

CONCLUSION

1. The setting of the research

Having presented separately the main results of my empirical studies, I am ready to draw some conclusions and to answer the questions that have driven my research. Before doing so, it is useful to recall quickly the path I followed to come to this point.

The subject of my research is the legal status and social practice of treatment directives in the Netherlands. Interests that lay at different levels motivated the choice of this subject. At the substantive level, there was the question how treatment directives work in Dutch medical practice. At the theoretical level, I was interested to study the effects of legal rules on the behavior of human beings. The theoretical underpinning of this question is the paradigm of the ‘social working’ of legal rules, a paradigm that deals with the direct effects of legislation on human behavior. The regulation of treatment directives offers an interesting field in which to apply the paradigm. The central question of my research was therefore: Do people follow the rules concerning treatment directives? And why – under what conditions – do they do so?

Another question also gave shape to my research: Does following the enacted legal rules, to the extent it occurs, have the social effects expected by the legislator? This question lies outside the scope of the paradigm of the social working of legal rules, but it was relevant for my research and I kept it as a point of reference throughout.

Beside a personal interest in the topic, my research was justified by the fact that empirical research on treatment directives in the Netherlands is sparse and unsystematic. As far as I am aware, no quantitative study explicitly dedicated to this subject was carried out before my research. The collection of empirical data on the social practice of treatment directives was therefore an original undertaking that offered the promise of stimulating further discussion.

Preparatory to my empirical research, I carried out a series of background studies. The first was a comparative survey of the legal status of treatment directives in several, mostly Western countries. This survey resulted in a typology that divided the countries into three groups according to the strength of the legal status of treatment directives. The first group consists of countries where treatment directives have a strong legal status: the instructions in a treatment directive are binding on a doctor who cares for a currently incompetent patient. In the countries of the second group, although some legal recognition of treatment directives has been achieved, the status of treatment directives is somewhat uncertain and takes the form of 'may-rules'. In such a case, a doctor can decide whether or not to follow the directive. Finally, in the countries belonging to the third group, treatment directives have no legal recognition at all. This analysis allowed me to locate the Netherlands among the countries belonging to the first group; it is one of the handful of countries where the legal status of treatment directives is particularly strong. Another insight that emerged from the comparative survey is that countries with a strong commitment to the doctrine of informed consent sooner or later seem compelled legally to recognize the binding force of treatment directives: denying to non-competent persons this way of achieving some measure of autonomy seems everywhere to be a position impossible to sustain. Finally, carrying out the comparative survey required clarification of the differences between different sorts of exercises of patient autonomy and the adoption of a systematic terminology, an enterprise that proved its value in the later stages of the research.

A second preparatory step was a survey of the international available empirical literature concerning treatment directives. A general comment is that much of the research carried out to date is based on non-representative samples and the results are often contradictory. An additional problem is the confusing use of varying terminology. This often makes comparing the results of different researches difficult. Moreover, almost all studies on the practice of treatment directives come from North America and their generalizability to other Western countries is uncertain. Despite these limitations, analysis of this literature was useful as a basis for elaborating a systematic and exhaustive scheme of the social practice of treatment directives. This scheme, including all the factors involved in the social practice, was used for building the telephone questionnaires used in the empirical part of my study.

The third preparatory step was a detailed analysis of the Dutch legislation on treatment directives and a survey of the scarce empirical material available for the Netherlands. The legal rules that provide for treatment directives are given in the Law on Medical Contracts (WGBO). It is important to emphasize that Dutch legislation only covers treatment directives containing a refusal of treatment. Positive treatment directives, where a patient requests specific treatment, are not provided for under the WGBO. Legal recognition of advance written requests for euthanasia exists, but such requests are regulated in the Euthanasia Law and are not binding on a doctor. In my research, I did not consider this kind of advance request. Finally, Dutch law recognizes the appointment in writing of a representative for health-care decision-making, should the author become incompetent.

