

## **CHAPTER V**

# **EMPIRICAL ANALYSIS OF THE SOCIAL PRACTICE OF TREATMENT DIRECTIVES**

### **1. Introduction**

The empirical part of my research seeks to analyze the effects of the legal recognition of treatment directives in the Netherlands. As defined in the previous chapters, a treatment directive is a document that contains a refusal of treatment addressed to the health care suppliers in case the author becomes incompetent. The point of giving treatment directives legal status is to extend the patient's power to give or withhold consent to medical treatment beyond the point at which he has become incompetent.

My research is aimed at clarifying the direct effects of the legislation on the behavior of the actors involved in the social processes connected with the legal rules at stake. The paradigm of the social working of legal rules offers a theoretical framework for analyzing this question.<sup>1</sup> The study focuses on the use of treatment directives by potential users and on the implementation of the instructions contained in treatment directives. I start from the assumption that if the conditions for the use of a specific right are met but potential users do not know about the right or are not in a position to exercise it in an effective way (for example because they lack crucial medical information), then the right has no practical social consequences. The same holds if treatment directives are not regularly honored at the point of implementation.

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<sup>1</sup> Griffiths 2003.

If the answers to such questions concerning direct rule-following effects are positive, a second, more general question arises concerning the indirect effectiveness of the legislation: do treatment directives promote the more general social objectives desired by the legislator?

The two questions can be stated succinctly as follows:

- Do people follow the rules concerning treatment directives?
- Does following the rules have the effects expected by the legislator?

The second question lies largely outside the scope of the paradigm of the social working of legal rules, but it remains relevant for my research.

Answering the question concerning direct effects entails studying a number of things:

- the legal rules whose effects are to be studied (described in chapter 4);
- the actors involved in the social processes connected with the rules at stake;
- the relations among the actors (referred to in the social-working-of-legal-rules paradigm as the ‘social structure of the shop-floor’).<sup>2</sup>

Having identified the factors to which attention must be addressed, some further fundamental steps must be taken:

- describing a model that simplifies the social structure in order to be able to cope with the complexity of reality (in practice: deciding which actors and relations are most important in the situation we are studying);
- selecting the most convenient methodology to answer the specified questions;
- translating the general questions stated above into more specific questions that can be directly put to the subjects of the study and serve as the indicators that are assumed to measure the effects of the legal rules on behavior.

In the following paragraphs, I will deal with the elements mentioned above in the case of a study of the effects of legislation on treatment directives: the actors involved in the social practice of treatment directives and the social structure of the practice (relations among the actors involved). I will then make explicit the research choices made in order to study the effects of the legislation (definition of the model, methodology). As far as the articulation of specific questions is concerned, I will organize them following the scheme of the social practice presented in Chapter 3. As far as the legal situation is concerned (the legal rules on treatment directive in the Netherlands), no further presentation is necessary because this has been done extensively in the Chapter 4. However, it is useful to reemphasize that the term treatment directive refers to a written document containing a refusal of treatment. The

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<sup>2</sup> Griffiths 2003.

binding legal status of such a document is stated in the patients' rights law (WGBO). Appointment of a representative (proxy directive) will be considered as an additional measure that can complement a treatment directive. Except for short references where necessary, I will exclude from the discussion advance requests for euthanasia (*euthanasieverklaringen*).

## 2. The main actors

In the following paragraphs, I briefly describe the main actors involved in the social practice of treatment directives: authors (patients), doctors, appointed representatives, family members, and legal and extra-legal consultants.

### *The users: authors*

Dutch law provides that every adult (16 or older) can write a treatment directive. However, not all residents of the Netherlands have the same interest in writing a treatment directive. And, as far as we can tell, only a minority of all persons 16 or older ever concretely considers the possibility of doing so. In considering the rate of use, we therefore need to make some distinctions.

