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## Whose suffering? Comments on M. Brouwer et al. Pediatric Brain Tumors: narrating suffering and end-of-life decision-making

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## Commentary: Whose suffering?

MARTIN BUIJSEN

### 'Let die'

Marije Brouwer et al. contend that collecting treatment experiences of newborns with life-threatening conditions can support both caregivers and parents in making difficult end-of-life decisions. They illustrate the importance of that understanding by narrating the heartbreaking story of the sisters Roos and Noor, two newborns in the last stage of their lives.<sup>1</sup>

The authors begin the story with the statement from Noor's father that he and her mother were thinking "about Wednesday." For the astonished physician, he added that it would be a good day to "let his daughter die."<sup>2</sup> In explaining this wish, the authors describe the couple's previous distressing experiences with the death of Noor's older sister Roos. Although it is certainly understandable that Noor's parents wanted to save her from the agony suffered by her sister, Roos' history involved sedation to suppress consciousness and avoid pain, but not with the intention of ending life. However, in Noor's case, the father did not ask for palliative sedation, he wanted active termination of her life, an act permitted under Dutch law.

Given Noor's circumstances, her father was clearly not speaking of discontinuing senseless medical treatment that would result in her death. The expression 'let die' here means active termination of life and can only be understood in an environment in which the active termination of a newborn's life is at least open to discussion. Those words may not have the same meaning elsewhere and here they must be understood within the Dutch normative context, specifically the legal one. Unlike other countries, the Netherlands has regulated active termination of the lives of newborns. My comments on the article by Brouwer et al. are set against the background of this regulation.

### Active termination of newborns' lives regulated

On February 1 2016, the Minister of Security and Justice and the Minister of Public Health, Welfare and Sport replaced the old regulation for the assessment of reported cases, dating from 2007, with a new one: the Late Pregnancy Termination and Termination of Life of Newborns Regulation.<sup>3</sup> According to its explanatory annex, this regulation applies to the termination of the life of a newborn up to the end of the first year of life. The circumstances must be such that the child is certain to die very soon despite intensive care, or could survive but with a poor prognosis and an extremely grim prospect, or who is not dependent on intensive care to survive but who is nonetheless facing a life of severe and hopeless suffering.<sup>4</sup>

The active termination of the life of a newborn does not fall within the scope of articles 293 and 294 of the Dutch Criminal Code, because the patient is not able to make a request. According to the first article, termination of life on request is a criminal offence; the second covers assisted suicide. The termination of the life of a newborn does, however, fall within the scope of articles 82a and 289 of the Criminal

Code. Therefore, such an act is punishable as murder; since, in principle, an appeal to *force majeure* in the sense of emergency (article 40 of the Criminal Code) can provide an exemption from criminal liability if the so-called due care criteria of the regulation were observed by the physician concerned. As with the Dutch Euthanasia Act, it is physicians who must meet certain requirements.

In the case of terminating the life of a newborn, physicians act with due care if: (a) they are satisfied that the suffering of the newborn is hopeless and unbearable; meaning for example, that discontinuing medical treatment would be justified on the grounds that intervention is senseless and that there is no reasonable doubt about the diagnosis and prognosis; (b) they have fully informed the parents of the diagnosis and the prognosis, and both physicians and parents are satisfied that there is no other reasonable solution for this newborn's situation; (c) the parents have agreed to the termination of life; (d) the physician consulted at least one other independent physician who has provided a written opinion on the due care criteria specified above; or, if an independent physician cannot reasonably be consulted, the attending medical team was consulted, which gave its written opinion on the due care criteria specified above; and (e) the termination of life was performed with due medical care.<sup>5</sup>