The provisions of the WGBO on treatment directives are extremely general and as far as the binding force of the instructions contained in a treatment directive is concerned are almost unconditional. Beside the obvious requirements of the identity, competence and age of the author, the only explicit formal requirement is that the instructions are in writing.¹ There are no other legal requirements for a valid treatment directive. As a consequence, the entrance threshold for potential users is rather low: practically every competent person can easily write a valid treatment directive, without the help of an expert. The only limitation on the binding force of a treatment directive is an escape clause in the law that allows a doctor not to follow a directive if he has ‘well-founded’ reasons for doing so. The exact scope of this provision is still a matter of discussion, but it clearly does not allow the doctor to override a treatment directive simply because it differs from his own judgment. There are precautions that can be taken to diminish the possibility of an appeal to the escape clause (for example, regular updating and the inclusion in the directive of the appointment of a representative).

In short, we can say that the legal status of treatment directives in the Netherlands is strong. However, the law is on some points rather vague and contains no provisions concerning implementation of the right recognized, nor any governmental or institutional guidelines been supplied to the actors involved in the process (mainly doctors, patients, relatives and representatives). The escape clause adds to the general aura of incertitude.

Dutch empirical material concerning treatment directives is scarce and often impressionistic. Unfortunately, the large studies carried out on end-of-life practices, commonly referred to as the ‘national euthanasia studies’, did not collect data that unambiguously pertain to treatment directives. And the recent evaluation of the WGBO did not cover treatment directives. The other studies available have a qualitative character. The only indications that seem to emerge from existing research

¹ See chapter 4, note 6, for doubts about even this formal requirement.

are that treatment directives are more frequent in the Netherlands than in other countries in Europe and that Dutch doctors prefer to base decision-making for their incompetent patients on their own medical judgment rather than on the wishes previously expressed in writing by their patients.

My research is thus an original attempt to shed some light on the social practice of treatment directives in the Netherlands. Two main groups of subjects were deemed particularly suitable for such research: doctors (who are potentially involved in the social practice of treatment directives from the information phase through implementation), and users/patients, whose welfare and autonomy are at stake. For practical reasons the choice fell on doctors (more easily approachable; fewer ethical concerns in requesting their participation; easier to recruit). Some information concerning users was gathered indirectly by asking the doctors questions concerning their patients (especially as far as the frequency of treatment directives is concerned). These data are less reliable than those directly collected from patients would have been, but have the advantage of supplying information on a larger pool of patients than could have been approached directly.

Among the general category of doctors, I chose nursing home doctors and family doctors. Nursing home doctors are relevant because their patients are mostly elderly people, both competent and no longer competent. Family doctors have a long-term relationship with their patients, who include most of the Dutch population, and are the doctors most often present at the deathbed. I supposed that they could be able to supply information concerning all sorts of patients in different phases of their lives and with different kinds of (potential) interest in treatment directives.

Incidentally, a possibility to study the role of notaries arose. Notaries being the legal experts most regularly consulted by Dutch citizen for help in drafting treatment directives, I decided to run a small survey to ask them some questions concerning their involvement in the social practice of treatment directives.

For all three studies, I opted for a quantitative methodology. The main instrument for collecting data was a structured questionnaire administered by telephone. The questionnaire followed the scheme of the social practice mentioned above. The content of the questionnaire was slightly different for the notaries, since their role in the social practice of treatment directives is largely limited to the drafting phase.

One recurrent difficulty in the construction of the instruments and later on in the collection of the data concerned the terminology to be used. What my systematic analysis of the social practice had lead me to designate as ‘treatment directives’ are often referred to by the experts studied with different (and crucially ambiguous) names. In particular, the expression ‘euthanasia directive’ is often used to refer to

treatment directives. This fact created some misunderstandings, especially in the first phases of the research. With the progress of the research and the experience accumulated in the earlier collections of data, I was able to refine the questions asked. Following chronologically the empirical studies, first notaries, then nursing home doctors, and finally family doctors, one can observe an improvement in the quality of the questions and a reduction of ambiguity in the answers collected.