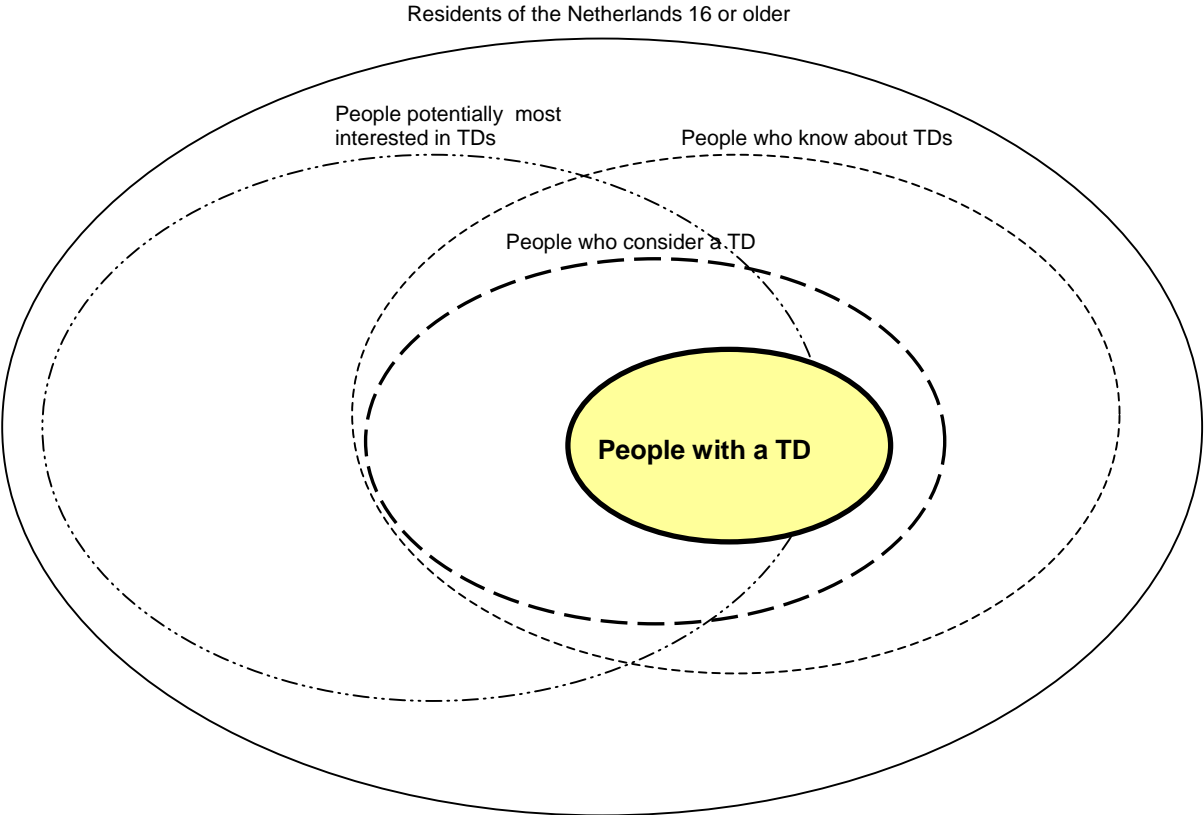
We can identify some groups that have a higher potential level of interest in treatment directives. Elderly people, persons affected by degenerative diseases and people with chronic or terminal conditions may be particularly interested. However, not all of them know about the possibility of drafting a treatment directive and of these only some actually consider the possibility of doing so; and an even smaller group actually does draft such a document. We can therefore distinguish the following groups and sub-groups (see figure 4):

- adult residents of the Netherlands 16 or older: holders of the right to autonomy;
- those potentially most interested in treatment directives (elderly people, patients with degenerative diseases);
- those who know about the possibility to draft a treatment directive;
- those who actually consider drafting a treatment directive;
- those who actually draft a treatment directive.

The group mostly involved in the social practice of treatment directives is composed of persons who consider drafting and actually do draft a treatment directive. Depending on the context, we will label these people either (potential) 'users', 'authors' or 'patients'. What is their position in the social practice of treatment directives?

If we consider the scheme of the social practice of treatment directives presented in Chapter 3, it is immediately apparent that the involvement of an author differs from phase to phase. In the early phases, especially in the drafting phase, he plays an active role as author of a directive. Later on, in the phase of implementation, his active involvement disappears almost completely since a treatment directive can only be implemented if the author has become incompetent and thus has lost most or all of his capacity to participate in the decision-making with other actors.

**Figure 4 – Groups of potential and actual users of treatment directives (TD = treatment directive)**



*Doctors*

The main counterparts to the author/patient are doctors, who are potentially involved in almost all phases of the social practice of treatment directives. Doctors are a potentially important source of general information about treatment directives for their patients. They can take the initiative to talk about treatment directives with their patients, or they can supply more specific information once a patient comes to them with a question. Doctors can also have an important role as consultants in the drafting phase. They can advise on how best to formulate the conditions under which the treatment directive will be effective and the treatments to be refused. They can also

give suggestions for increasing the likelihood that a patient's treatment directive will be implemented (for example: making the existence of the document known to other people and regularly updating it). Moreover, doctors are the key actors at the time of implementation, when decisions concerning treatment for the incompetent author must be taken. In this phase, their knowledge (legal, medical and practical) and attitudes concerning the role of written treatment instructions may be crucial to determining the weight such instructions have in the decision-making process.