The Dutch Burials and Cremations Act also applies. In the case of termination of life of a newborn, the attending physician cannot issue a natural death certificate.<sup>6</sup> Such a death must be reported as an unnatural death by the attending physician to the municipal coroner,<sup>7</sup> who carries out an autopsy and reports to the public prosecutor.<sup>8</sup> If there are concrete indications of a criminal act and the physician cannot invoke *force majeure* in the sense of emergency, the public prosecutor will determine whether it is necessary to initiate a criminal investigation and order an inquest. In that case, the Board of Procurators General, in charge of the prosecution service, must be informed as soon as possible. The Board may then decide that: (a) an investigation must be started before a definitive decision can be reached; (b) the case will be dismissed, whether or not subject to certain conditions; or (c) the physician will be prosecuted.<sup>9</sup>

To be able to review a case properly, the Board of Procurators General obtains all relevant information, including an assessment of the so-called Assessment Committee.<sup>10</sup> This national committee consists of four physicians, one lawyer, and one ethicist.<sup>11</sup> Although the assessment does not determine the Board's decision, it does carry considerable weight. If the Assessment Committee concludes that the physician acted with due care, there is no reason for the Board of Procurators General to institute a criminal investigation or prosecution. The case will then be closed with an unconditional *nolle prosequi*.<sup>12</sup>

If the Assessment Committee arrives at a different conclusion, and following investigation, the Board of Procurators General decides that the physician has committed a crime and can be held liable, then prosecution is indicated. In principle, because the Board states in its guidelines that when considering the expediency of criminal prosecution, the *nature* of the infringed standard is decisive; in other words, only the infringement of a *substantial* due care criterion warrants prosecution. In all other cases, a conditional or unconditional *nolle prosequi* is appropriate. The question of which due care criteria are substantial and which are not is left aside by the Board of Procurators General. The Board is only explicit with regard to the criterion of suffering—the requirement that the physician is satisfied that the suffering of the newborn is hopeless and unbearable. That is a substantial due care criterion.<sup>13</sup>

## Hopeless and unbearable suffering

Readers familiar with Dutch euthanasia law will have noticed similarities. Terminating the life of a newborn is a criminal offence just like termination of life on request (euthanasia) and assisted suicide, and an appeal to *force majeure* by a physician is equally possible. That appeal can succeed if certain due care criteria are met, and whether they have been met will be assessed afterwards by a committee.

There are also differences. The regulation applies only to infants less than one year old; the Euthanasia Act applies to legally competent patients aged twelve years and older. The regulation's due care criteria are not statutory requirements, unlike those of the Euthanasia Act. And unlike the Regional euthanasia review committees that implement the Euthanasia Act, the Board of Procurators General is also informed when the Assessment Committee deems a notification as showing due care.

Obviously, the regulation lacks the requirement of the Euthanasia Act according to which the physician must be satisfied that the request by the patient was voluntary and well-considered.<sup>14</sup> But the main sentence of the legal provision containing the criterion of suffering agrees almost word for word. According to the regulation as well, there must be hopeless and unbearable suffering.<sup>15</sup>

In the context of the Euthanasia Act, the patient's suffering is considered *hopeless* if the disease or condition causing the suffering cannot be healed and it is not possible to alleviate the symptoms sufficiently to make them tolerable. The hopelessness must be considered in relation to the patient's disease or condition and the associated symptoms. A situation is considered hopeless when there are no realistic curative or palliative treatment options that are reasonable for the patient. As the diagnosis and prognosis are key to evaluating the hopelessness of the suffering, the judgment must be based on the prevailing medical insights.<sup>16</sup> For these reasons, hopelessness can be called the *objective* aspect of the criterion of suffering. In the regulation, 'hopeless' does not have another meaning; the additions to the main sentence can be considered as further objectification.

The Regional euthanasia review committees state in their guidelines that it is sometimes hard to establish whether suffering is *unbearable*, 'for this is a subjective notion.'<sup>17</sup> What is bearable for one patient may be unbearable for another; according to the euthanasia review committees: 'This depends on the individual patient's perception of his situation, his life history and medical history, personality, values and physical and mental stamina.'<sup>18</sup> Therefore, 'unbearable' clearly refers to the *subjective* aspect of the criterion of suffering.