To select the subjects to be interviewed, I always applied sampling procedures that guaranteed a reasonable level of representativeness. Unfortunately, the actual process of data collection was affected by a rather high level of non-response, which may have reduced the representativeness I was striving for. However, the composition of the samples was very similar to that of the populations sampled, and considering the high level of homogeneity in behavior among the groups of professionals studied, the main results can with appropriate caution be generalized to the populations as a whole.

2. Results

Two main results emerge from my research:

- a. the frequency of treatment directives in the Netherlands is low;
- b. the treatment directives that do exist probably have little effect on medical decision-making.

The two points will be presented in more detail.

2.1. The frequency of treatment directives

The frequencies detected in my research are presented on Table 69.

Table 69. Frequency of treatment directives by category of patients

	Current patients	Patients who died in the previous year
Nursing home doctors	4.5%	4.7%
Family doctors	0.3%	8.6%

In Dutch nursing homes, approximately 5% of the patients have a treatment directive, and this frequency does not differ if we consider current patients or patients who died in the previous year. This means that there are not many patients who complete a treatment directive shortly before dying. This is understandable if we consider that many deaths in nursing homes are related to degenerative syndromes.

In the practice of family doctors, the frequency of treatment directives is drastically different if we consider all current patients or just those patients who died in the

previous year. The reason for such a difference reflects on the fact that family doctors treat patients of all ages, and many of these patients, being young and healthy, do not address much attention to death and dying. The frequency among all patients is therefore very low (less than 1 patient in 100). But those patients who died in the previous year show a much higher frequency of treatment directives (almost 1 in 10 of those patients had one). This confirms the natural assumption that the potential interest in and the actual drafting of treatment directives is limited to a small part of the population, namely people who are confronting the fact of their own mortality. The relevance of age and health condition as factors that influence the chance that a person writes a treatment directive was also found in the survey of the empirical literature.

The fact that the frequency of treatment directives is much higher among patients of family doctors who died in the previous year compared to the same category of patients in nursing homes is consistent with another of the findings of the survey of the empirical literature: old age together with the onset of senile dementia is a factor that diminishes the chances of completing a treatment directive.

The question now is how to interpret these frequencies. Are they high or low compared with other countries? The answer depends on the terms of comparison: the US or Europe. A selection of the studies considered in Chapter 3 is given on Table 70.

Table 70. Frequency of treatment directives detected in representative samples in the US

Country	Year	Frequency of treatment directives	Specific population	Study
USA	2000	36%	Nursing home residents	Minimal Data Set Brown Medical School
USA	1992-1994	18%	Seriously ill hospitalized patients, post-PSDA	SUPPORT – Phase 2 (Teno et al. 1997)
USA	1989-1991	13%	Seriously ill hospitalized patients, pre-PSDA	SUPPORT – Phase 1 (Teno et al. 1997)
Netherlands	2001-2002	13%	Deaths where an end-of-life decision was taken	Van der Heide et al. 2003
Netherlands	2003	9%	Family doctor (deceased patients)	My research on family doctors
Netherlands	2002	5%	Nursing home patients	My research on nursing homes doctors
5 European countries*	2001-2002	<5%	Deaths where an end-of-life decision was taken	Van der Heide et al. 2003
England	2000	0%	Elderly (>65) in hospital	Schiff et al. 2000

* Denmark, Sweden, Switzerland, Belgium and Italy.

Although the frequency of treatment directives detected in my studies is slightly lower than the frequency found by Van der Heide et al. (2003), the difference can be explained by the fact that Van der Heide considered only deaths where an end-of-life decision was taken,² while I included all deaths without distinction. In either case, the Netherlands is the country with the highest frequency of treatment directives in Europe. This relatively high frequency (in European terms) is presumably a result of the strong legal status of treatment directives (among the countries studied equivalent only to that in Denmark) and the quite open approach of the Dutch concerning end-of-life issues.