### *Appointed representatives*

A treatment directive can be complemented by the written appointment of a representative, either to ensure the fulfillment of the instructions in the treatment directive or to decide on the behalf of the incompetent patient. In Dutch law, such a figure takes precedence over all other possible representative of the patients, except when a court has appointed a legal guardian or a mentor. Having a representative directly appointed by the patient can avoid conflicts among relatives concerning who is authorized to give or withhold consent to (further) treatment. If the author has chosen his representative well and taken care that his treatment wishes are understood, the instructions the representative gives will serve to effectuate the author's autonomy. The role of the appointed representative in the implementation phase is critical since the patient's doctors must inform him of the decisions they are taking concerning the patient's treatment and secure his consent. But a representative can also play a role during the drafting phase, helping to make sure that the treatment directive is clear about what exactly the author does and does not want.

### *The patient's family*

The family member of the patient who comes highest in the statutory priority list of representatives if none has been appointed can also be an important actor in the social practice of treatment directives.<sup>3</sup> In the absence of a representative appointed by the patient, this person is responsible for securing the implementation of the instructions contained in the treatment directive. However, in practice, the identification of the family member who will serve as representative is not always straightforward. One weakness of the Dutch statutory arrangements is the absence of a procedure for determining which family member is to serve as representative, if it is not clear who is available or if there are more than one person in a specific category (such as 'children'). Moreover, family members lower on the list or not on it at all do not always agree with the decisions of the legally-indicated representative and conflicts within the family can arise about how to implement the treatment directive. If the

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<sup>3</sup> My research deals only tangentially with the practical problems that may arise. Most of the ideas presented here on problems connected with the representation of incompetent patients come from my collaboration with Hans Konst, doctor and director of a Dutch nursing home, who carried out research on this matter simultaneously with my research.

conflicts among them cannot be settled, a doctor may have to ask the court for the appointment of a legal representative (mentor).

#### *Legal and extra-legal consultants*

Drafting a treatment directive is not as simple as it might seem. Potential users often do not have the skills and knowledge to write legally valid and medically effective documents. We have noted above that a doctor can be consulted by a potential author, especially concerning the medical aspects of a treatment directive. Lawyers, especially notaries, can be consulted as far as the legal aspects of a treatment directive are concerned. Moreover, organizations devoted to the promotion of patient's rights and self-determination often encourage the use of treatment directives and supply information and support to persons interested. In the Netherlands, the NVVE is one of the main sources of information concerning treatment directives and supplies to its members both personal advice and a carefully designed standard form (as we will see, this form influences the advice given by other consultants).

As we have seen, in the US hospitals and nursing homes are legally required to give information about treatment directives to patients upon admission. In the Netherlands, policies or protocols developed by such institutions could serve the same function and, if the US experience is any indication, would substantially increase the use of treatment directives. Institutions can also provide information, give support in drafting, promote registration in the medical records of the patients, regulate internally the role of written instructions in the decision-making process, and generally stimulate a positive attitude among their staff toward the use of treatment directives. At the present, however, nothing is known about the extent of such policies and practices.

### **3. A short description of the social structures and relationships involved in the practice of treatment directives**

Having indicated the main actors involved, it is important to consider briefly the dynamic process that begins with the idea of writing a treatment directive, through the decision to do so, the actual drafting, and eventually to its implementation.

A precondition to the all process is the fact that the potential user has the necessary knowledge concerning the possibility of drafting a treatment directive and how to go about it. Given this knowledge, a person can consider drafting a treatment directive. This idea can have different origins. Given the required knowledge, the initiative may lie entirely with the author, motivated either by personal ideas or following the diagnosis of a specific serious disease, or as a consequence of witnessing the death of someone close. The stimulus may come from the author's social surroundings, whether immediate (family, friends, colleagues) or more distant (e.g. the media). But it

is also possible that the initiative comes from a physician who suggests the appropriateness of the author putting his treatment wishes on paper well before the point at which he is no longer able to make decisions concerning his health-care. Or the initiative can be built into a standard procedure at the occasion of a specific event, such as admission to a hospital or to a nursing home.

Once a person has decided to make a treatment directive, he may do so entirely independently, or consult a doctor or another expert. His family members or other close social relations may be involved. A specific situation is where a person is to be appointed the representative of the author in the treatment directive: this person will normally at least be informed concerning the wishes of the author and will give his consent to assuming the role of representative.

