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THE LEGAL STATUS AND SOCIAL PRACTICE OF TREATMENT DIRECTIVES IN THE NETHERLANDS

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CHAPTER I

AUTONOMY FOR INCOMPETENT PATIENTS AND ADVANCE DIRECTIVES

1. Introduction

This book deals with the legal status and the social practice of treatment directives:[1] written documents in which the author gives instructions to health-care providers while he or she is still competent, to be implemented by them in the event he or she becomes incompetent.

Treatment directives must be understood against the background of growing acceptance of the doctrine of informed consent. Once informed consent was recognized as fundamental to the relationship between doctors and patients, the problem had to be faced of persons not capable of expressing consent at the time decision-making concerning treatment takes place. Awareness of the problem was stimulated both by reflection on the implications of recognition of the principle of autonomy of the patient and by the increasing number of cases in which medical technology enables doctors to keep non-competent patients alive indefinitely. These developments have called increasing attention to the following question: Is it possible to extend the principle of autonomy, specifically the right to give or refuse consent, to incompetent patients? Treatment directives represent a potential answer to this question.

[1] For the definiton of 'treatment directive', usually referrred to as 'living will' in North American literature, see the next paragraph.

The problem of respect for the autonomy of incompetent patients can be approached from several perspectives. I indicate here three that appear to be particularly relevant:

- an *ethical perspective*: is there a moral foundation to the claim that incompetent patients retain some autonomy?
- a *legal perspective*: do legal systems recognize a right to autonomy for incompetent patients and, if so, what tools do they offer to effectuate this right?
- a *sociological perspective*: supposing that legal tools exist to effectuate autonomy when a person becomes incompetent, how do they work in practice?

The legal and sociological perspectives will be the central focus of this book. As far as the ethical perspective is concerned, I briefly present in the last section of this chapter the arguments for and against treatment directives generally given in the bioethical discussion.

My research will adopt a comparative approach in considering the legal aspects of patient autonomy and treatment directives and in presenting the results of empirical studies carried out by others. My own empirical research focuses on the Netherlands.

Although treatment directives have been legally recognized in the Netherlands since 1995 and despite considerable interest in the subject,[2] information concerning the actual use and working of these documents is unavailable. No systematic research has dealt specifically with such questions. An evaluation of the Dutch law on patients' rights did not deal with this part of the legislation.[3] As a result, very little is known about the practical effects of the legislative recognition of treatment directives.

2. Definitions

Over the years a number of terms have been used in the discussion of treatment directives. The idea of such a document was introduced by Luis Kutner, a human rights lawyer and activist, in an article that appeared in 1969.[4] Although rejecting the legalization of 'euthanasia', Kutner addressed the situation where a patient cannot express his will concerning medical treatment.[5] The author's proposal was to extend the right to refuse treatment to incompetent patients by means of a document he called a "living will". He described the document in the following way:

[2] Legemaate 1995; Dillmann and Kastelein 1994; Dillman 1995; Dilmann et al. 1997.
[3] Dute et al. 2000.
[4] Kutner 1969.
[5] Under the then current legislation (1969), a constructive consent was always presumed when a patient was not able of giving consent.

> *[…] the individual, while fully in control of his faculties and his ability to express himself, indicates to what extent he would consent to treatment. The document indicating such consent may be referred to as "a living will" […].*[6]

Such a document was also referred to by Kutner as a "declaration determining the termination of life", a "testament permitting death", a "declaration of bodily autonomy", a "declaration for ending treatment", and a "body trust". None of these expressions was particularly successful and, eventually, the term "living will" became the common way to refer to these documents, at least in the US. The term refers only to written instructions concerning the consent to or refusal of a specific treatment.

Other kinds of instructions can be contained in a document written in advance concerning health-care decisions. In particular the author can appoint a health-care agent, who will decide on behalf of the principal should he become incompetent and authoritatively interpret any specific instructions contained in the document. In some countries, such as the United States, the appointed health-care representative is referred to as having been given a 'durable power of attorney'. The document that provides for such an appointment is therefore generally called a 'durable power of attorney' or 'medical power of attorney', but it may also simply be referred as 'advance appointment of a representative' or, simply, 'proxy directive.'

In the North American bioethical, medical and legal debate another label grew in popularity, one that covers documents containing a living will, a durable power of attorney, or both: *advance directive*. This label (or some variation of it, as "advance care directive") is at the moment commonly used, and this is reflected in the choices made by the most influential scholars dealing with the subject. For example, Capron gives the following definition:

> *An advance directive is a statement made in advance of an illness about the type and extent of treatment one would want, on the assumption that one may be incapable of participating in decision-making about treatment when the need arises. […] It may name a person to make decisions on one's behalf, give instructions on what treatments should or should not be provided or do both.*[7]

The success of the label is also confirmed by its use in more popular sources such as Internet medical encyclopedias. An example follows:

> *"Advance Directives" […] pertain to treatment preferences and the designation of a surrogate decision-maker in the event that a person should become unable to make medical decisions on her or his own behalf.*[8]

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[6] Kutner 1969: 551.
[7] Capron 1999: 261.
[8] Source: www.medicinenet.com, visited on 10/11/2004.