The picture changes if we compare the Dutch data with those from the US. Since the beginning of the 1990s, the frequency of treatment directives among American patients has been higher than the current frequency in the Netherlands, no matter what category of patients is considered. The data of 2000 referring to all nursing home residents (Minimal Data Set) show, for example, that approximately one in three such residents has a treatment directive. Since there seems no reason to believe that the potential interest in treatment directives is lower among Dutch patients than among US patients, we can suppose that currently in the Netherlands there is a large potential demand for treatment directive that is not being met: many people potentially interested in drafting a treatment directive do not do so.

One general explanation of these differences can be given in terms of time-lag before a new practice spreads among the population. In the US, the relevant State legislation began to be enacted at the end of the 1970s, and Federal legislation promoting treatment directives (Patient Self Determination Act, PSDA) was enacted in 1990. In the US there have been therefore almost three decades of legal recognition of treatment directives. In the Netherlands the law providing for treatment directives dates from 1995. In the other European countries where treatment directives have a strong legal status, legal recognition similarly took place only recently.

If the temporal factor were the only thing influencing the frequency of treatment directives, we could expect to see in the coming years, first in the Netherlands and then in the other European countries where the legal status is strong, the development that has already occurred in the US. This idea, however, is not supported by the findings of my research. To the question “Has the use of treatment directives increased or remained stable in the previous five years?” only a minority of the professionals I interviewed answered that the use of treatment directives had increased. More than

² Namely: abstention (including refusal of treatment), pain relief (including terminal sedation), euthanasia (frequently requested in a document that also includes a treatment directive), and termination of life without request. Obviously, one would expect the prevalence of treatment directives in at least some parts of the population (death due to abstention and to euthanasia in particular) to be higher than among all persons who died.

half the interviewees said that the use had remained stable. The figures are presented in Table 71. These data do not unambiguously establish that no increase has been taking place, but they also do not seem to reflect a strong, rapid growth in the frequency of the practice. If we therefore assume a slow growth rate, it is difficult to imagine that in the coming years the Netherlands will catch up with the US.

Table 71. Opinion about the development in the use of treatment directives by professional groups surveyed

	The use of treatment directives remained STABLE in the previous 5 years	The use of treatment directives INCREASED in the previous 5 years
Family doctors	65%	35%
Nursing home doctors	55%	45%
Notaries	71%	29%

If the temporal explanation does not in itself seem powerful enough to explain the difference between the US and the Netherlands, what other, additional explanation could be advanced? There is also a difference in the relevant legislation between the US and Europe. The American PSDA requires all health-care institutions funded by the Federal Medicare and Medicaid programs to inform incoming patients of their right to complete a treatment directive. From the studies conducted before and after the enactment of the PSDA, it seems that this law increased the use of treatment directives, although it is difficult to prove a causal connection. In no European country is there a similar example of proactive legislation. Moreover, in the Netherlands, the Royal Dutch Medical Association has not issued guidelines concerning treatment directives, and institutions such as nursing homes and hospitals have been similarly passive: not a single nursing home of those surveyed had a guideline or protocol concerning treatment directives. Furthermore, the lack of information given by institutions to their patients is not compensated for by the actions of individual doctors, who rarely take the initiative to inform their patients about the possibility of drafting a treatment directive. If my analysis is correct, and the lack of a proactive program encouraging the use of treatment directives is the most important factor, we can expect that the gap between potential demand and the actual use of treatment directives will not be filled in the coming years.

2.2. The effects of treatment directives

Are treatment directives effective? That is, does the presence of a treatment directive influence the decision-making process for an incompetent patient? From the answers of the doctors, recapitulated on Table 72, it seems that this is not the case. If a treatment directive differs from or is opposed to the medical judgment of the doctor to

whom it is addressed, he will be strongly inclined not to follow the instructions in the document. This holds more for family doctors than for nursing home doctors.