Once a treatment directive is in place, there is a shorter or longer period of time a time before it becomes relevant, that is, before the author becomes incompetent. In this period, discussions concerning the author's wishes with some or all of the actors previously mentioned can continue. The author's doctor may also regularly discuss the treatment directive and his treatment wishes more generally with him.

If and when the author becomes incompetent, the treatment directive becomes potentially relevant for further health-care decision-making. The conditions under which the treatment directive is applicable and the concrete meaning of the instructions given may require more or less difficult work of interpretation. In addition to the doctor, the author's representative and the member(s) of his family may all be involved. They may agree or disagree on the proper decisions to take. In case of disagreement, a process of adjustment or bargaining may take place. We can suppose that generally a satisfactory solution will be reached without involving third parties (in fact, recourse to legal resolution of disputes about the application of treatment directives is extremely rare).

Although very sketchy, the above account makes clear that the social practice of treatment directives is complex and that there are many points at which the relevant legal rules may influence behavior.

#### **4. The research choices**

The main objective of this research is to see how and under what conditions the legislation on treatment directives influences the behavior of the actors involved in the social practice just sketched. The complexity of the social practice and the external constraints to which my research – like all research – has been subject (finances, time, and so forth), meant that a number of strategic choices had to be made concerning the

actors on whom to focus, the questions to address and the kind of information to collect.

*The principal focus of the research: doctors*

I chose first to privilege the patient-doctor relationship, considering patients and their doctors the most important actors involved in the practice. The other actors do not appear in my model as independent actors but only as possible sources of influence on the potential choices of the two main actors.

Following this choice, the problem of finding the most efficient way to collect information had to be faced. Eventually the decision was made to use only doctors as sources of information. This was because the authors of treatment directives are difficult to locate and to approach<sup>4</sup> and patients whose dying process was influenced by a treatment directive are unavailable. Furthermore doctors can supply information both on their own behavior and on that of their patients.

Interviewing doctors is efficient because they can supply information on a large number of patients, and they are involved in many phases of the social practice of treatment directives, including the final responsibility for the decisions concerning their incompetent patients. Last but not the least, it is relatively easy to draw a sample of doctors.<sup>5</sup>

Nonetheless, choosing doctors as the primary research subjects has some disadvantage. First of all, it is difficult to convince doctors to participate in empirical studies. These difficulties generally result in a low response rate.<sup>6</sup> Moreover, it must never be forgotten that information about patients coming from doctors is always filtered and interpreted by the doctor who provides it. One must be very cautious in using such information, especially when it concerns the motivations and attitudes of patients. Finally, although doctors do know something about treatment directives, their actual experience is still fairly limited, and therefore their answers to questions concerning the practice are often based on a small number of concrete cases.

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<sup>4</sup> Moreover, in a situation where the behavior one is interested in is rare in the population, it is very time-consuming and expensive to identify an acceptable number of persons who can supply relevant information and will agree to cooperate.

<sup>5</sup> Details on the construction of the samples will be presented in the chapters concerning each study.

<sup>6</sup> For example, a postal survey among Dutch family doctors on the classification of problematic medical behavior carried out by my colleague Donald van Tol resulted in a 40% response rate (see Van Tol, 2005). Strong institutional support, especially from the Ministry of Health and the Medical Association, brought a higher response rate to the national studies on euthanasia carried out in the Netherlands (see Van der Mass 1991, Van der Wal et al. 1996, Van der Wal 2003). However, this was exceptional, also compared to similar studies carried out in other European countries. See Van der Heide et al. 2003.



Weighing the positive and negatives aspects of using doctors as research subjects, I decided that such a decision was acceptable, given my aims and my resource constraints.

Since doctors are not a homogeneous group, I then faced the problem of deciding which sorts of doctors are likely to have the most experience with patients with treatment directives. Nursing home doctors, who treat both competent and incompetent elderly people, can have experience both with patients potentially interested in drafting a treatment directive and with dying incompetent patients who earlier have drafted a treatment directive. Family doctors also seem to be an interesting group because they deal with a large number of patients, including many elderly people. Of all doctors, family doctors deal with the largest number of deaths in the Netherlands.<sup>7</sup> Choosing these two groups of doctors had the additional advantage of permitting me to study whether differences in institutional framework influence behavior related to treatment directives.

