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Blurring the Distinctions: Euthanasia vs. Withdrawal of Care

by

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"... word and language form the medium that sustains the common existence of the human spirit as such. The reality of the word in eminent ways makes existential interaction happen. And so, if the word becomes corrupted, human existence itself will not remain unaffected and untainted."¹

A man is struck and killed by a car as he crosses the street. Was it murder or an accident? What information would you need to make such a distinction? A crucial bit of information is the intent of the driver. Suppose that in one case the driver had been waiting for the man to enter the street, fully intending to run him down; in the other case an elderly man having difficulty adjusting to the sun's glare did not see the victim until it was too late. Both cases would look identical if captured on film. Is the moral culpability of the driver identical in both cases?

Does the intent of the physician affect the morality of an end of life decision? Does it make a difference whether the intent of the physician is to relieve pain and suffering or cause the patient's death? This and other controversial points including the voluntariness of the act by the patient, and the method used - commission vs. omission - are key elements in understanding euthanasia.^{2,3,4,5}

This paper examines the differing interpretations of the recently released "Report of the Dutch Governmental Committee on Euthanasia," [the Rummelink Report⁶]. The interpretations differ primarily in their assessment of the intent of the physician in end-of-life decisions. One interpretation affirms the moral impact of the intent of the physician while the other interpretation discounts "intent" as being morally irrelevant. Unfortunately, the widely quoted interpretation of the popular press and medical journals is that which ignores physician intent in defining euthanasia.

We argue that denying the moral impact of the intent of the physician in

end-of-life decisions blurs the distinction between euthanasia and withdrawing or withholding care. The consequences of failing to make this important distinction are discussed.

The Rummelink Report

Background

Euthanasia, although technically illegal, has been permitted in the Netherlands for over two decades. There have been many criticisms of this practice from both inside and outside the Netherlands. A major concern has been the lack of reliable data describing what euthanasia practices Dutch physicians are actually performing. These factors resulted in the formation of a commission to study euthanasia in the Netherlands. The report of this commission, generally referred to as the Rummelink Report, was released on September 10, 1991.⁶

The study consisted of three sections. The first involved detailed interviews with 405 physicians concerning their previous use of euthanasia and related end-of-life questions; the second section was a retrospective chart review of 7000 deaths; in the third section, these same 405 physicians were prospectively followed for 6 months and interviewed about every death in their practice. All three sections yielded similar results.^{6,7} The definitions used in the study are listed in Table 1.

The study distinguished three types of intention by the physician: 1) the definite aim being to shorten the patient's life, 2) shortening the patient's life being one of the doctor's intentions, and 3) accepting the side-effect of shortening the patient's life.^{6,7}

Interpretation

There have been two distinct interpretations of the Rummelink study, one authored principally by Fenigsen (Table 2)^{8,9} and other by van der Maas (Table 3)⁷. At first glance, one would have difficulty understanding how Tables 2 and 3 were compiled from the same data. Let us examine and account for the disparities (summarized in Table 4).

Two key elements in the definition of euthanasia (Table 1) underlie the different conclusions:

1) Fenigsen interprets "intentional" as involving either a primary (definite) aim or a secondary (partial) aim of the physician. Van der Maas does not incorporate the concept of physician intent into the category of euthanasia.

2) Fenigsen interprets "action to terminate life" as any commission (direct) or omission (indirect) on the part of the physician in which the intent is to shorten life. Van der Maas allows only acts of commission, thus eliminating non-treatment decisions from the category of euthanasia:

To illustrate, in the case of direct euthanasia:

1. The Rummelink Report tells us that 22,500 patients died of an overdose of morphine sulfate.
2. In 36% of these cases the intent of the physician was to shorten life. (Rummelink Table 7.2) Fenigsen classifies these deaths as euthanasia.

3. Thus, 8,100 (22,500 X 0.36) patients directly euthanized by morphine sulfate overdose.
4. Of these, 39% were voluntary and 61% involuntary. (Rommelink Table 7.7)
5. Therefore, there were 3159 (8,100 X 0.39) cases of direct voluntary euthanasia and 4941 (8,100 X 0.61) cases of direct involuntary euthanasia.