Table 72. Behavior of nursing home doctors and family doctors in hypothetical situations

Would you follow a treatment directive if:	Nursing home doctors		Family doctors	
	Yes (1)	No (2)	Yes (1)	No (2)
- it differs somewhat from your medical judgment	74%	26%	53%	47%
- it is completely opposed to from your medical judgment	41%	59%	13%	87%

(1) ‘Yes’ brings together ‘Surely yes’ and ‘Probably yes’.
 (2) ‘No’ brings together ‘Surely no’ and ‘Probably no’.

If we add to this that more than 50% of the family doctors consider their medical situation of the patient the best ground on which to base decision-making for an incompetent patient with a treatment directive, we can expect that treatment directives will not have the influence on medical treatment that the law requires. Furthermore, these reactions of the doctors are to a hypothetical treatment directive whose meaning in the situation is clear; in practice, as my data have confirmed, treatment directives are rarely concrete and unambiguous.

How to explain this low effectiveness? Two main factors affect the effectiveness of a treatment directive:

- a. the willingness of the treating doctor to follow it;
- b. its medical quality, that is the clearness of the instructions contained and, possibly, the inclusion of the appointment of a representative.

What can we say about these two points, considering the findings of my research?

As far as the attitudes of doctors toward treatment directives are concerned, Table 73 shows that although they in theory support the principle of respect for autonomy and are ready to use treatment directives as supplementary information in the decision-making process for an incompetent patient, doctors are simply not prepared to subordinate their medical judgment to a written refusal of treatment and, as consequence, they do not accept the binding force of treatment directives.³ These attitudes, more pronounced among family doctors, are consistent with the way doctors predict their behavior in a hypothetical case (Table 72).

³ Kleijer’s research among intensive care doctors in the Netherlands gives very similar results. See Kleijer 2005.

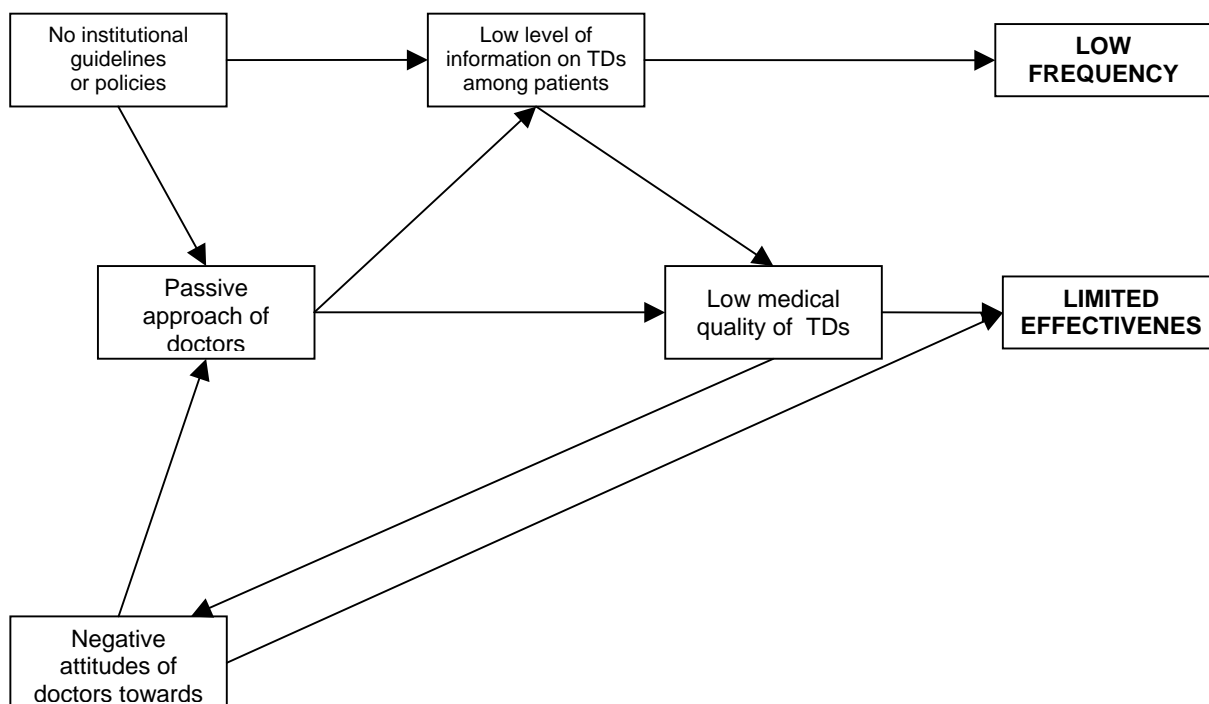
Table 73. Attitudes of nursing home and family doctors concerning the role of treatment directives in medical decision-making (row percentages)

