Euthanasia for the Elderly: Multiple Geriatric Syndromes and Unbearable Suffering According to Dutch Euthanasia Review Committees

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Abstract
The public debate on voluntary termination of life by elderly people, which has been an intensely controversial subject in the Netherlands for some time, has centered around the issue of “completed life” in recent years. In 2016, an ad hoc governmental advisory committee concluded that the already existing Euthanasia Act provided sufficient scope to resolve most of the problems related to the issue. Most of the older adults who feel they no longer have anything to look forward to in their lives and who have developed a wish to die as a result would be able to invoke this Act. Partly for this reason, the committee considered broadening the legal options relating to assisted suicide undesirable. Analysis of the assessment practice of the regional euthanasia review committees reveals that the room for interpretation offered by the Euthanasia Act is indeed considerable.

Keywords: euthanasia; unbearable suffering with no prospect of improvement; completed life; multiple geriatric syndromes

Introduction
On September 2, 2019, Member of Parliament Pia Dijkstra announced that she would be presenting a legislative proposal in 2020, making euthanasia (termination of life on request or assisted suicide) possible for people of advanced age who are tired of living. According to the plans, an older adult with a wish to die should be able to contact a specially trained euthanasia counselor, who will then decide whether the desire for euthanasia is persistent and voluntary via discussions with that person and close relatives over a period of several months, during which alternatives will also have to be explored and discussed.1

Mrs. Dijkstra’s announcement is the culmination of a public debate that was initiated back in 1991 by former Supreme Court Justice Huib Drion, who published a controversial essay in a national newspaper in which he wrote that “undoubtedly many elderly people would find immense peace of mind if they were to have at their disposal the means of terminating their lives – given their expectations for the future – in an acceptable manner at a suitable point in time.”2 The means, which became known as “Drion’s Pill,” could be prescribed by the general practitioner (GP) or a physician designated for this purpose.

Since 1991, the issue has come to the forefront in various ways. In 2002, when the Euthanasia Act was drafted, the Dutch Supreme Court delivered its judgment in the Brongersma case. Eighty-six-year-old former senator Edward Brongersma suffered terribly because of his deterioration and dependence on others, his loneliness, and a tremendous sense of futility. His wish to die resulted from his deep-rooted fear that his existence might continue for many interminable years and that he might eventually be incapable of committing suicide as he wished. His general practitioner concluded that this wish to die

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was consistent, that he had made his request voluntarily, that the burden of suffering experienced by his patient was understandable given his situation and history, and that there were no longer any options for treatment available to him. After having consulted a fellow GP and a psychiatrist, Mr. Brongersma’s GP determined that this was a case of unbearable suffering with no prospect of improvement. Subsequently, he provided his patient with the requested suicide assistance. The GP was criminally prosecuted and convicted. For the Euthanasia Act to be applicable, according to the Supreme Court, suffering must be “caused to a significant extent by a medically classifiable (somatic or psychiatric) illness or disorder.”

Since the Supreme Court’s judgment was seen by many to limit the scope of the Euthanasia Act, advocates of Drion’s Pill started looking for other legal possibilities. Eight years after the Supreme Court’s ruling, a group called Uit Vrije Wil (Out Of Free Will) started a citizens’ initiative on completed life. When this initiative was submitted to Parliament in May 2010, almost 117,000 signatures had been collected. Since the Dutch Constitution requires citizens’ initiatives to be sufficiently specific as well, the group also submitted a specimen act. In many respects, Mrs. Dijkstra’s plans appear to resemble that specimen act.

Partly in response to this citizens’ initiative, the Royal Dutch Medical Association (KNMG) published an opinion on the physician’s role in voluntary termination of life in 2011, in which the aspect of “multiple geriatric syndromes” was mentioned in connection with the scope of the Euthanasia Act for the first time. It also stated that “the nonlinear sum total and complexity of complaints that are frequently nonfatal” can be justifiable grounds for the invoking of that Act.