In Table 4 we see that Fenigsen has summed up all direct voluntary euthanasia cases in which physicians intentionally and directly shortened a patient's life. This includes the 2,300 that van der Maas reports as "euthanasia" plus an additional 400 that van der Maas reports as "assisted suicide," plus the 3159 calculated above as "direct voluntary" cases of morphine overdose categorized by van der Maas as "alleviation of pain and symptoms" (APS).

The same calculations hold for the involuntary direct column: 1000 that van der Maas reports as "involuntary" plus 4,941 direct involuntary deaths as calculated above.

Using similar data available in the Rimmelink Report for indirect euthanasia, one can calculate that there were 13,506 cases of withdrawal or withholding of treatment with the intent of shortening the patient's life. Of these, 4,756 occurred with the patient's consent and 8,750 were without the patient's consent.^{6,7,8} Van der Maas categorizes all of these as non-treatment decisions (NTD), rather than euthanasia. (See Table 4)

Discussion

These widely disparate interpretations of the same data result from failure to agree on the definition of euthanasia. Hence, van der Maas can conclude that euthanasia is responsible for 1.8% of all deaths in the Netherlands while Fenigsen, working with the same data, puts the rate at 19.4%.

Fenigsen and van der Maas' fundamental disagreement concerns the intent of the physician in end of life decisions. Fenigsen acknowledges the moral impact that results when the intent of the physician is to shorten the life of the patient and defines deaths from such intent as "euthanasia." In contrast, van der Maas ignores the physician's intent and categorizes these deaths under "alleviation of pain and symptoms" or "non-treatment decisions." Thus, when Fenigsen defines euthanasia as the intent to shorten a patient's life, a significant increase in deaths categorized as euthanasia (19.4%) is observed. Reclassifying these deaths as "alleviation of pain and symptoms" (APS) or "non-treatment decisions" (NTD), and ignoring the intent of the physician, as van der Maas does, substantially reduces the number of euthanasia deaths (1.8%).

The World Medical Association¹⁰, Dutch^{4,11} and American² experts commonly use the word "deliberate" to describe the physician's intent in euthanasia. The term "deliberate" implies a specific moral significance - a planned and willful act.

The intent of the moral agent is recognized as paramount in long-standing common law tradition. The American Bar Association Commission on Legal Problems of the Elderly, in a recent statement concerning aid-in-dying legislation, unanimously agreed that such legislation "... eliminates a long-

standing, just and clear demarcation in criminal law based upon intent to kill. "Without it, we risk the classic 'slippery slope' to state-sanctioned death."¹² State laws concerning murder and manslaughter distinguish different degrees of guilt or innocence based largely on intent.¹³ In daily life we routinely acknowledge the moral impact of the intent of the moral agent - "Pardon me, I didn't mean to bump into you." And all would agree that the first driver in our opening scenario is guilty of first-degree murder, while the second driver, who did not intend to hurt anyone, is the victim of a tragic accident. Thus, to ignore the importance of intent in defining euthanasia is to deny a key aspect of the definition of euthanasia, a basic legal tenet, and common sense.

It is commonly accepted that there is no moral difference between withdrawing therapy already started and withholding therapy never begun,¹⁴ chiefly because the intent of the physician is not to shorten the life of the patient but to relieve the patient of the burdens of therapy. Arkes et. al. summarize:

Medical treatments can be refused or withheld if they are either useless or excessively burdensome. No one should be subjected to useless treatment; no one need accept any and all lifesaving treatments, no matter how burdensome. In making such decisions, the judgement is about the worth of treatments, not about the worth of lives. When we ask whether a treatment is useless, the question is: "Will this treatment be useful for this patient, will it benefit the life he or she has?" When we ask whether a treatment is burdensome, the question is: "Is this treatment excessively burdensome to the life of this patient?" The question is not whether this life is useless or burdensome . . . We can and should allow the dying to die; we must never intend the death of the living. We may reject a treatment; we must never reject a life.¹⁵

Thus, the discontinuation of a ventilator may be euthanasia (the intent being the death of the patient) or the withdrawal of therapy (the intent being to remove burdensome therapy). To an observer, the two scenes would appear identical, yet they would be morally distinct, since in the first situation a person has been killed, while in the second a person has been allowed to die. Thus, the failure to consider physician intent in defining euthanasia vs. withdrawal-withholding of treatment has obscured the very real ethical and legal implications of such acts.