Statement	Nursing home doctors			Family doctors		
	Completely agree	Partly agree	Disagree	Completely agree	Partly agree	Disagree
S1. Treatment directive as supplementary information	57	30	13	63	28	9
S2. Treatment directive and current refusal same strength	29	37	34	20	42	38
S3. Written treatment refusal prevails over medical judgment	15	43	42	8	27	65
S4. Treatment directive as binding	7	37	56	5	26	69

Such negative attitudes toward the binding force of treatment directives seem not only to have a direct influence on the effectiveness of the documents at the time of implementation, but also to influence the behavior of doctors in previous phases of the social practice of treatment directives. As we have seen, doctors rarely take the initiative to inform their patients about the possibility of writing a treatment directive. They are rarely involved in the drafting of treatment directives. They limit themselves to receiving documents drafted by their patients, usually without any expert support, and to suggesting to the author that he inform other people of the existence of the document. This passive approach in the drafting phase, which is fostered by the lack of institutional policies demanding more active involvement by doctors, contributes to the generally low quality of treatment directives. According to doctors, the treatment directives of their patients are very often expressed in generic terms, failing clearly to specify the conditions of applicability and the treatment refused. The circle is complete if we suppose that the practical experience of doctors with directives of low quality - too vague and general to drive the decision-making process - has a feed-back effect that reinforces the negative attitudes of doctors toward treatment directives and their disinclination to promote the use of the instrument.

This is the picture that emerges from my empirical analysis of the social practice of treatment directives in the Netherlands. To sum up: On the one hand, the low level of information about treatment directives keeps the frequency of these documents low among the Dutch population. This low level of information is not corrected by a proactive approach of institutions and individual doctors. On the other hand, the negative attitudes of doctors toward the binding force of treatment directives and the widespread low quality of the documents, fostered among other things by the passive approach of doctors and by the low level of information among patients, prevents treatment directives from being effective in the decision-making process for incompetent patients. The graph below synthesizes the findings.

Figure 5. Synthetic scheme of the findings



The low frequency of treatment directives and their limited effectiveness occur despite the strong status that treatment directives enjoy in Dutch legislation. It appears that legal recognition of the binding force of treatment directives is not sufficient to assure their use and effectiveness and hence to promote the realization of patient autonomy. Considering the several factors that produce these results, we can conclude that it is deficiencies in the law itself that prevent the Dutch legislation from achieving its objectives.

Neither the law itself nor an actively supportive governmental policy provides for a public information campaign nor for expert help in drafting treatment directives. Everything has been left in practice to the NVVE, whose reach, however, is largely limited to persons potentially interested in euthanasia. The law also does not provide for any measures addressed to institutions such as hospitals or nursing homes to promote the use of treatment directives and to establish protocols and guidelines to be followed in case of decision-making for an incompetent patient with a treatment directive. The position of these institutions has therefore remained passive, thereby possibly influencing the approach of individual doctors, who feel no institutional pressure to support a more vital social practice of treatment directives.