Ultimately, only two of the smaller political parties in Parliament decided to support the citizens’ initiative. At the request of the Minister for Public Health, however, a study was carried out into the issue of a completed life. In 2016, the so-called Schnabel Committee (named after its chairman Paul Schnabel) considered a separate law—in addition to the Euthanasia Act—to be undesirable, amongst other things, because it estimated that in many cases, there would already be suffering due to a medical condition, with no prospect of improvement and unbearable as required by the Act. The Schnabel Committee did not look into the assessment practice of the Euthanasia Review Committees (ERCs).

The “completed life” debate made the headlines again in 2017 when the Coöperatie Laatste Wil (Last Will Cooperative) claimed to have found a readily available and safe euthanasia product. Within a short period, tens of thousands of people contacted the organization. The first thousand were meant to have the lethal powder sent by April 2018. However, it never got that far because the Public Prosecutor’s Office forced the Cooperative to discontinue its activities.

From the amount of interest in the initiative of the Coöperatie Laatste Wil and the support that Uit Vrije Wil was able to mobilize, the social need for the legalization of voluntary suicide of older adults who are finished with life would appear to be quite considerable. Until now, however, the legislature has been unwilling to meet this demand, and the Public Prosecutor’s Office has consistently acted against unlawful practices. Because the KNMG and the Schnabel Committee have indicated that the Euthanasia Act offers room for interpretation and might be applicable, the question arises whether (and to what extent) the apparent social need for the termination of life in the event of “completed life” is already being met by the ERCs.

Suffering According to the Euthanasia Act

In the Netherlands, euthanasia (termination of life on request and assisted suicide) is considered a crime. However, the Euthanasia Act grants immunity from criminal prosecution for physicians who perform euthanasia, but only if they have notified the coroner and if they have met statutory requirements of due care. Whether or not a physician has acted in accordance with these requirements is to be determined by one of five regionally operating ERCs.

According to the second requirement of due care, the physician must be convinced that there is unbearable suffering on the part of the patient, with no prospect of improvement. The requirement recognizes two aspects of suffering. The suffering of a patient is considered to be without any prospect of improvement (or hopelessness) if the illness or disorder causing the suffering is incurable, and it is impossible to alleviate the symptoms in such a way that the unbearableness disappears. For determining hopelessness, a medical opinion is decisive. The unbearableness of the suffering is subjective in that the
perceptions of the patient predominantly define it.\textsuperscript{14} Because unbearableness is difficult to objectify, the ERCs assess whether this aspect was “understandable” for the physician.\textsuperscript{15}

In its Brongersma ruling, the Supreme Court stated that the suffering must be “caused to a significant extent by a medically classifiable (somatic or psychiatric) illness or disorder.”\textsuperscript{16} In other words, it implied that the suffering can also have nonmedical causes. Furthermore, according to the ERC guidelines, the suffering does not have to be caused by just one illness or disorder. A combination of disorders or illnesses can be the cause of suffering within the meaning of the Euthanasia Act.\textsuperscript{17} And a combination of illnesses or disorders that are not actually life-threatening in and of themselves can also be the cause of the suffering.\textsuperscript{18} Especially, it would seem, in the case of older adults.

**Method**

An answer in the affirmative to the question would have to be supported by the assessment practice of the ERCs. Therefore, all the judgments published by the joint ERCs under the heading of “multiple geriatric syndromes” need to be analyzed.\textsuperscript{19} It is precisely these judgments that relate to cases in which the suffering also had nonmedical causes. Up to August 10, 2019, 49 such judgments had been published on the joint ERCs website, of which only one led to the conclusion “due care criteria not complied with.” The other 48 judgments were studied to see what information was given about the nature of the suffering.

