

The Norwegian Medical Association's lack of clarity on «active help in dying»

In 2015, the Medical Ethics Council of the Norwegian Medical Association formulated a new clause on so-called active help in dying (in Norwegian: «aktiv dødsbistand»), which was unanimously adopted in the same year by the Representative Body of the association. However, the wording of the clause is unclear and potentially confusing. This is unfortunate for the clinical, ethical and political debate on this topic. This article proposes an alternative wording which is more precise.

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In recent years, different variants of «active help in dying» have been legalised in several Western countries. In 2002, both the Netherlands and Belgium passed laws that regulate the practice, followed by Luxembourg in 2009 (1). In 2014, the lower age restriction under Belgian law was removed, so that now even young children can request euthanasia (2). In the same year, a euthanasia law was adopted in Quebec, Canada, and following a Supreme Court judgment, euthanasia was legalised in all Canadian provinces from June 2016 (3).

In 2013 and 2015 respectively, the US states of Vermont and California passed laws on physician-assisted suicide, and this kind of legal regulation already existed in Oregon, Washington and Montana (1). In 2015, Germany adopted a law on assisted suicide which regulates a practice not unlike that which has existed in Switzerland for many years (1). The UK, where a number of legislative proposals have been put forward based on the Oregon model, may be next (4).

Norwegian conditions

In the new Norwegian General Civil Penal Code, which came into force in 2015, the ban on euthanasia is maintained in the wording of section 276: «if any person is killed with his own consent» (5). However, there is robust political opposition. In 2009, the Norwegian Progress Party passed a resolution in principle to work for legalisation (1), and several county chapters of AUF, the youth division of Norway's Labour Party, have recently adopted a resolution in favour of «legalising a strictly regulated form of active help in dying» (6).

In a study published in 2013, two out of ten Norwegian medical students (19%) responded that they would permit eutha-

anasia in cases of terminal illness, and as many as 31% would permit physician-assisted suicide in such cases (7). In response to questioning about the future, Svein Aarseth, Chair of the Medical Ethics Council, replies that «he believes the euthanasia debate will be pivotal» (8).

New Clause 5 in the Code of Ethics for Doctors

Precisely for that reason, it is essential to be clear on what is meant by «euthanasia» and associated terms. However, the Norwegian Medical Association is not.

Firstly, the term «euthanasia» does not appear in the new Clause 5 of the Code

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of Ethics for Doctors: «Doctors shall not perform active help in dying or assisted suicide. Withdrawing or not initiating futile treatment (limitation of treatment) shall not be considered as active help in dying» (9).

Secondly, the new Clause 5 does not include any justification as to why limitation of treatment «shall not be considered as active help in dying». Instead, this is put forward as an assertion – and therefore prompts the question «why not?» It is clearly an act that limits the treatment of a patient with amyotrophic lateral sclerosis to the extent that the patient dies after extubation. Thereby the way lies open for mis-

construing this normal medical action as «a form of active help in dying» (1).

This could have been clarified by pointing out that limitation of treatment causes the patient to die naturally of the disease, whereas injection or oral intake of lethal drugs *is the cause of death*. This distinction is indisputable in the context of the Netherlands, illustrated by the fact that doctors who perform euthanasia are obligated to report the death as «unnatural» (10).

«Active and passive help in dying»

It was the philosopher James Rachels who launched the concept pair «active and passive euthanasia» in a now classic article with the same title in the *New England Journal of Medicine* in 1975 (11). In Norway, this is translated as «active and passive help in dying». However, in the Netherlands this concept pair was rejected many years ago (1, 2, 10), nor does the distinction exist in their research literature (12). Dutch research has set the standard for international research (13).

By choosing to use the term «active help in dying», the Norwegian Medical Association is thus using a term that is both potentially confusing (1) and outdated (2) – and with no basis in research. The Norwegian Medical Association should rather act as a public information channel by using and explaining the accurate standard designations of «euthanasia» and «physician-assisted suicide» (1, 2, 7, 13, 14).

Another unfortunate aspect of «active help in dying» is that it is left to legalisation activists to play the «passive help in dying» card, as they consistently do (15). We are thus placed on the defensive and have to respond as to why the one is prohibited while the other is permitted, when the clinical outcome, death, is the same in both cases. It is particularly important to meet this challenge in those cases where death follows with around the same rapidity in the case of euthanasia as when life-sustaining interventions are withdrawn – for example,

a patient may die within only a few minutes post-extubation.

On the other hand, the fact that «active help in dying» is the term most easily recognised among the Norwegian general public and in Norwegian legal literature (16, 17) is in itself an argument for using this particular term. It is then possible to add, as the Medical Ethics Council has done in the media, that this is considered as euthanasia – which is then explained (18).