Conclusions

1. The Rummelink Report has been interpreted and reported in ways which obscure its true implications. Fenigsen defines all cases in which the primary intent of the physician was to cause death as "euthanasia", while the popularly quoted van der Maas denies physician intent by categorizing the same deaths as "alleviation of pain and symptoms" or "non-treatment decisions." A full English translation of the Rummelink Report is not yet available. Meanwhile, the official interpretation (that of van der Maas) is being published in the popular press and medical journals, barely mentioning the details of the study.¹⁶ As a result, the Rummelink Report — the most significant and extensive compilation of data on euthanasia practices available — has been largely misinterpreted. One purpose of this paper is to encourage frank and open discussion of this study.

2. Ignoring the moral impact of physician intent blurs the distinction between euthanasia and withdrawing or withholding care. At a time when practicing physicians most need the support of clear bioethical thinking, this thinking is being muddled.

A recent survey by the American Society of Internal Medicine asked 402 internists "Have you ever taken a deliberate action that would directly cause a patient's death?" Eighty physicians (20%) said "Yes",¹⁷ Are we to believe that 20% of internists have performed direct euthanasia, an act that is illegal throughout the U.S.? We suggest that the vast majority of these "deliberate actions" were instances of withdrawing or withholding care and that the responding physicians were not considering the intent of their actions. Similarly, Wilson *et. al.* in a study of the use of sedatives and analgesics in patients from whom life support was being withdrawn or withheld found that physicians ordered drugs "to hasten death" in 39% of patients.¹⁸ The authors were troubled enough by this finding to go back and talk to those involved and subsequently concluded that caregivers had been "guided by the ethical principle of double effect." They had foreseen the hastening of death as an unavoidable side effect of the use of sedatives and analgesics, but had not intended to hasten death.

There are cases in which it is almost impossible to separate the motivations underlying physician action or inaction. As human beings our motives are frequently mixed. These cases should not cause us to deny that our intentions ever make a difference. Rather, we need to study and clarify our decision making process.

3. Acronyms depersonalize and further blur our ability to make distinctions. The introduction of the terms "MDEL", "APS", and "NTD" serve more to confuse than to clarify. Their definitions are so broad and vague that a wide variety of disparate actions could be described in any one of them. They are at best a misguided attempt to simplify bioethical discourse and at worst a subterfuge.

4. Blurring the distinction between euthanasia and withdrawing or withholding care diverts attention from the real issues of caring for the patient. Euthanasia is easier, quicker and cheaper than hospice care, which is recognized world-wide as a standard of care for dying patients. However, hospice care does not include using doses of narcotics that will intentionally shorten the patient's life. A superficial inspection would lead one to believe that "alleviation of pain and symptoms" fits in with the concept of hospice. Yet we have seen that a significant number of patients in the "alleviation of pain and symptoms" category were given narcotics with the intention of shortening their lives, *often without their consent.*

5. Blurring the distinction between euthanasia and withdrawing or withholding care subverts the patient's trust in the medical profession. We as physicians may not distinguish our intent (see #2 above) or we may hide behind acronyms (see #3 above) but our patients will know what we are doing. There is anecdotal evidence of widespread fear of hospitals and doctors among Dutch elderly and reports of patients going to neighboring countries for their health care. Some aged patients in the Netherlands have formed "Sanctuary", an anti-euthanasia group.¹⁹ Despite reassurances, the Dutch elderly know what their doctors are doing. They are supported in their fears by the finding of the Rammelink Commission that 58% of euthanasia deaths are involuntary. (see Table 2)

6. Blurring the distinction between euthanasia and withdrawing or withholding care undermines the value of human life. Physicians need no longer concern themselves with whether or not they are committing euthanasia if they are

"APSing" or "NTDing" the patient. The definitions of the various degrees of murder and manslaughter are based in large part on the intention of the moral agent. Denying these distinctions would effectively allow an end-run around the definition of murder.

