns suffering from MMC<sup>43</sup>. However, the GP relies on this view<sup>42</sup>. According to a study, newborns can "endure 14 pain procedures per day, on average<sup>48</sup>. Neonatal units have established certain neonatal pain scales<sup>46,49</sup>. However, further research and establishment of certain assessment tools (evidence-based, bevond pain scales), are needed<sup>49</sup>. In any case, physicians can more easily estimate whether there is generally any suffering and disability of the newborn compared with the parents. Physicians can more easily consider death preferable to disability<sup>28</sup>. It is not by chance the fact that, while bioethicists remained split in terms of the GP between supporters and opponents, the neurosurgical community remained mute<sup>17</sup>. The decision-making process must not obey any simple rules. It seems that pain treatment is "grossly underused" among newborns28. In addition, among newborns, it is very difficult to evaluate other forms of suffering apart from pain, including itching or nausea.

b) The meaning of the newborn's "best interest" is unclear, especially when there is a prediction of a short 200 VOULTSOS P

life expectancy and serious damage. Such a case of Edwards syndrome (trisomy 18) is cited in the literature<sup>50</sup>. The newborn's best interest must be examined from many aspects (e.g. cultural), not only from a medical aspect<sup>3</sup>. Verhagen and Sauer<sup>7</sup> think that, if parents and the medical team believe that intensive care is not in the best interest of the child, then withholding/withdrawing is considered a "good practice". Pediatricians coming from many European countries disagree, regarding the meaning they attribute to the "best interest of the newborn"<sup>51</sup>. It is highly possible that the "best interest" of the community is behind the best interest of the newborn<sup>52,53</sup>.

c) The GP allows physicians to estimate the minimal acceptable "quality of another life" and assess the very ethical acceptability of their actions. And this is very dangerous. What is estimated is whether there is suffering and a poor QOL (functional disability, pain, discomfort, poor prognosis, hopelessness, lack of self-sufficiency, hospital dependency, inability to communicate), along with the expectation of a prolonged survival. Nevertheless, a supporter of GP (Manninen)<sup>20</sup> thinks that the GP does not evaluate life from a qualitative point of view, but it rather constitutes a human alternative for suffering and dying newborns, which is applied under very strict conditions, under extreme and exceptional circumstances, among terminal newborns, and under well-defined circumstances.

Assessment of QOL is very difficult, especially when poor prognosis and serious damage coexist. An objective assessment of QOL is even more difficult. In 92% of the cases, physicians think that great importance is given to the future QOL<sup>23</sup>. The GP most refers to MMC, whose prognosis has improved, especially through the development of fetal surgery. Based on a number of studies that have been published after the GP, it is considered that the burdens of MMC were overestimated<sup>17,42,54</sup>. Scientific evidence may change. However, any decisions made in medical ethics are not only determined by evidence-based medicine. There is no evidence-based ethics<sup>43</sup>.

d) It is doubtful whether consent of the parents may replace that of the newborn, or at least whether it may serve the best interest of the newborn. In addition, full information of the parents is probably impossible<sup>11</sup>. Kodish<sup>47</sup> thinks that the criterion of parental consent is more incoherent and objectionable than the criterion of assessment of unbearable suffering.

Parental consent in end-of-life decisions should be maximal: if not decisive, it should be substantial and significant. It is an expression of the "autonomy of the family unit". The parents bear the physical, emotional, social, and financial burden of the child. It is possible that, under the best interest of the newborn set out by them, their own interest to free themselves from this burden, or even their fatigue, is covered 52,53. In the context of his thesis on a wide, responsible self-determination (personal utilitarianism), Lecaldano 55 accepts, by way of exception, that only the parents may evaluate the newborn's quality of life. Certainly, parents probably make decisions based