Nevertheless, it is insufficient for the patient to appeal to the Euthanasia Act merely by claiming (in word or writing) that he suffers unbearably. However, some objectivity is deemed desirable, according to the review committees, as it must be *palpable* to the physician, that this particular patient's suffering is unbearable. The physician must therefore not only be able to empathize with the patient's situation, but also see it from the patient's point of view.<sup>19</sup> It is, after all, the physician who must be satisfied as regards the suffering. Not only in keeping with the Euthanasia Act but also with the regulation.

The article by Brouwer et al. focuses on the question of the definition of unbearable suffering of the newborn. In my interpretation of the article at least, it is a struggle with that concept, and an adequate explanation of my reading must undoubtedly be sought in the legal context as well. One thing is clear, however, the manner in which unbearable suffering is operationalized under the Dutch

Euthanasia Act will not be of much help for physicians contemplating terminating the life of a newborn. There is no patient who can express his suffering in words. There is no such starting point.

### **Suffering as discomfort**

Brouwer et al. cite Eric Cassell's frequently used definition of suffering: "the state of severe distress associated with events that threaten the intactness of a person."<sup>20</sup> According to the authors, proof that children with brain tumors do not actively suffer from them may never be taken for granted; and they add that the suffering of these children does not depend solely "on the possibility that they can actively experience the symptoms caused by the tumor."<sup>21</sup>

In September 2013 an evaluation committee established by the Dutch government found the earlier rendition of the current regulation to be inadequate. According to this committee, a number of the due care criteria were unclear; and physicians especially had little faith in them with respect to the termination of life of newborns. Not all cases were apparently reported.<sup>22</sup>

Under the previous regulation only one case was reported, in 2009.<sup>23</sup> This report, Case One, concerned a newborn diagnosed with Junctional Epidermolysis Bullosa, type Herlitz. Actual cases illustrate what these babies endure. The prognosis for this condition is poor. Ninety per cent of children with this condition die in their first year of life. When they are touched, washed or laid down, their skin comes off and a blister forms. Wounds develop with an extremely poor chance of healing. The mouth and pharynx are affected, often severely, which is extremely painful and makes feeding very difficult. The child cannot drink enough, becomes pale, stops growing and then loses weight. Ultimately, the child starves to death. For children with this condition, the blisters and wounds are very painful; just changing their diaper (approximately eight times a day) is extraordinarily painful. Changing their bandages, which must be done daily or every other day, also produces very painful episodes. Even with intensive pain medication, this pain cannot be entirely avoided.<sup>24</sup>

Just three weeks after his birth, it was decided to admit this baby boy to hospital for palliative comfort care. Upon admission, the child appeared increasingly tired, whimpery, and with progressive blistering. The lower half of his body had already lost its skin. He continued to lose weight, and it was increasingly difficult to make him comfortable; often the medication had no effect. He also became so weak that he could barely open his eyes, and it was more difficult to administer medication. His parents felt their son's suffering was no longer bearable and requested active termination of life. Their request seemed consistent and well-considered. Given the hopeless nature of the situation, combined with the unbearable suffering of the child, the physician acceded. Ten weeks and six days after birth, the child's life was actively ended. For a week and a half prior to the time of death, it had been impossible to make him comfortable, even with increasingly large doses of painkillers and sedation.<sup>25</sup> The Assessment Committee found that the physician had acted in accordance with the due care criteria.<sup>26</sup>

Case Two: After the revision of the regulation on 1 February 2016, which included amendments to the due care criteria, a second case was reported in 2017.<sup>27</sup> This time it concerned a newborn who had undergone genetic testing and had been diagnosed with a severe neurological condition. The prognosis was very poor. The condition's

symptoms included severe psychomotor retardation, severe restlessness, involuntary movements, reflux, vision and feeding problems, and severe sleep disturbances. The clinical status was expected to worsen, which occurred, despite many pharmaceutical and other interventions. There were recurrent epileptic episodes and an increased risk of complications such as choking and difficulty swallowing, with possible pneumonia and difficulty in breathing as a result. The condition was incurable, and no improvement of the child's condition could reasonably be expected. The child's suffering consisted of ceaseless crying, screaming, whimpering and barely sleeping. The child suffered from severe motoric restlessness and was inconsolable. His discomfort and agitation were extreme and would only get worse.<sup>28</sup>