#### *Legal and extralegal consultants: notaries*

Although the focus of my research is on doctors, I exploited opportunities that arose to collect information on aspects of the social practice of treatment directives that fall outside the medical sphere. In particular, it was well known that assistance in drafting treatment directives is one of the services Dutch notaries offer to their clients.<sup>8</sup> However, no empirical research had been carried out concerning the role of such legal advisors in the social practice of treatment directives. When the opportunity presented itself, I therefore decided to include in my research a small empirical study of the involvement of notaries.

#### *The methodology: quantitative survey*

Once the subjects of the research were chosen, two approaches to data collection were considered: a quantitative one and a qualitative one, the first consisting of more or less structured interviews, the latter including either qualitative interviews and/or some form of observation. The decision to opt for one of the two methodologies can be taken on different grounds, varying from objective criteria to the personal preferences of the researcher. Given my background in quantitative methodology and the fact that I am not a native speaker of Dutch, I felt better equipped to carry out a quantitative study. Moreover, no quantitative studies on the subject existed for the Netherlands.<sup>9</sup> Only impressionistic information and ethnographic studies of the use of such

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<sup>7</sup> The acquaintance of family doctors with elderly and dying patients is confirmed by the fact that the majority of cases of euthanasia are performed by family doctors (5200 of 8900 in 1990; 6400 of 9700 in 1995). See Griffiths et al. 1998: 212, Table 5.3.

<sup>8</sup> After this study, the policy toward treatment directives of the Royal Notarial Association (KNB) changed. The KNB now advises its members not to assist clients in drafting treatment directives but instead to refer them to the Voluntary Euthanasia Association (NVVE).

<sup>9</sup> See chapter 4, paragraph 3.1.

documents were available. The quantitative data produced by my research are therefore entirely new and, as such, an original contribution to the public discussion.

As far as methodology is concerned, I decided to carry out the research mostly by means of structured questionnaires<sup>10</sup> administered through CATI (computer assisted telephone interviews).<sup>11</sup> The interviews were carried out by Christa Wiggers, Maartje Bijl (notaries and nursing home doctors) and Francisca de Jong (family doctors), student assistants of the Department of Legal Theory, University of Groningen.

In some cases, I supplemented the information coming from the interviews with a short paper questionnaire, especially when the data to be collected required the interviewed doctors to search for information in their files. Extensive descriptions of the research instruments will be given in the chapter describing the specific empirical studies.

## **5. The research questions**

The two main questions guiding the research are, as we have seen in paragraph 1 of this chapter:

Question 1: Do people follow the rules concerning treatment directives? More generally, do legal rules concerning treatment directives influence the behavior of doctors and patients?

Question 2: Does following the rules have the effects expected by the legislator? More specifically, is the right to autonomy for incompetent patients realized in the Netherlands under the current legislation?

Having determined the main questions to be addressed, it is necessary to specify and articulate them into sub-questions that can be operationalized in form of questions to administer to the research subjects. To this end, it is helpful to refer to the scheme of the social practice of treatment directives, set forth in chapter 3. Table 9 lists all the aspects of the social practice of treatment directives investigated in my empirical research, the respective indicators and the questions actually administered. The specific questions will be discussed in the following paragraphs.

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<sup>10</sup> Structured questionnaire exhibits some of the general limitations. The questions were sometimes oversimplified and the answer categories did not cover the whole spectrum of possibilities. I tried to minimize these negative effects by constructing the questionnaire with the help of experts and carrying out a pilot study with a preliminary version of the questionnaire.

<sup>11</sup> The interviewers carry out the interviews by phone in front of a computer that shows in succession the questions in the questionnaire.

This scheme holds for the studies of nursing home doctors and of family doctors. As far as the notaries are concerned, although many questions are common to the questionnaire administered to doctors, the study focuses on only a small part of the social practice of treatment directives: the drafting phase. I will deal with the specific questions and indicators concerning the notaries in the chapter where I present the results of that study.