**Results**

**The Assessment Practice of the ERCs**

Since 2013, “multiple geriatric syndromes” (called “multiple geriatric complaints” in 2014 and then changed to “multiple geriatric syndromes” in 2015) have been included as a category in the joint annual reports of the ERCs. Regarding the number of cases of euthanasia in connection with multiple geriatric syndromes that have been reported each year since then, there is no clearly discernible trend. In any case, there has not been a relative increase or an absolute increase in the number of notified cases of euthanasia. See Table 1.

From 2013 to 2018 (the year covered by the latest annual report studied for this article), there were 1,433 notifications of euthanasia in connection with multiple geriatric syndromes.\textsuperscript{20} See Table 1. Although an unknown number of cases of euthanasia in connection with multiple geriatric syndromes were also notified before 2013,\textsuperscript{21} and the number of notifications in 2019 and 2020 was not yet known at the time of writing, 49 published judgments represent around 3\% of the total number of registered notifications in this category. In all these cases except one, the ERCs ruled that the physician had complied with the statutory due care criteria. In the one exception, the physician could not substantiate why she was convinced that there was a well-considered request and unbearable suffering with no prospect of improvement and that no other reasonable solution was available.\textsuperscript{22}

What the published judgments say about the general assessment practice in relation to cases with multiple geriatric syndromes is somewhat unclear. The number of 49 judgments is minimal compared to the total of 1,433, but they were apparently worthy of attention since the ERCs decided to publish them. However, the exact reason for their publication is often not revealed.\textsuperscript{23} The vast majority of cases in this category apparently do not deserve public attention. Although it is unclear precisely what is being revealed by publishing these judgments, they are all that a researcher has to go on.

A total of 38 patients were female and 11 were male. All the patients were age 80 or over, of which 38 were age 90 or over. Furthermore, it is noticeable that the year 2018, with 13 judgments, makes up a large proportion of the 49 published judgments. The year 2019, in which five judgments had been published up to August 10, 2019, is on course to have a more significant number of published judgments than the years before 2018.

Nonetheless, the figures in Table 1 do not show that a growing number of requests made by elderly people for euthanasia on the basis of “completed life” or “completed life”-type arguments have been carried out since 2013.
Nature of Suffering

Based on the number of notifications, it cannot be argued that the Euthanasia Act currently meets the apparent public demand for termination of life in the case of “completed life.” This does not mean, however, that the Euthanasia Act is unable to accommodate such requests. To determine if, and to what extent, it can accommodate requests for termination of “completed life,” the texts of the judgments need to be reviewed. What conclusions can be drawn from these? Put another way, in cases involving multiple geriatric syndromes, how many syndromes do there have to be?

As pointed out, up to August 10, 2019, judgments had only been published in 48 cases where the due care criteria were deemed to have been complied with. However, it has to be remembered that the researcher can only go on the sparse information about the facts in each case that the authors of the judgments were willing to provide under the heading “Nature of the patient’s suffering,” information that is primarily derived from documents that are not publicly available: the form completed by the coroner, the report of the physician, the report(s) of the consultant(s), last wills and testaments, patient journals, and letters and statements from medical specialists.

However, in all published judgments, the section headed “Nature of the patient’s suffering” is divided into two parts. The first part usually ends with the conclusion “improvement was not possible (any longer). The treatment was exclusive of a palliative nature.” This part relates to the objective component of the criterion (the hopelessness of the suffering) and describes the medical condition. The second part, which relates to the unbearable nature of the suffering, often starts with “The suffering of the patient consisted of (...)” and usually ends with “The patient experienced his suffering as unbearable.”

In the first part, a summary is given of the illnesses and disorders that existed before the patient died: medically classifiable illnesses and disorders such as osteoporosis, rheumatoid arthritis, decompensatio cordis, diabetic retinopathy, decubitus, and glaucoma; illnesses and disorders that are not life-threatening in and of themselves, and which are usually associated with advanced age. In medical terms, the illness or disorder causing the suffering is described.