According to the report, the parents and the attending physician agreed on active termination of life given the child's extreme discomfort, lack of quality of life and the poor prognosis. This was intended to spare the child further hopeless and unbearable suffering. According to the physicians who were consulted from outside the region, the criterion of hopeless and unbearable suffering had been met as specified in the regulation. They felt that the hopelessness was primarily determined by the impossibility of alleviating the child's current suffering, coupled with the fact that he had been diagnosed with a condition with a short life expectancy and no hope of quality of life. The unbearable aspect was determined by the already long-term signs of severe discomfort that the child demonstrated almost ceaselessly; signs that were also interpreted by the parents as indications of unbearable suffering. Ultimately, the Assessment Committee found that the physician concerned had also acted in accordance with the due care criteria.<sup>29</sup>

Both newborns exhibited signs (continuous crying, whimpering) of extreme discomfort that could simply be interpreted by caregivers and the parents as signs of suffering. It was clear to all involved that these children were in a 'state of severe distress.' When the 'active experience of symptoms' is so evident, opinions can only vary as to the *extent* of suffering. In the second case, except for one physician, there was a general consensus among the attending multidisciplinary team about the request for termination of life. This physician was not certain that the child was suffering *unbearably*.<sup>30</sup>

Depending on how evident the newborn's 'active experience of symptoms,' the differences of opinion can increase regarding the presence of suffering. In situations in which extreme discomfort cannot be ascertained conclusively, as in Noor's case, consensus will be less obvious. And if there is doubt concerning the presence of suffering, when will it be interpreted as *unbearable* suffering? According to Brouwer et al. the stories of Roos and Noor demonstrate that in such patients suffering is not merely about pain, or extreme discomfort, "we have to give more meaning to the concept of suffering."<sup>31</sup> In their opinion, suffering is also about "dignity, social aspects and lack of quality of life in all its facets."<sup>32</sup>

### Quality of life, dignity?

In Case One, the report did not mention quality of life, but in Case Two it did. According to the Assessment Committee report, "given the child's extreme discomfort, lack of quality of life and the poor prognosis, the parents and the attending physician agreed on termination of the child's life to spare the child further hopeless and unbearable suffering."<sup>33</sup> Quality of life was not defined anywhere in the report,

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but the parents and caregiver apparently agreed that its lack was one of the reasons to decide on termination of life. The Committee contemplated that “the hopelessness was determined by the impossibility of alleviating the current suffering and the fact that the child had been diagnosed with a condition with a short life expectancy without any hope of improving its quality of life.”<sup>34</sup> Strangely enough, the Assessment Committee associated quality of life with the hopelessness of the suffering, the objective aspect of the criterion.

Quality of life is a familiar term in (health)care. Although medicine undoubtedly sets out to improve quality of life, this does not mean that for physicians it can play a role in medical evaluation in individual physician-patient relationships. In 1995, a Dutch medical disciplinary court concluded that quality of life is not a medical matter, that physicians must exercise great caution and never take their personal opinion as benchmark.<sup>35</sup>

Because evaluating other aspects of human life exists outside the scope of the medical profession, a decision based on a lack of quality of life cannot be a decision made by a physician about a patient. Consequently, a decision about quality of life must remain a patient’s subjective decision. But what if the patient is incapable of making such a decision?