7. Blurring the distinction between euthanasia and withdrawing or withholding care "greases the slippery slope" toward ever more liberal use of means to shorten patient's lives. Singer and Siegler distinguish four ways in which a policy of voluntary euthanasia could lead to involuntary euthanasia.² *Cryphtanasia* (secret euthanasia) is well documented in the Rummelink Report, both as involuntary euthanasia previously mentioned, and in other data showing that the majority of physicians performing voluntary euthanasia do not document this fact, frequently falsifying death certificates.^{6,8} *Encouraged* euthanasia (patients pressured to choose euthanasia) has been documented by Hilhorst.²⁰ *Surrogate* euthanasia (a euthanasia decision made by someone other than the patient or doctor) is documented in the Rummelink report.^{6,7,8} *Discriminatory* euthanasia, albeit in small numbers and difficult to document, occurs in some cases of newborns with disabilities, psychiatric patients, and others.^{7,8}

8. Blurring the distinction between euthanasia and withdrawing or withholding care is a corruption of language and as such will affect and taint human existence itself. Pieper's warning that heralded this paper is being played out in the care of the elderly and terminally ill today. Clarifying the language we use to talk about decisions made in the dying process is one of the first steps we must take to return to the roots of our profession — to cure sometimes, to relieve often, to comfort always.

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Table 1

**REMMELINK REPORT
Definitions**

- | | |
|-------------------|---|
| Euthanasia | ● the intentional action to terminate life, performed by someone other than the involved person, upon the latter's request |
| MDEL | ● major decisions concerning the end of life
● the prescription, supply or administration of drugs with the explicit intention of shortening life, to include euthanasia at the patient's request, assisted suicide, and life-terminating acts without explicit and persistent request |
| NTD | ● non-treatment decisions
● the withholding or withdrawal of treatment in situations where the treatment would probably have prolonged life |
| APS | ● alleviation of pain and symptoms
● the use of opioids in such doses that the patient's life might have been shortened |

Table 2
REMMELINK REPORT
Fenigsen Interpretation

	Direct Euthanasia # of deaths (% of all deaths)	Indirect Euthanasia # of deaths (% of all deaths)
Voluntary	5859 (4.5%)	4756 (3.7%)
Involuntary	5941 (4.6%)	8750 (6.7%)

Total Euthanasia Deaths: 25,306 or 19.4% of all deaths

Fenigsen, *Issues Law Med.*, 1991

Table 3
REMMELINK REPORT
van der Maas Interpretation

	# of deaths (% of all deaths)
Euthanasia	2300 (1.8%)
Assisted Suicide	400 (0.3%)
Involuntary	1000 (0.8%)
Alleviation of pain and symptoms (APS)	22,750 (17.5%)
Non-treatment decision (NTD)	22,750 (17.5%)

van der Maas, *Lancet*, 1991

Table 4
REMMELINK REPORT
Reconciliation of Interpretations

	Direct Euthanasia # of deaths	Indirect Euthanasia # of deaths
Voluntary	2300 (van der Maas 1.8% Euthanasia) 400 (van der Maas 0.3% Assisted Suicide) <hr style="width: 10%; margin-left: 0;"/> 3159 (van der Maas*) 5859 (Fenigsen)	4756 (Fenigsen) (van der Maas†)
Involuntary	1000 (van der Maas 0.8% Involuntary) <hr style="width: 10%; margin-left: 0;"/> 4941 (van der Maas*) 5941 (Fenigsen)	8750 (Fenigsen) (van der Maas ‡)

* van der Maas "APS" from Rummelink Vol. II pg. 58, table 7.2; pg 61 table 7.7; intent to shorten life.

† van der Maas "NTD" from Rummelink Vol. I pg 15; Vol II, pp 64,66; intent to shorten life.

‡ van der Maas "NTD" from Rummelink Vol. II pg 72; intent to shorten life.

Fenigsen, *Issues Law Med.*, 1991

van der Maas, *Lancet*, 1991