However, the authors rarely use medical terms exclusively. For in the first part such terms as “pain,” “tightness of the chest,” “tiredness,” and “impaired vision,” or “bedridden,” “dependent on care,” “limited mobility,” “loss of strength,” and “loss of vitality” are almost always included as well. These types of terms are used to describe both the direct and indirect consequences of illnesses and disorders as they are experienced and reported by the patient. After all, impaired vision is a consequence of glaucoma. Poor eyesight is a symptom, and retinopathy is the disease. And being bedridden might be a consequence of severe backache, which in turn might be a consequence of osteoporosis.

It would be logical for the reported symptoms to be mentioned exclusively in the second part of this section, but often both the underlying disorder(s) or illness(es) and the symptoms are described in the first part. And occasionally, only the symptoms are described in the first part, without any mention of underlying disorders or illnesses. In the first case, this can suggest the presence of many syndromes, whereas in the second case, it is unclear exactly which illnesses or disorders are involved. In that case, either

<table>
<thead>
<tr>
<th>Year</th>
<th>Notifications based on multiple geriatric syndromes</th>
<th>Total number of notifications</th>
<th>Percentage (%)</th>
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<tbody>
<tr>
<td>2013</td>
<td>251</td>
<td>4,829</td>
<td>5.5</td>
</tr>
<tr>
<td>2014</td>
<td>257</td>
<td>5,306</td>
<td>4.8</td>
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<tr>
<td>2015</td>
<td>183</td>
<td>5,516</td>
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<td>2016</td>
<td>244</td>
<td>6,091</td>
<td>4.0</td>
</tr>
<tr>
<td>2017</td>
<td>293</td>
<td>6,585</td>
<td>4.4</td>
</tr>
<tr>
<td>2018</td>
<td>205</td>
<td>6,126</td>
<td>3.3</td>
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<tr>
<td>Total</td>
<td>1,433</td>
<td>34,453</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Table 1. Multiple Geriatric Syndromes

4 Martin Buijsen

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the causes were simply not identified, or a distinction is not generally made between the illness or disorder and its symptoms, as is the case with incontinence.26 Therefore, a certain amount of overlap usually exists between the information provided in the two parts of this section in the published judgments.

“Pain,” “dependent on care,” “tiredness,” and “limited mobility” are also to be found in the second part of this section, in which they are used to describe the unbearable aspects of the suffering in the second part of this section. Virtually always, they are complemented by descriptions of circumstances that contribute to the severity of that suffering.

These “aggravating circumstances” (Table 2) can relate to: (1) the patient’s life history or personality (“the patient had always been extremely active,” “the patient had always been extremely independent,” “the patient (…) had always had control over his own life,” “due to the character of the patient, it was impossible for her to accept the circumstances,” and “the patient had a character that was very centered around her independence”); (2) the patient’s values (“the patient suffered because of his dependence on others,” “the patient felt she was losing control over her life and that she was becoming increasingly dependent on others, something she found unacceptable,” “the patient suffered unbearably because of loss of autonomy,” “the patient experienced help as an infringement of her autonomy,” and “the patient suffered under the loss of dignity”); (3) the patient’s social circumstances (“the patient hardly went outside” and “the patient was becoming increasingly socially isolated”); (4) the patient’s stamina and perspective (“the patient suffered because of fear of further complications,” “the patient did not want to go to a nursing home,” and “the patient did not want to go through any further loss of bodily functions”); and (5) the patient’s sense of purpose (“the patient perceived her life as pointless,” “the patient considered his life to be completed,” and “the patient (…) did not see the point of living any longer”).

Factors from the first category (pain, limited mobility, etc.) were mentioned in all the 48 cases assessed as complying with the criteria of due care, followed by circumstances that fall under the headings of “stamina and perspective,” “values,” and “life history and personality.” A lack of a sense of purpose was mentioned in 23 judgments.

