

Non-Treatment Decisions in Dutch Medical Practice¹

Abstract

Recent developments in the field of medicine and the increased interest in palliative care have resulted in a growing awareness that medical decision-making in the terminal stage of life not only concerns choosing which interventions are appropriate, but also which interventions are inappropriate. This paper gives an overview of Dutch research on decision-making with regard to whether or not to apply life-prolonging treatment. In 1990, the *Remmelink study* was the first to indicate that non-treatment decisions frequently precede death in the Netherlands: 28% (95% confidence interval [CI], 26%-29%) of all deaths were preceded by such a decision. In 1995, a second study showed that this percentage was 30% (95% CI, 28%-31%) and may be on the increase. Non-treatment decisions quite frequently concern elderly patients who die in nursing homes. The majority (67%) of non-treatment decisions concern patients who are not (fully) competent and cannot decide for themselves at the time of the decision-making. Non-treatment decisions not only involve technologically advanced interventions but also, and most frequently, the withdrawal or withholding of antibiotics (25%) and artificial nutrition or hydration (25%). End-of-life decision-making seems to be at least as common for the mentally handicapped as for competent patients. It is concluded that the increasing importance of end-of-life decision-making warrants further research into its clinical and epidemiological aspects, and that such research should also address ethical, societal and internationally comparative issues.

Advances in the field of medicine have greatly improved the possibilities to treat seriously ill patients and to prolong life or postpone death. However, these advances also increasingly urge physicians and patients to decide on which interventions are appropriate and which are not. Although it is obvious that many patients greatly benefit from modern medical technology, it is also clear that these developments have their disadvantages. This may hold even more strongly for patients who are in the terminal stage of their lives, when the traditional medical

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goals of sustaining and prolonging life are no longer self-evident. One of the main challenges of medical decision-making at the end of life is to determine which interventions are appropriate at what time, while taking into account the shift in aims from cure and prolongation of life to contributing to a high-quality terminal stage of life. One of the resulting issues is decision-making with regard to whether and when to refrain from applying potentially life-prolonging medical interventions. Such medical interventions may range from technologically advanced methods of treatments, such as surgery, mechanical ventilation and renal dialysis, to relatively simple interventions, such as giving antibiotics or the artificial administration of nutrition and fluids. The right of competent patients to refuse such interventions, even if this may entail a 'premature' death, is nowadays widely accepted in many countries. When end-of-life decision-making concerns patients who are no longer able to adequately speak and decide for themselves, the decision-making is more complicated. There is a broad consensus among physicians that they will not at the request of patients or family apply treatment that is, according to scientific or professional standards, 'medically futile'. However, the definition of medical futility is often not clear, due to scientific and probabilistic uncertainty and differences in underlying concepts among the parties involved. Furthermore, when the decision-making is considered to be guided by the patient's best interest, opinions may vary on how this best interest is defined, which decision serves the interests of the patient best, and whether physicians, relatives or others are best able to determine the interests of the patient.

Overview of Dutch research

The increasing awareness that high-quality palliative care for patients in the terminal stage of life includes appropriate decision-making on whether and when to apply or refrain from life-prolonging interventions, has yielded a need for empirical research. Medical practice at the end of life may, just like other areas of medical decision-making, benefit from a solid base of evidence. In this paper, an overview is given of Dutch research in this field in the last decade of the 20th century. This research has mainly focused on assessing epidemiological characteristics of non-treatment decisions, that is, decisions to withhold or withdraw potentially life-prolonging treatment, in terms of frequency and main backgrounds.

1990 Rimmelink study and 1995 replication study

In 1990, the Dutch government commissioned a committee to investigate medical practices concerning the end of life. The committee, named after its Chairman Professor Jan Rimmelink, who was attorney general of the Supreme Court at that time, was asked to explore the incidence and backgrounds of euthanasia, together with other end-of-life decisions. As a result, not only euthanasia and assisted suicide were studied, but also decisions to administer potentially life-shortening drugs to alleviate pain or other symptoms, and decisions to forgo potentially life-prolonging treatment. The study was performed at the Department of Public Health of the Erasmus