on their own value system<sup>25</sup>. In France, parents are not taken into consideration in such decisions, while, in recent years, some legislative attempts have been made to include participation of the parents<sup>9</sup>. Disregard of the parent's consent in cases of active termination of the newborn's life have been reported for years before the GP in the Netherlands11. In the UK, parents take part in such decisions, even at marginal gestational ages in terms of viability (22-25 weeks), with the Nuffield Committee of Bioethics seeking their maximal participation (i.e., wishing them to have not a significant but rather a decisive role)<sup>24</sup>. An end-of-life (EOL) decision about the newborn, especially in terms of his/her active euthanasia of the GP must be collective (parents and other doctors). Good communication between the doctors and also between the doctors and the parents, as well as patience and dedication of time, are required<sup>48</sup>. Besides, this is how conflicts between doctors and parents are avoided. In any case, there is no ex officio right of the parents to make a decision for their child. However, the GP model is medico-centric, it seeks to strike a balance between medical responsibility and parental autonomy. Eijnden and Martinovici<sup>8</sup> think it correct the legal frame of newborn's euthanasia to be relied both on legal principles and standards developed in euthanasia among adults and late abortion.

- e) It is doubtful whether the most palliative and accepted medical standards are applied during the application of the GP. In addition, it is questionable whether the opinion of another (independent) physician is sufficient, or whether (more rightly) the opinion of a committee of experts (medical, legal, bioethical) is required. It is also questionable whether active euthanasia of newborns may be characterized as a "good medical standard", since it violates the principles of pediatric ethics, as Kodish<sup>47</sup> points out.
- f) The supporters<sup>20</sup> of the GP think that it only concerns terminal newborns; its opponents think, however, more rightly, that it also concerns newborns with severe, non-terminal congenital anomalies<sup>42</sup>. Therefore, evaluation of the QOL by third parties, including physician, parents etc., acquires great importance as an unacceptable gradation of human life.
- g) The GP does not make a clear distinction between a positive prognosis of death and the ability to continue to live.
- h) The acceptance of the GP will be an obstacle to research on the medical treatment of severe anomalies of the newborns.

Chervenak<sup>56</sup> and Barry<sup>17</sup> think that the GP is scientifically invalid. Barry rightly notes that "the amount of medical resources" and "numerous admissions and operations" should not favor the acceptance of the GP<sup>17</sup>.

The degree of acceptance of the GP is substantially a culturally defined issue. A recent study has showed that different European countries deal with the issue of active euthanasia of newborns very differently. Important differences are seen between European countries regarding EOL decisions (as influenced by the cultural and social

systems of every country)<sup>51</sup>. What is typical is the fact that in Belgium, which is one of the few European countries (along with France, Denmark, Sweden, the Netherlands, and Luxemburg) where there is high public acceptance of euthanasia<sup>57</sup> (according to a survey conducted in 2013) and which allows direct active adult euthanasia by law (2002), as the Netherlands, under well-defined conditions, in a recent law (2014) on active children euthanasia, it is not the age, but rather the capacity of the child for discernment which is evaluated depending on the case (by a multidisciplinary pediatric team, including a clinical psychologist), while a proxy request for euthanasia is excluded<sup>57</sup>. It is to be noted that in Belgium there is (according to studies) failure of transparency "with only 52.8% of acts of euthanasia reported to the authorities in Flanders"35.

### 4. Conclusion-Recommendation

Despite the advances in medicine, early active euthanasia remains a problem. However, the GP is closely related only to the Dutch legal and bioethical culture. It is not adopted, not even in Belgium. Admissibility of voluntary active adults' euthanasia (under certain conditions) constitutes a prerequisite, but is not sufficient for adoption of the GP. Some circumstances in the field of bioethics favor (and are favored by) acceptance of the GP. However, they are deemed inadequate. The GP is in conflict with certain international laws, including universal principles of bioethics, predisposes to a slippery slope and contains uncertainties and requirements which are hard to establish in each individual case.

The issue of early active euthanasia should not be regulated by guidelines allowing it, even under strict conditions. The view that it is better when some newborns are in a state of unbearable suffering (which is rather rare with the use of modern methods of anesthesia), as inhuman as this may be, seems right, rather than some nonunbearably suffering newborns being euthanized. The virtue ethics58 that emphasizes the moral character or virtues of the individual (moral agent) and recognizes a wide discretion of the attending physician (based on his/ her culture, experience, skill, flexibility, courage, resoluteness, responsibility, respectfulness, sincerity, etc.), which verges on medical paternalism and approaches the patient in a holistic way, has much of a role in the countries of the so-called "Mediterranean bioethical zone". Great importance is given to the relation between physician and patient, whose personal character is highlighted. The Mediterranean bioethics<sup>59</sup> has an ethical and relational character and approaches the person not in an absolute way (as an isolated individual), but as a co-participant. It gives great importance to values including beneficence, friendship and happiness, and the medical paternalism in favor of the patient's life and health of Hippocratic origin, is typical.