The effectiveness of treatment directives depends not only on their medical quality – however important this is and however neglected it has been by the legislator and policy maker – but also, as the review of the literature demonstrated, on the appointment of a representative. Treatment directives in fact rarely include the appointment of a representative to help in interpreting the written instructions if necessary to and insist on their implementation. Although the law provides for the appointment of a representative and specifically gives the representative a key role in the implementation of a treatment directive, little has been done to promote such appointments. Given the fact that, due to their generic formulation, problems of interpretation of treatment directives are frequent, the presence of an appointed representative would afford an opportunity to promote decisions more respectful of the autonomy of the now incompetent author. Moreover, the representative could also call for the enforcement of the treatment directive, in case the treating doctor is not inclined to comply. But the law fails effectively to provide this or any other mechanism of enforcement, and as a result – among other things - not a single court decision about a treatment directive has been rendered since the enactment of the WGBO.

The absence of any attention to practical aspects of the social practice of treatment directives in Dutch legislation has been coupled with a passive position of the Royal Dutch Medical Association, which has not engaged in any sort of education campaign directed to its members in order to promote more frequent and effective treatment directives. Even very simple things, such as the distribution of proper forms for drafting a treatment directive, have apparently not even been considered.

In such a situation, the law has had only marginal effects on the behavior of doctors. They are generally informed about treatment directives, although they fail to make proper distinctions between different kinds of advance directive (treatment, proxy and euthanasia directives). They are also ready to use treatment directive as supplementary information in the decision-making process. But even when a treatment directive is unambiguous, most doctors simply do not accept its binding force.

We are now in a position to answer the main questions underlying my research.

Do legal rules concerning treatment directives influence the behavior of the doctors and patients?

If the core of the legislation on treatment directives lies in their binding force in the medical decision-making for incompetent patients, this question must be answered negatively.

- Doctors follow their medical judgment rather than the will of an incompetent patient laid down in writing before incompetence. In the last instance, doctors consider the instructions in a treatment directive only as supplementary

information. In case of disagreement or conflict between the written instructions and their medical judgment, the latter will prevail. Influence of the legislation on the behavior of doctors is perhaps not completely absent, but it is rather marginal.

- In the absence of public information and expert support, most potential users do not complete treatment directives, and most treatment directives are of low medical quality. The vague and generic terms used in most directives in effect lets doctors off the hook.

Does the law on treatment directives contribute to the realization of patient autonomy? Given the above conclusion concerning the direct effects of the law on the behavior of those to whom it is addressed, it is hard to see how the law could be considered to have contributed much to its more ambitious indirect objective, the realization of greater patient autonomy.

3. Reflections and policy implications

Having summarized the main results of my research, I conclude with some reflections that flow from them. I will consider first the concept of ‘engineering rights’, as a way of analyzing the empirical relations involved in a particular social practice, if one seeks to regulate it in an effective way. Then I will give some concrete policy suggestions that would make the practice of treatment directives more effective in the Netherlands and elsewhere. Finally I will touch on some methodological implications of the work I have carried out.

3.1. Engineering rights

In order effectively to regulate a social practice, merely enacting a new substantive right will often not suffice. The new right will require various forms of support if it is to be expected that people will make use of it. This is particularly true in the case of the establishment of a new facility (here, the right to draft a treatment directive), where the success of the legislation largely corresponds with the actual use that potentially interested people make of the facility.