**Table 9. The questions included in the questionnaires for nursing home and family doctors (TD = treatment directive)**

Phase of the social practice (concepts)	Research questions	Questions in the questionnaire
Use/frequency	Frequency of TDs among specific populations	How many patients have a TD?
Demand	Specific groups interested in TDs Reason to draft a TD	Are there specific populations particularly interested in TDs? What are the reasons to draft a TD?
Doctors' experience with TDs	Frequency of TDs among current and deceased patients	How many of your current patients / patients who died in the last year have / had a TD?
Information: Legal and practical knowledge about TDs	Sources of information for doctors  Information supplied to patients	Have you consulted any materials on TDs? What materials?  Have you read the law (WGBO)?  Have you exchanged information about TDs with your colleagues?  Do you inform potential users informed about the possibility to draft a TD?
Drafting: assistance to patients	Frequency of doctor assistance in drafting	Have you assisted in drafting TDs?  Have you used a standard form?  In case you consider a patient who want to draft a TD not competent to do that, what do you do?
Drafting: contents of TDs	Condition of applicability Treatments refused Suggestion to include specific provisions	What are the contents of TDs? Are they clearly formulated or vague and in generic terms?  Which provisions are included?
Latency: increasing effectiveness of TDs	Updating and making TD known Use of special devices	Do you suggest updating a TD from time to time and informing other people of its existence?  Do you suggest using special devices to make a TD known?
Implementation	Interpretation of the legal rules and attitudes of doctors	What do you think should be the role of TDs in decision-making for incompetent patients?
Implementation	(Potential) effects on the decision making process	What happens when an incompetent patient has a TD?

## 6. Discussion of the questions

*Frequency: how many people have a treatment directive?*

The fact that legislation recognizes the right to autonomy for incompetent patient does not mean that the right exists in practice. An effective right requires that doctors comply with the advance requests of patients. But compliance by doctors is not enough. A successful implementation of legislation acknowledging the right of autonomy for incompetent persons requires that people who want to keep control over medical decision-making even after they become cognitively impaired, in fact make use of the possibility to draft a treatment directive. Otherwise the right remains ink on paper. It is important therefore to have an idea of the frequency of treatment directives among the patients of the interviewees.

In the interviews, I asked doctors how many of their current patients have a treatment directive and how many of their patients who died in the last year had such document. Although it might seem easy to collect this information from doctors, in practice some confusion still exists between treatment directives and advance requests for euthanasia (*euthanasieverklaringen*). Despite their fundamental differences, the same document often contains both a request for euthanasia and a refusal of treatment, and respondents reflect the confusion prevalent on this matter, often making no clear distinction between the two. Notaries, for example, use '*euthanasieverklaring*' as a label that covers both kinds of documents. Doctors are also not always able to distinguish between the two documents. To minimize these problems, I always introduced the question on the frequency of treatment directives by specifying the definitions being used, and emphasized in a variety of ways that the information I sought concerned treatment directives. However, in the case of notaries this strategy did not work, because the label *euthanasieverklaring* is so embedded in their practice that they get confused if a different term is introduced.

*Demand: who writes a treatment directive and why?*

From the empirical literature on the subject (see chapter 3), we know that treatment directives are not homogeneously distributed over the population. It therefore seemed interesting to collect some information from doctors about the characteristics of users of treatment directives. I asked doctors what groups of people are most commonly interested in treatment directives and what they believe are the most common reasons for drafting a treatment directive.

*Practical experience: how often do doctors encounter treatment directives?*

How a doctor behaves in relation to a treatment directive can be influenced by his experience with such documents. Each such encounter involves a process of learning in the practical situation. A doctor can avoid acquiring or updating his knowledge about treatment directives so long as none of his patients asks for information, or for

assistance and advice in drafting one, or presents him with a directive to be kept on file. When one of these events occurs, the chance that a doctor will acquire relevant legal and practical knowledge is increased. Being involved in the process of implementing a treatment directive will likewise afford an opportunity for practical learning. To estimate the experience of the doctors with treatment directives I used the data concerning the frequency of such documents among patients in their practice.

*Legal and practical knowledge: what do doctors know about treatment directives?*

A rule can influence the behavior of an actor only if the actor is aware of its existence. The amount and quality of information that doctors have about treatment directives is therefore an important variable in assessing the potential effects of such documents in medical practice.

One can differentiate between different sources: written material of different origins (medical or legal publications), lectures on the subject, or direct reading of the law on patient's rights. Colleagues who can supply information and answer questions in a difficult situation represent an additional source. The following questions were asked:

- Have you consulted written material on treatment directives, and of which type?
- Have you attended lectures on the subject?
- Have you read the WGBO?
- Have you exchanged information with your colleagues?

*Legal and practical knowledge: what do patients know about treatment directives?*

A counterpart to the knowledge doctors have about treatment directives is the legal knowledge patients have. If they lack the relevant information, they will miss the chance to exercise their right to autonomy, although they might have wanted to do so. Since I do not have information directly from the patients, I inferred the level of knowledge among patients from information received from the doctors on two questions:

- Does your institution have a standard procedure to inform incoming patients about treatment directives? (this question was addressed to nursing home doctors)
- How often do you supply a patient information concerning treatment directives on your own initiative?