Only two judgments mentioned factors and circumstances from just one category. These judgments only referred to pain, limited mobility, and so forth. The other 46 judgments mentioned a combination of factors and circumstances from several categories. Only two judgments referred to factors and circumstances of all categories. See Table 3.

The phrase “multiple geriatric syndromes” can be somewhat misleading. The phrase suggests that if the number of medically classifiable illnesses and disorders is high enough, then the statutory requirement of suffering will have been met. It seems to imply that there is a “tipping point,” where the most recently diagnosed degenerative disorder is, as it were, the proverbial straw that breaks the camel’s back and thus makes the case eligible under the Euthanasia Act.

However, the number of judgments that described the unbearable nature of the suffering exclusively based on the factors in the category of pain, limited mobility, and so on, was limited to just two. Most of the judgments mentioned circumstances of other categories as well, circumstances that contributed to the unbearable nature of the suffering experienced by the patient. Analysis of the published judgments reveals that the number of syndromes does not have to be very high at all. Although there are indeed judgments that mention many syndromes in the first part,27 there are also judgments that mention just a few.28 Therefore, the number of syndromes does not appear decisive: Under the “right” circumstances, only one syndrome will be enough to meet the requirement. Whether

<table>
<thead>
<tr>
<th>Table 2. Reported Factors and Circumstances of Unbearable Suffering</th>
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<td></td>
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<tr>
<td>---------------------------------------------------------------</td>
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<tr>
<td>Number of judgments (n = 48)</td>
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<td>%</td>
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or not the suffering is “caused to a significant extent” by one geriatric syndrome will depend on the syndrome and its direct and indirect consequences (factors immediately or indirectly contributing to the severity of suffering, such as pain and limited mobility), but also—and very much so—on the circumstances of the case, more specifically, on circumstances seen as aggravating.

### Two Hypothetical Cases

Until now, the figures do not support the conclusion that the Euthanasia Act provides a “way out” for elderly people who want to have their “completed” lives ended. There is no clearly identifiable trend in the number of requests for the euthanasia of patients based on “multiple geriatric syndromes”; moreover, there has not been any increase in the number of notifications in this category, either in absolute terms or in relative terms. This does not mean, however, that the Euthanasia Act does not have the potential to provide a “way out.” For the Act to be applicable, the Supreme Court stated that the suffering must be “caused to a significant extent by a medically classifiable (somatic or psychiatric) illness or disorder.” Considering how the ERCs have applied the criterion, there would seem to be a great deal of room for interpretation.

Let us explore the possibilities by considering two hypothetical cases. For example, a man of advanced age develops a severe hearing disorder because of presbycusis. He will eventually lose most, if not all, of his hearing. Medically, little can be done, and there is no way to slow down the hearing loss. This man, a former professional musician, has always lived for his music. His entire social life revolves around music. He is suffering enormously from the fear of losing his hearing altogether. For this man, a life without music is inconceivable. His life will then be stripped of all meaning. He experiences this suffering as entirely unbearable. This suffering did not exist before the onset of the presbycusis. The musician, who has no other medical complaints, asks his doctor to help him commit suicide.29

Does his suffering meet the requirement? Intuitively, many will be inclined to disagree since it is just one disorder; moreover, loss of hearing is commonly associated with the advancement of age. However, the case’s particular circumstances also must be considered. After all, properly functioning hearing is a necessary condition for this specific man’s quality of life. Without adequately functioning hearing, this man’s life is bereft of all quality.

Now take the hypothetical case of an older woman suffering from being alive. This former teacher has never been married and never had children. Furthermore, she no longer has any family, and all her friends have already died. She no longer genuinely desires to see or talk to other people. This woman is independent and healthy, but nonetheless, she is suffering tremendously under the prospect of inevitable physical and mental degeneration. She feels she has lived a good life. She has managed to fulfill all her ambitions in life. But enough is enough, and there is no need to drag it out any longer. One day, she goes to see her doctor because of pain in her joints. The doctor tells her she has arthritis. This woman, who has no other medical complaints, then asks the doctor to assist in her suicide. This case also involves just one of the many frequently occurring geriatric syndromes.