University Rotterdam, by a research group headed by Professor Paul J. van der Maas.^{1,2} The study consisted of three parts. Firstly, face-to-face interviews were held with a randomized sample of 405 physicians, including general practitioners, nursing home physicians and physicians from 5 clinical specialties that are frequently confronted with the death of patients. The response rate for this part of the study (study I, interview study) was 91%. The second study consisted of postal questionnaires that were sent to physicians who had reported a stratified sample of 5197 deaths to Statistics Netherlands, from August through November 1990. The response rate for this part of the study (study II, death certificate study) was 73%. In the third part of the study, physicians who were interviewed for part I were asked to complete the questionnaire used in part II for each patient in their care who died during a period of 6 months after the interview. Of the 405 physicians interviewed, 322 (80%) agreed to participate in this third part of the study (study III, prospective study).

In 1995, the Dutch government commissioned an evaluation of the recently established public notification procedure for physician-assisted death. This evaluation study included a replication of the 1990 Rimmelink study, so that any possible developments or changes in the incidence and backgrounds of end-of-life decision-making could be studied, resulting in an informed discussion of the benefits and drawbacks of the notification procedure. This notification procedure did not include the reporting of non-treatment decisions, and will be further described elsewhere in this volume. The 1995 study was performed at the Department of Public Health of the Erasmus University Rotterdam and the Department of Social Medicine of the Vrije Universiteit Amsterdam. The research groups were headed by Professor Paul J. van der Maas and Professor Gerrit van der Wal, respectively.³ The 1995 study replicated study I (interview study) and study II (death certificate study) of the Rimmelink study. Study I was, however, limited to end-of-life decisions that included the administration of life-shortening medication. Study II also addressed non-treatment decisions, and was based on 5146 deaths (response rate, 77%). Details of the design of both the 1990 Rimmelink study and the 1995 replication study are described in detail in the paper by Onwuteaka-Philipsen in this volume.

Incidence of non-treatment decisions, 1990-1995

Both the 1990 and the 1995 study showed that, in the Netherlands, death is frequently preceded by a decision to withhold or withdraw potentially life-sustaining treatment (see Table 1). In 1990, 28% (95% confidence interval [CI], 26%-29%) of all deaths and 39% (95% CI, 38%-41%) of all non-sudden deaths were preceded by such a decision.⁴ In 1995, these percentages were 30% (95% CI, 28%-31%) and 43% (95% CI, 42%-45%), respectively. Approximately 30% of all non-treatment decisions were followed by the administration of (potentially) life-shortening drugs, and this had a more decisive life-shortening effect. Therefore, non-treatment decisions were the most important end-of-life decision in 18% (95% CI, 17%-19%) of all deaths in 1990, and in 20% (95% CI, 19%-21%) of all deaths in 1995.^{6,7}

Table 1. Non-treatment decisions in the Netherlands, 1990 and 1995.

	1990 (n=5197)	1995 (n=5146)
Death was	%	%
Sudden and unexpected	30	31
Non-sudden, not preceded by non-treatment decision	43	39
Non-sudden, preceded by non-treatment decision	28	30
Non-treatment decision was most important end-of-life decision	18	20

The relative number of non-treatment decisions seems to be on the increase between 1990 and 1995, which also holds for euthanasia but not for other end-of-life decisions, such as physician-assisted suicide, ending of life without the patient's request or the administration of opioids in potentially life-shortening doses.⁷ Non-treatment decisions are the most frequent medical end-of-life decisions, together with decisions to administer potentially life-shortening doses of opioids. Non-treatment decisions quite frequently concern elderly patients: in 1990, 33% of all deaths among patients aged 80 years or over were preceded by a non-treatment decision, and in 1995 this percentage was 36% (Table 2). Furthermore, non-treatment decisions are made relatively often for female patients.

Table 2. Frequency of non-treatment decisions according to patient characteristics and specialism of the physician.