Of course patients can also receive information from other sources, for example the NVVE. However, since we have seen that the relation between doctor and patients is crucial to the practice of treatment directives (Chapter 3), I privileged information received from doctors in estimating the patients' level of knowledge about treatment directives.

### *Counseling on drafting*

When a patient has decided he wants a treatment directive, he will rarely have the necessary medical knowledge to draft effective instructions. It must not be forgotten that a treatment directive implements the right to refuse consent to a specific treatment. Such a right can only be exercised if the patient has enough information about his situation, knows of the possible alternatives to a given treatment, and is aware of the consequences of his refusal. It follows that, in general, the contents of a treatment directive should be discussed with a doctor. Since the clarity of the instructions in the treatment directive is very important, it is easy to appreciate how important the role of the doctor during the drafting phase can be.

Several questions were addressed to this point. Some were directly addressed to the frequency with which doctors help patients write treatment directives. But I also wanted to know what a doctor actually does when asked by his patients for assistance. Does he use a pre-formulated model? Does he suggest including specific provisions (for example the appointment of a representative) in order to increase the potential effectiveness of the document? Does he advise the patient to consult a legal expert?

Another crucial point concerns the way the doctor assesses the patient's competence. The competence of the patient at the time of drafting the document is a requirement explicitly stated in the law. I therefore asked what actions the doctor would take if he doubted a patient's competence.

### *Form and contents of treatment directives: legal and medical quality*

In order to influence the medical decision-making process, a treatment directive must be legally valid and medically sound. I call these two dimensions the legal quality and the medical quality of a treatment directive. I will shortly describe them.

#### *Legal quality*

The legal quality of a treatment directive depends on its compliance with legal requirements and on its coverage of a number of matters known to be necessary if a treatment directive is to be effective in practice. The following elements are important:

- fulfilment of the explicit legal requirements: in the Netherlands, voluntariness and competence of the author, who is required to be 16 or older;
- technical quality: careful distinction between legally different situations (for example between a refusal of treatment and a request for euthanasia), and use of appropriate terminology;
- appointment of a representative to help interpret the document and see to its implementation;
- suitable arrangements for making the document available when relevant;
- up-dating of the document.

Problems of validity can be largely met by using a standard form, for example the one supplied by the NVVE. However, direct involvement of a legal expert can ensure that the document is suited to the author's specific situation and wishes. This aspect of the social practice is of particular relevance in the study concerning the role of notaries. I assume that the reason people seek the involvement of a notary in drafting treatment directives stems from the desire to guarantee the legal quality of the document.

### *Medical quality*

The medical quality of a treatment directive concerns the clarity of the medical instructions it contains. These instructions must be capable of being translated into practical decisions by doctors. A refusal of consent to treatment must do two things. 1) It must specify explicitly the treatments refused: a general refusal of 'life-sustaining treatment' does not make clear which treatments (antibiotics, artificial feeding and hydration, etc.) are included. 2) It must state clear conditions of applicability: for example, in the case of the treatment directive of a person anticipating dementia, if the treatment directive refers to 'no longer recognizing my loved ones' it will not be clear to the doctor whether this refers to all of them, at all times, nor what 'recognition' precisely entails. Vague formulations can and often will be interpreted as a generic preference for less treatment, but they leave the final decision to the doctor. Moreover, there is empirical evidence suggesting that the interpretation of generic instructions is often, in a concrete situation, inconsistent with what the author meant when drafting the document.<sup>12</sup>

We therefore asked how often the treatment directives doctors encounter are expressed in generic terms. To the doctors who had encountered well-specified treatment directives, we asked what treatments and what conditions of applicability are most often mentioned in the documents.

### *Latency: making the treatment directive effective*

In the period between the drafting of a treatment directive and its implementation (named the 'latency phase' in chapter 3), there are things a doctor can do to increase the directive's effectiveness. First of all, he can suggest to a currently competent patient with a treatment directive that it is a good idea to update the document from time to time. This is because one of the main arguments that can be used for not complying with the requests stated in a treatment directive is that they do not represent the current wishes of the patient (see chapter 1), and this argument has more strength if a treatment directive was written a long time before the patient became incompetent. Regularly updating a treatment directive reduces the possibility that, at the time of implementation, there can be an appeal to 'well-founded reasons' (see chapter 4 on the

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<sup>12</sup> Schneiderman et al. 1992 and Schneiderman et al. 1993.

Dutch legal situation) for departing from the instructions contained in the treatment directive.