Greece is the motherland of the (South-European) Mediterranean bioethics, since it dates back to the thinking of Aristotle, Plato, and to the spirit of the Hippocratic Oath. Greek culture is not fanatically focused on individualism and a "right to die" can hardly be acceptable.

In this study, it is suggested that an approach to the sensitive and controversial ethical dilemmas with regard to the severely ill newborn be done not through the GP, but, rather, through the combination of virtue bioethics (especially in the countries of the "Mediterranean bioethical zone") and the principles of principlism, which is enriched, however, with the "principle of mutuality" proposed by DeMarco<sup>60</sup> (enhancement of all principles), in order to achieve a "maximal" bioethical approach (by especially enhancing the principles of beneficence and justice), along with the establishment of circumstances and alternatives minimizing or eliminating the relevant ethical dilemmas and conflicts among the fundamental principles formed whenever certain dilemmas are to be solved ("decision-making") based only on the principlebased bioethical approach (so that certain principles are necessarily, and probably deliberately, eliminated): the GP is supposed (which is not at all certain, however) to serve the bioethical principle of "beneficence", which, in this particular case, is considered to dominate over the bioethical principle of "do-no-harm". Virtue bioethics can be integrated into the principalism<sup>58</sup> of Northern Europe and "ontological personalism"61 of Southern Europe, where human life is fully protected, starting from conception of the fetus.

Thus, the dilemmas are not solved by defeating certain values (e.g. autonomy) in favor of others, but, rather, by enhancing values (changing circumstances, investigating alternatives, e.g. educating patients, parents) that allow for less harm, greater autonomy, greater justice, more good (although the principle of beneficence is never fully satisfied). Therefore, the rightest/fairest and "best" choices will be done (by trained parents and physicians) considering all interests involved as much as possible, including that of the community in general. Given that health care resources are limited, costs incurred by the health service may be taken into account in the decisionmaking process in some extreme cases; however, they do not play the leading part<sup>50</sup>. Any conflicts arising should be solved by independent clinical ethics committees2, and courts should only constitute an "ultimum refugium" 48.

Instead of the unacceptable evaluation of the QOL of another person, which takes place in passive and, much more, in active euthanasia of severely ill newborns (GP), it is more appropriate to make efforts to improve the quality of life of newborns, at state/community level: institutions, medical associations, physicians, psychologists, social-workers, nurses, clergy etc. Thus, creating the appropriate circumstances and enhancing prevention (e.g. antenatal screening policy), the number of unbearably suffering newborns can be reduced to a minimum level (maybe, only in case of the rare disease "osteogenesis imperfecta"). It is noting woth that the infant mortality rate represents an important marker of a country's public health<sup>62</sup>.

In cases of EOL decisions, the physician should have

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a good relationship and wide and substantial communication with the parents (and should have received a relevant training)², accepting the intervention of a third party consultant, while having a wide and decisive discretion and initiative (virtue ethics). What might possibly help such an assessment would be the establishment of Health-Related QOL (HRQOL) measures for newborns as well<sup>63</sup>. For such cases, one solution is to justify the act of killing of the newborn on a guilt level of the "perpetrator" through the mechanism of lifting liability of the physician who faces a conflict of equivalent duties.

In any case, the active termination of a newborn's life cannot be acceptable (imprecise terminology and vagueness, impossible to predict with certainty the future QOL, conflict with "no discrimination principle" etc)<sup>54</sup>, especially in the Hippocratic-Mediterranean Greek bioethical view and legislation, where the bioethical approach has a deontonogical, rather than a utilitarian character. In addition, the misused (active) palliative treatment, which legitimately replaces the curative treatment in some cases, must be prevented from degenerating into an active termination of the newborn's life. Nevertheless, the GP may give rise to an international discussion and improvement in the palliative treatment of newborns<sup>47,57</sup>.

### **Conflict of interest**

None declared by authors

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