In 1995, in a criminal case brought against a physician who had actively terminated the life of a three-day-old baby with severe congenital deformities, the Amsterdam Court of Appeal was firm.<sup>36</sup> In that case the physician invoked *force majeure*, and the question was whether, in the given circumstances, and, after careful consideration of the mutually conflicting obligations and interests, he had made the right decision by deliberately and actively terminating the baby’s life. In order to answer that question, the judge accepted as a starting point that assessing decisions that result in terminating a life must be made with great care. According to the court, this applies even more strictly when it concerns the life of a legally incompetent subject, and “no benchmark is suitable that is based on subjective, personal value judgments about the quality of a patient’s future life when that patient cannot express his own judgment of the quality of his life.”<sup>37</sup>

If the patient is a newborn and, therefore, unable to judge the quality of his own life, and if it is improper for the physician as caregiver to decide for any patient, then it is up to the patient’s parents to make the decision. If more meaning needs to be given to the concept of suffering, as is the contention of Brouwer et al., then it can only be done with judgments on quality of life by the parents of children like Roos and Noor, and their perspective on dying with dignity.

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The judgment of the quality of life depends on a person’s concepts about life, their moral concepts, religious convictions, view of society, character, social network, expectations, past experiences, experience of sickness and of health, stamina, age, bad or good fortune in life, and so on. How people think about dying, and the views they cherish about dignified dying, will depend on little else. Just like the judgment of what constitutes quality of life, a person’s concept of the dignity of a death cannot be more than their personal and subjective value judgment.

Brouwer et al. conclude their article with the statement that “By collecting and analyzing more stories like the one of Roos and Noor, we gain more insight into the variety of what parents see as suffering, and how it motivates them to make

decisions.”<sup>38</sup> This quotation cannot be understood in any other way than that the authors are arguing that caregivers of newborns who are *not* suffering severe discomfort must be led by the experiences, opinions and judgments of the parents. If they ‘see’ suffering in the absence of severe discomfort, their opinion will have to guide the caregivers. And if the parents qualify that suffering as unbearable, the physician will have to link the consequences to their decision, including termination of life if that is what they want. That is what I consider to be the import of *Pediatric Brain Tumors: Narrating suffering and end-of-life decisionmaking*.

What exactly is meant by the authors when they refer to the importance of *analyzing* stories like the one of Roos and Noor is unclear. But it seems to me that things that are hard to unravel are difficult to analyze. Is the suffering of these newborns distinguishable from that of their parents? It is very revealing that in the report of Case Two, even the suffering of that newborn baby, which consisted of extreme discomfort that was also evident to the physician, was described together with that of the parents in one section entitled “Suffering of child and parents.”<sup>39</sup> In cases where it is difficult, or even impossible, to distinguish the suffering of the parents from that of their child, physicians face the difficult decision as to whether requests by the parents should be the only consideration in justifying terminating the life of the child.

## Notes

1. Brouwer M, Maeckelberghe E, ten Brincke HJ, Meulenbeek-ten Brincke M, Verhagen E. Pediatric Brain Tumors: Narrating suffering and end-of-life decisionmaking. *Cambridge Quarterly of Healthcare Ethics* 2020;29(3):338–45.
2. See note 1, Brouwer et al. 2020.
3. Late Pregnancy Termination and Termination of Lives of Newborns Regulation. *Staatscourant* 2016, 3145; available at <https://wetten.overheid.nl/BWBR0037570/2018-08-01/> (last accessed 5 May 2019).
4. Explanatory annex to Late Pregnancy Termination and Termination of Lives of Newborns Regulation. *Staatscourant* 2016, 3145:5; available at <https://wetten.overheid.nl/BWBR0037570/2018-08-01/> (last accessed 5 May 2019).
5. See note 3, Late Pregnancy Termination and Termination of Lives of Newborns Regulation, Article 7.
6. Burials and Cremations Act, Article 1, paragraph 1; available at <https://wetten.overheid.nl/BWBR0005009/2018-08-01/> (last accessed at 5 May 2019).
7. Burials and Cremations Act, Article 7, paragraph 3.
8. Burials and Cremations Act, Article 10, paragraph 1.
9. Directive on prosecution of late pregnancy termination and termination of life of newborns. *Staatscourant* 2017, 69445:1–3; available at <https://wetten.overheid.nl/BWBR0040270/2017-12-01/> (last accessed 5 May 2019).
10. Directive on prosecution of late pregnancy termination and termination of life of newborns. *Staatscourant* 2017, 69445:3.
11. See note 3, Late Pregnancy Termination and Termination of Lives of Newborns Regulation, Article 3, paragraph 1.
12. See note 9, Directive on prosecution of late pregnancy termination and termination of life of newborns, 2017, at 4.
13. See note 9, Directive on prosecution of late pregnancy termination and termination of life of newborns, 2017, at 4.
14. Termination of Life on Request and Assisted Suicide (Review Procedures) Act, Article 2, paragraph 1, subsection b; available at <https://wetten.overheid.nl/BWBR0012410/2018-08-01/> (last accessed 5 May 2019).
15. See note 3, Late Pregnancy Termination and Termination of Lives of Newborns Regulation, Article 7, subsection a.