Another obvious but important thing that requires attention in order to make a treatment directive effective is its presence at the time of decision-making. If at that time the treating doctor is the one who helped the patient to draft the document, there will be no problem. But if the patient has, for example, been transferred to an institution (nursing home or hospital), it is important that the new treating doctors are informed of the existence of the treatment directive. It is therefore important that admitting institutions are informed. Does the treating doctor personally inform the admitting institution? In what way? And is the procedure institutionalized? To increase the chance that a treatment directive will be known to those involved in treatment decision, and to reduce the risk of surprises and hence of conflict, it is also important that the patient's family is informed of the existence and contents of the treatment directive, but is this usually the case? And do patients usually appoint a representative?

A special case, in which there is a high risk of failing to spot the existence of a treatment directive, is an emergency situation. The treating doctor can reduce the risk that a treatment directive will be overlooked in this situation by suggesting to the patient to use specific devices such as bracelet or cards to call attention to the existence of a treatment directive. I asked the doctors whether they suggest to patients with a treatment directive to update it, to inform other people of its existence, and to carry special devices in order to make sure that the existence of the document will be known in an emergency case.

*Implementation: interpretation of the legislation on treatment directives*

Not only knowledge of the legal rules but also the actor's interpretation of them can have an effect on his behavior (see Griffiths 2003). In the questionnaire, I therefore asked the doctors to express their opinion on the role of treatment directives in the medical decision making process. By means of these questions, I checked whether their interpretation of the legal rules is consistent with the aims of the legislator. Moreover, these questions also offer an indicator of the attitudes of doctors concerning the implementation of treatment directives.

*Implementation: what happens when an incompetent patient has a treatment directive?*

The actual effectiveness of a treatment directive can only be checked at the time of implementation. Does the presence of a treatment directive make a difference in the decision-making process? Unfortunately, this is also the most difficult dimension to investigate in a general quantitative survey with closed questions. One reason is that it is difficult to define what exactly the effectiveness of a treatment directive refers to. In my opinion the effectiveness of a treatment directive refers to the *capacity* of the document to influence the health-care decisions concerning the author once he has



become incompetent, and not to its *actual effect* on the medical decisions. It can happen, for example, that a qualitatively good treatment directive has no actual effect, either because the conditions of applicability are not fulfilled or because the decision the doctor would have taken anyway is the same as the instructions given in the treatment directive. In both cases, the result of the decision-making process will not be different from the one to be expected if the treatment directive had not been present. Nevertheless, it seems that there is no reason to consider the treatment directive ineffective since it would have influenced the decision-making had the conditions mentioned been fulfilled or had the instructions differed from what the doctor would have done. But ‘capacity to influence’ is obviously difficult to study quantitatively.

Another reason that makes it difficult to assess the effectiveness of treatment directives in general is that doctors believe that each case is specific and that it is impossible to generalize about the effectiveness of such documents. However, it is possible to formulate a hypothetical situation and to ask whether the doctor would act differently if a treatment directive were in place. Moreover, I asked doctors to assess the influence of some characteristics of a treatment directive on the chances that they would follow the instructions given (clear formulation, up-to-dateness, provision for an appointed representative, involvement of a doctor in the drafting). Additionally, to assess the importance of specific conditions that can vary from case to case (for example: acquaintance of the doctor with the patient; terminal phase of the patient’s disease; doctor, family and representative agree with the instructions), I asked doctors to estimate their influence on the implementation of a treatment directive.

A final question, designed as an indicator of the doctors’ recognition of the right of a patient to refuse treatment even if he has become incompetent, concerns the grounds on which decisions for an incompetent patient should be based. The doctors were asked to choose among the three options found in the literature: a) the instructions expressed in a treatment directive; b) general assessment of the medical situation by the treating doctor; c) the preferences of the family.<sup>13,14</sup>

## **7. Organization of the empirical part**

The following chapters present the empirical data I gathered to study the social practice of treatment directives in the Netherlands. Chapter 6 covers the practice of notaries, while chapters 7 and 8 present the results of the studies of nursing home and family doctors. Finally in chapter 9, using all the information collected, I will assess

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<sup>13</sup> Classification of the grounds for medical decision-making from The et al. 2002.

<sup>14</sup> Questions concerning the characteristics of treatment directives, the relevance of specific conditions on actual implementation, and the grounds for medical decision-making were included only in the questionnaire for family doctors.

the overall practice of treatment directives in the decision-making process for incompetent patients, considering both whether the legislation has influenced the behavior of the actors involved and whether the objective of the legislator - to realize autonomy for non-competent patients - has been accomplished.