One of the main shortcomings of the Dutch legislation on treatment directives lies in the fact that many social and institutional conditions surrounding the contemplated new practice were not taken into account. The law was limited to stating in unconditional terms the right of a patient to continue to control the medical decision making-process should he become incompetent. More concrete support for the practice was not provided. For example, the attitudes of doctors concerning decision-making in the case of incompetent patients were not considered, and no measures were taken to change them or to create conditions favorable to implementation such as institutional

protocols. Even more relevant, information and support for potential users was completely neglected. In this way, although the right to autonomy for an incompetent patient was theoretically provided for in the law, the people interested did not know about this, and if they did complete a treatment directive it was generally of poor quality.

If such elements had been taken into account in the law, all indications in the literature and in my research suggest that the chances of achieving the objectives that the legislator had in mind would have substantially increased. I speak of ‘engineering rights’ to indicate the process of analysis of and deliberation about the concrete social practice involved that should precede the enactment of a law, if it is to be effective. The objectives of the law are a matter of political choice and are not under discussion here. What I mean is that, once the Dutch parliament had decided that recognition of the binding force of treatment directives would serve to protect the autonomy of incompetent patients and improve care at the end of life, the legal rules enacted should have included supportive provisions to maximize the chances of success.

3.2. Policy suggestions

My study establishes that so far the objectives of the legislator have not been achieved. Following the above analysis and focusing on the scheme presented just a few pages before, it is possible to imagine a number of actions that could correct this situation.

First, a series of measures to increase the chance that potential users are informed of their rights could promote better knowledge of treatment directives and have as a result a higher completion rate and a better quality of the documents. An example of such measures can be taken from the Patient Self Determination Act in the US, which makes it compulsory for most hospitals and nursing homes to inform incoming patients of their right to draft a treatment directive. In the Netherlands, such responsibility for informing potential users could also be part of the job of family doctors.

The government might also consider drafting and distributing a standard form with accompanying instructions and suggestions. The NVVE form is well-designed. However, the NVVE is a right-to-die interest group whose form is only available to members and includes a request for euthanasia. Its availability and acceptability are therefore considerably reduced.

Another potentially effective measure would be to promote a more active involvement of doctors in advising patients who want to draft a directive. More active involvement of doctors in the first phases of the social practice of treatment directives should also have the effect of modifying their attitudes towards the usefulness and importance of

these documents. Eventually this will have a spin-off effect on the effectiveness of treatment directives at the time of their implementation.

A final measure would be to promote a greater connection between treatment directives and proxy directives, for example by requiring that every treatment directive include the indication of a person to participate in its interpretation and see to its implementation.

This set of policy suggestions holds in a situation like the Dutch one, where a law already exists. But the findings of my research can be useful also for those jurisdictions where treatment directives currently have only weak or no legal status but a public discussion about the possibility of enacting to enact legislation is ongoing. Legislators in such countries could learn from the mistakes of others and not repeat them.

3.3. Methodological reflection

A final reflection concerns the methodology used in my research. As I said at the beginning of this chapter, I opted for structured questionnaires that allowed me to get quantitative information concerning the social practice of treatment directives in the Netherlands. Such an approach seemed particularly valuable considering the fact that no such information was available. Nonetheless, some limitations are evident. For example, the scheme presented in the previous paragraph suggests the existence of specific relations among several variables considered (for example, the attitudes of doctors and the effectiveness of treatment directives), a subject on which I can really only speculate. In short, more research will be required if we want to achieve a better understanding of the social practice of treatment directives. In particular, qualitative studies aimed at uncovering the causal mechanisms that underlie the relations detected are important. Furthermore my research chose for practical reasons to secure information from professionals involved in the social practice.⁴ Similar information from members of the general population involved in the social practice of treatment directives (to answer questions such as: why do people decide to draft – or not to draft – one?) is unavailable but highly important. Therefore studies focusing on populations of potential users are needed. My results represent only a first step in the direction of the insight required for a more effective social practice and a better theoretical understanding of the social working of this sort of legislation.

⁴ Most prior studies followed the same strategy. Studies of patients population, otherwise, have either been small and non representative groups, or dealt only with patients with persons who already had a treatment directive, or were retrospective.