	1990		1995	
	total n	%	total n	%
Age, years				
0-64	1160	21	1313	23
65-79	1999	26	1792	26
80 and over	2038	33	2041	36
Sex				
Male	2665	24	2611	26
Female	2532	31	2535	34
Cause of death				
Cancer	2174	34	2119	31
Cardiovascular disease	1103	15	910	15
Neurological disease	572	37	466	43
Pulmonary disease	379	30	306	41
Other	969	30	1345	36
Specialism of the reporting physician				
General practitioner	2356	29	2493	17
Clinical specialist	1766	20	1560	35
Nursing home physician	986	46	929	52

Decision-making process

In the Netherlands, just over 40% of all deaths are reported to the central death register by general practitioners and most of these deaths occur at home.⁸ Approximately 40% of all deaths occur in hospitals and approximately 18% occur in nursing homes. Non-treatment decisions quite frequently concern patients who die in nursing homes. Of all non-treatment decisions, 42% were made by clinical specialists, 32% by nursing home physicians, and 23% by general practitioners.⁵ This over-representation of nursing home physicians is partly explained by the fact that they are less often than other specialists confronted with the unexpected death of their patients, but even when the denominator is restricted to non-sudden deaths, nursing home physicians appear to make non-treatment decisions more frequently (in 59% of all non-sudden deaths, 1995 study) than clinical specialists (48%) or general practitioners (28%). This difference is to some extent related to differences in the age of the patients and the underlying diseases.

Table 3. Characteristics of non-treatment decision-making for patients for whom a non-treatment decision had been the most important end-of-life decision.

	1990 (n=991) %	1995 (n=1097) %
Estimated shortening of life*		
< 24 hours	41	42
1-7 days	28	28
1-4 weeks	15	15
> 1 month	7	8
Unknown	9	7
Competent patients#	23	26
Decision was discussed with patient	100	93
Not (fully) competent patients#	62	67
Decision was discussed with patient	11	14
Patient's wish was known from previous discussions	12	12
Decision was discussed with relatives	71	71
Decision was discussed with		
Colleagues	48	52
Nursing staff	55	47
Decision was not discussed with anyone	7	5

* Estimated amount of time by which life was shortened as a result of the non-treatment decision.

Competency was unknown for 15% of all patients in 1990, and for 7% of all patients in 1995.

Non-treatment decisions mostly concern patients who are in the very last stage of their disease: over two thirds of all non-treatment decisions in 1995 involved an estimated shortening of life of one week or less (see Table 3). One of the most important issues in making non-treatment decisions is the involvement of the patient in the decision-making. Such involvement is largely determined by the competence of the patient, that is, the degree to which the patient is able to adequately evaluate his situation and make the necessary decisions about it. In both the 1990 and the 1995 study, details of the decision-making process were assessed for all cases in which an end-of-life decision had been made, and for the most decisive one in case of multiple decisions. It was found that of all cases in which a non-treatment decision had been the most decisive end-of-life decision, approximately 25% concerned competent patients (see Table 3).

The patient had been involved in making the decision to withdraw or to withhold potentially life-prolonging treatment in virtually all those cases. Thus, the majority of non-treatment decisions concern patients who are not (fully) competent and cannot decide for themselves at the time of the decision-making. This obviously complicates the decision-making process. In such cases, non-treatment decisions are virtually always made after discussions between the attending physician and one or more other persons involved. Only a small minority of all non-treatment decisions were made solely by the attending physician. When a patient is completely or partially incompetent, physicians either try to find out about the opinion of the patient (11% in 1990, 14% in 1995), or they take into consideration information from previous discussions with the patient (12% in both years) or the opinion of relatives (71% in both years). Furthermore, approximately half of all non-treatment decisions were made after the attending physician had consulted one or more colleagues or the nursing staff.

Types of treatment

Whereas the growing capacity of medicine to postpone death seems to be one of the causes of the increasing importance of non-treatment decisions at the end of life, this does not imply that such decisions only or predominantly concern technologically advanced interventions. Of all non-treatment decisions that were studied in 1995, 25% involved the withdrawal or withholding of antibiotics, and 25% involved forgoing artificial nutrition or hydration.⁵ Other types of treatment that were relatively frequently forgone were vasopressor medication (11%), other types of medication (18%), mechanical ventilation (10%), surgery (9%) and hospital admission or diagnostic procedures (8%). Nursing home physicians and general practitioners predominantly forewent artificial nutrition or hydration, antibiotics, other medication and diagnostic interventions, while decisions not to apply mechanical ventilation or surgery were mostly made by clinical specialists.