The assessment practice of the ERCs indicates that one illness or disorder may suffice. That practice also indicates that its impact on the patient will depend on the case’s specific circumstances. Although many will object intuitively against the application of the Euthanasia Act in both hypothetical cases, it is, in fact, very likely that an ERC would accept that the elderly musician’s suffering is indeed suffering...
“caused to a significant extent by a medically classifiable illness or disorder.” In this case, all suffering is, in a way, a consequence of the illness. There would not have been any suffering without the presbycusis. But the former teacher’s suffering, does that meet the statutory requirement as well? Again, many would intuitively disagree. Not only because of the presence of merely one common geriatric syndrome, arthritis but presumably also because of a perceived difference in cause and consequence, which is considered somehow relevant. For this woman, life itself was already “unbearable” before arthritis occurred. Many would therefore argue that her suffering is not “to a significant extent caused by a medically classifiable illness or disorder.” They would argue that it clearly has other, nonmedical causes. Consequently, arthritis will be seen by many as nothing but an alibi. Surely, the Euthanasia Act is not meant to justify the acts of a physician granting such a request. But would an ERC really have good reasons for disapproving such action?

Of course, the musician’s suffering would completely disappear if his presbycusis could somehow be cured. And, of course, even if her arthritis could be treated successfully, the teacher would continue to suffer severely. But the perceived difference between both hypothetical cases is nonsensical. The fact that, in the musician’s case, all suffering can easily be linked to a medical condition, which cannot be done in the former teacher’s case, makes for a rather presumptuous difference in appreciation. Pain, deafness, and lack of mobility can be seen as consequences of an illness or disorder, but an individual’s personality, life history, or values cannot. Seeing the musician’s all-pervasive passion for music as a cause of his suffering is seriously misreading the facts. It is as much a cause of his suffering as it is the result of his age-related loss of hearing; it is a circumstance. Likewise, the teacher’s personality, her loneliness, and her perception of her life as complete and pointless are circumstances. The fact that her suffering cannot be fully explained by a medical condition, her arthritis, is irrelevant because the musician’s presbycusis cannot fully explain his suffering either. Both cases are similar in that respect. At first sight, many would consider the musician’s case as different in a relevant way, but it does not take much reflection to learn that there is no basis for making such a difference in reality. There is no reason to assume that an ERC would conclude that the statutory requirement was not met in the former teacher’s case. Such a conclusion would be at odds with the logic of the assessment practice.

Conclusion

For a proper understanding of the way ERCs interpret the requirement of suffering and, therefore, of the scope of the Euthanasia Act, it is essential to realize that in their judgments, they refer to circumstances — facts they do not see (conceive or choose to conceive) as other causes, moreover, not as causes that can be removed to eliminate the unbearableness of suffering. According to the published judgments, that is how the ERCs interpret the statutory requirement, as explained in the Brongersma ruling by the Supreme Court in cases of multiple geriatric syndromes. An active lifestyle, independence, autonomy and self-control, social isolation, stamina, fear of further loss of functions, and sense of futility are all presented as facts by the ERCs. Although the Dutch Euthanasia Act does not at present provide a “way out” for elderly people intent to have their “completed lives” ended, there can be little doubt about its potential.

Notes

1. Interview Pia Dijkstra, Algemeen Dagblad 2019 Sep 2.
12. Euthanasia Act, Section 2, paragraph 1, under b.
20. See note 15.
22. See Judgment 2015-01.
23. Although in some judgments, the relevant case was described as being illustrative; see Judgments 2018-44 and 2017-19.
24. See, for example, Judgment 2014-90.
25. See, for example, Judgment 2019-17, with 13 illnesses, disorders, and complaints.
27. See note 25.