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16. Regional euthanasia review committees. *EuthanasieCode 2018*, at 22; available at <https://www.euthanasiacommissie.nl/de-toetsingscommissies/uitspraken/brochures/brochures/euthanasiecode/2018/euthanasia-code-2018/> (last accessed 5 May 2019).
17. See note 16, Regional euthanasia review committees, 2018, at 22.
18. See note 16, Regional euthanasia review committees, 2018, at 22–3.
19. See note 16, Regional euthanasia review committees, 2018, at 23.
20. Cassell EJ. *The Nature of Suffering and the Goals of Medicine*. New York, NY: Oxford University Press; 1991:33.
21. See note 1, Brouwer et al. 2020.
22. Van de Vathorst S, Gevers JKM, Van der Heide A, Bolt LLE, Ten Cate K. *Evaluatie Regeling centrale deskundigencommissie late zwangerschapsafbreking en levensbeëindiging bij pasgeborenen* [Evaluation Regulation on Central Expert Committee Late Pregnancy Termination and termination of Life of Newborns]. Den Haag: ZonMw; 2013:13; available at <https://publicaties.zonmw.nl/evaluatie-regeling-centrale-deskundigencommissie-late-zwangerschapsafbreking-en-levensbeëindiging-bij-pasgeborenen/> (last accessed 5 May 2019).
23. Central Expert Committee Late Pregnancy Termination and Termination of Life of Newborns 2009 December 1; 2009/LP/001; available at <https://www.lzalp.nl/procedure/documenten/publicaties/websitepublicaties/adviezen/2009/2009lp01/> (last accessed 5 May 2019).
24. See note 23, Central Expert Committee Late Pregnancy Termination and Termination of Life of Newborns 2009, at 2.
25. See note 23, Central Expert Committee Late Pregnancy Termination and Termination of Life of Newborns 2009, at 3.
26. See note 23, Central Expert Committee Late Pregnancy Termination and Termination of Life of Newborns 2009, at 8.
27. Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns *Annual Report 2017*, at 6–8; available at <https://www.lzalp.nl/documenten/publicaties/websitepublicaties/jaarverslagen/2017/jaarverslag-2017/> (last accessed 5 May 2019). Till date, two cases have been reported, not three as stated by Brouwer et al. in note 1.
28. See note 27, Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns 2017, at 6.
29. See note 27, Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns 2017, at 6–7.
30. See note 27, Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns 2017, at 6.
31. See note 1, Brouwer et al. 2020.
32. See note 1, Brouwer et al. 2020.
33. See note 27, Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns 2017, at 6.
34. See note 27, Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns 2017, at 7.
35. Medical Disciplinary Court, The Hague 1995 Mar 22, *TvGR* 1996/8.
36. Court of Appeal Amsterdam 1995 Nov 7, *TvGR* 1996/1.
37. See note 27, Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns 2017, at 6.
38. See note 1, Brouwer et al. 2020.
39. See note 27, Assessment Committee on Late Pregnancy Termination and Termination of Life of Newborns 2017, at 6.