However, the «side-effect» of taking this terminological detour is that it does not do away with the antithesis, «passive help in dying». In the same way that «evil» does not disappear as a concept if one speaks only of «good», one cannot speak of «active» without it being accompanied by «passive» like a monkey on your back. And thus more fuel is added to the fire of those who want to (mis)use the term «passive help in dying» right, left and centre.

Two conflicting interpretations of «active help in dying»

As we see from Clause 5, the Norwegian Medical Association distinguishes between active help in dying and physician-assisted suicide, and in this they are in line with Rachels (11). Nevertheless, this distinction in itself may give rise to confusion, as active help in dying is generally used as a collective term for euthanasia and physician-assisted suicide. This is, for example, the case in NOBAS (Norwegian Bioethics Attitude Survey) from 2015 (19). Morten Horn, debater and senior consultant in neurology does the same: «Active help in dying may be euthanasia (the doctor administers a lethal injection), or physician-assisted suicide (the doctor prescribes a lethal poison which the patient him/herself takes)» (20). This conflation is natural, since it is also active to help a patient to die from assisted suicide.

Contrary to this, the following appears in an article by Karsten Hytten, Vice Chair, and Aarseth, Chair of the Medical Ethics Council, consistent with Clause 5: «Active help in dying (euthanasia) entails that a doctor injects a lethal drug at the request of the patient. Put simply, it means that the doctor kills the patient. Physician-assisted suicide means that the patient takes drugs received from his/her doctor such that the patient has the opportunity to take his/her own life» (18).

Limitation of treatment and «futile» treatment

It is also a matter of some amazement that in the opinion of the Norwegian Medical Association, limitation of treatment encompasses only «futile» or meaningless treatment. This is neither clinically nor legally

the case. The Patients' Rights Act states in Section 4–9 that «a dying patient has the right to refuse life-prolonging treatment» (21). For example, antibiotic treatment of a terminal cancer patient is considered as life-prolonging. If the patient refuses more antibiotics, we have a case of limitation of treatment where he or she refuses potentially «appropriate» or meaningful treatment.

A further matter is that the terms «meaningless» and «futile» are far from clear (14). A recently published multicentre

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study of practice in intensive care departments is a case in point: In 4 % of cases in which further life-sustaining treatment was considered futile and was therefore withdrawn, the patient was discharged alive (22). In other words, it was assumed that the benefit of further treatment was non-existent or absolutely marginal, so even in paradigmatic examples of futility, it is possible to be radically mistaken. This only goes to illustrate the difficulty of this entire territory.

The Norwegian Medical Association simply takes the term «futile» for granted in the new Clause 5, as does one of the Journal of the Norwegian Medical Association's editors in a recently published editorial (23, 24). This is striking, also in light of the Directorate of Health's national guidelines *Decision-making processes in the limitation of life-prolonging treatment*, which discuss and address the issues relating to the term in some detail (25).

Final remarks – and a proposal

According to Aarseth, Chair of the Medical Ethics Council, the new Clause 5 – which was adopted unanimously by the Representative Body – represents an «improvement through simplification» (26). Einstein's view was that «everything should be made as simple as possible, but not simpler» (27). It appears that the Medical Ethics Council, and with it the Representative Body, have

fallen into this trap of simplification. This is unfortunate for clinical, ethical and political debate on the highly intricate topic of euthanasia and physician-assisted suicide.

Based on the arguments above, the following rewording of Clause 5 should be adequate: «Doctors shall not perform euthanasia and physician-assisted suicide such that the patient dies unnaturally from drugs administered for the purpose of taking life. However, limitation of life-prolonging treatment and withholding or withdrawing treatment that is presumed to be futile, is normal medical practice; in such an instance the patient dies of his/her disease.»

This is only slightly longer than the newly introduced Clause 5. Ethical rules are generally very succinct, but to clarify what is meant by the terms used, the clause could be annotated with the following footnote to avoid misunderstandings – or the explanatory text published elsewhere, with a link to this from Clause 5:

«Euthanasia entails the injection of lethal drugs by a doctor at the voluntary request of the patient; in the case of physician-assisted suicide, a patient who is competent to give consent takes such drugs as have been prescribed to them by a doctor, with the purpose that the patient shall take their own life. In both cases, drugs are used in order to take life, so that the patient's death is unnatural. However, limitation of potentially life-prolonging treatment, including end-of-life palliative sedation when symptom control is escalated, constitutes normal medical practice. The same applies to withholding or withdrawing what is considered as futile treatment. In all these cases, the patient dies naturally of the underlying disease.»

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