Whether or not patients should receive artificial nutrition or hydration in the terminal stage of their life is a subject that frequently arises in discussions concerning non-treatment decision-making. Here again, decision-making is especially difficult when it is related to incompetent patients. In the terminal stage of dementia, for instance, a patient's refusal to take food or fluids may be the result of practical

problems, such as difficulties in choosing what to take, bringing a spoon to the mouth or chewing, but it may also be an inherent part of the concluding disease process which results in the death of the patient. Opinions vary on whether the fact that nutrition and hydration are basic requirements for all human life has any relevance to the decision-making. It is obvious that total withholding of food and fluids results in the short-term death of the person involved, but the palliative or life-prolonging effects of artificial administration of food and fluids remain unclear. Research in this field is difficult, but the few observational studies that have been carried out do not seem to provide any evidence for the beneficial effects of administering nutrition and hydration to terminal patients.^{9,10} In the 1995 study, it was found that 8% of all deaths and 23% of all deaths occurring in nursing homes were preceded by the decision to withhold or withdraw artificial nutrition or hydration.¹¹ Such decisions most frequently concerned elderly female patients who were no longer able to decide for themselves. Relatives were involved in the decision-making process in most cases (89%).

Non-treatment decisions in the mentally handicapped

In 1997, Van Thiel et al. reported in the *British Medical Journal* on the results of a study on end-of-life decisions for mentally handicapped people living in institutions in the Netherlands.¹² In this study, 89 physicians caring for mentally handicapped people were retrospectively questioned about the most recent case of death that had been preceded by an end-of-life decision. It was found that the death of mentally handicapped people had been preceded by the decision to withhold or withdraw treatment (as the most important end-of-life decision) in 30% of all cases, compared to the 20% of cases found in the 1995 national survey. Physicians had discussed such decisions with the patient in 5% of all cases, whereas the patient's relatives or representative had been involved in 80% of all cases. The authors conclude that end-of-life decision-making is at least as common for the mentally handicapped as it is for competent patients. However, the debate on these aspects of terminal care is not as open as one may wish, even in the Netherlands, which may have its consequences for the quality of the empirical knowledge in this field.

Conclusions

It may be expected that non-treatment decisions will become even more important in medical care at the end of life in future decades. Technological developments are evolving, resulting in a growing ability to fine-tune medical interventions to individual characteristics, which inevitably yields an increasing need for establishing treatment goals, balancing the benefits and drawbacks of interventions and making adequate and evidence-based decisions. One of the most important requirements for high quality end-of-life decision-making is that physicians are aware that choosing and making decisions are inevitable ingredients of end-of-life care. Adequate and appropriate decisions can only be made when it is clear which alternatives are available

and which interests may or should be served. As a result, high quality decision-making is above all shared decision-making, that is, decision-making that involves patients, physicians, other professional care-givers, and relatives.

Important research questions

Further research in the following areas may contribute to high quality end-of-life care and non-treatment decision-making:

1. Knowledge about how, and in which circumstances, people actually die is limited and should be improved, including knowledge about the determinants of why patients and relatives experience a dying process as positive or negative, and the role of decisions about the provision of life-prolonging treatment.
2. In clinical practice, the focus of medical care is often not just a question of either prolonging life or providing palliative care, but some subtle combination of the two. Clarification of the concept of non-treatment decision-making may contribute to the rationality and basis of decision-making.
3. The relationship between the need for, and the use and evaluation of palliative care services and non-treatment decision-making should be studied. At this moment it is not clear why in some patient groups non-treatment decisions in themselves are sufficient to allow patients to die peacefully, whereas in other groups the administration of life-shortening medication seems to be needed much more frequently.
4. Further exploration is needed of the attitudes among the general population, and in various professional groups, towards decision-making with regard to life-prolonging treatment for various patient groups and the motives that may lead to such decisions, for example in situations which involve allocation problems.
5. International collaborative research is very important to determine the universal versus country- and culture-specific characteristics and determinants of end-of-life care, so that measures to improve quality in health care and in public health policies can be suited to the various different circumstances.

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