In the Netherlands the terminological situation is complicated by the fact that advance requests for euthanasia are also provided for in law. The general word that more or less corresponds to 'advance directive' is *schriftelijke wilsverklaring* (literally: written statement of will). The term that specifically indicates a request for euthanasia is *euthanasieverklaring* (literally: euthanasia statement). However, it is not rare that requests for euthanasia are understood to be included in the general concept of *schriftelijke wilsverklaring*, and, viceversa, that the term *euthanasieverklaring* is meant to include refusals of treatment and/or the appointment of a representative.

The best terminological distinctions in the Netherlands can be found in the standard forms supplied by the NVVE, the Dutch Association for Voluntary Euthanasia. Each form contains three parts:

- a *behandelverbod* (prohibition of treatment), that is, a refusal of treatment;
- a *volmacht* (mandate), that is, the appointment of a representative;
- an *euthanasieverklaring*, that is, an advance request for euthanasia.

However, such precise terminology has not become widespread and it is common to encounter confusion when talking about written medical directives. For example, notaries, one of the professionals who may assist people in drafting treatment directives (as we will see in chapter 6) call all three sorts of documents simply *euthanasieverklaringen*, not distinguishing among their contents. And if a doctor is asked how many of his patients have an advance directive (*schriftelijke wilsverklaring*), he usually includes in his answer requests for euthanasia.

This terminological confusion was a constant problem during the empirical parts my research. It is therefore important to clarify the terms I will use in this book.

Advance treatment directive (shortly referred as 'treatment directive') refers to a document in which the author specifies the treatment he does or does not want under specified conditions. A treatment directive can be addressed directly to the responsible doctor, or indirectly via an appointed representative, or both. It corresponds to the expression 'living will' especially popular in North America.

A treatment directive can be either positive or negative. An example of a negative directive is the refusal of mechanical breathing support under specified conditions, such as a persistent vegetative state. In a positive directive the author requests specific life-prolonging treatment (such as resuscitation). However, if a given treatment is not medically indicated, it is doubtful that even a patient who is competent at the time could force a doctor's hand by insisting on it, and this applies a fortiori to a request made in advance. The legal significance of positive directives is therefore limited. The

major importance of negative treatment directives derives from the fact that in an increasing number of cases medical technology enables doctors to keep patients who are no longer competent alive, imposing on them life-sustaining treatment they would not have wanted and that can add to their suffering and that of their families.

A **proxy directive** is a document in which the author – either as an alternative to or in combination with a treatment directive – empowers another person to express the author's wishes concerning treatment on his behalf. The mandate can be unconditional, or dependant on specific wishes or values stated by the author.

Advance care directive (shortly referred as 'advance directive') is the term I use as an umbrella-concept to indicate a document written by a competent person (author) containing instructions concerning health-care to be applied in case the author should become incompetent. The term 'advance care directive' is therefore general and does not specify if the document contains a treatment directive, an appointment, or both.

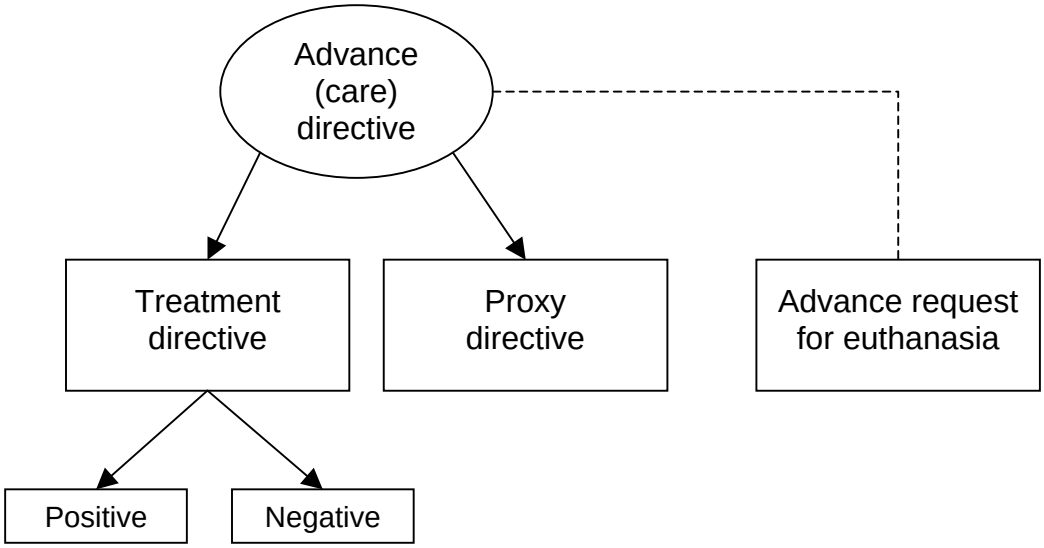
A final label must be introduced specifically for the Netherlands: **written advance request for euthanasia** (also referred with the Dutch term *euthanasieverklaring*). This is a document containing a request for the responsible doctor to perform euthanasia, should the author of the document become incompetent.[9] The term 'advance' in the label is important to avoid confusion with another kind of document, namely the written request of a competent patient to document his or her firm and persistent request for euthanasia.

This book deals with treatment directives, in particular negative treatment directives. However, as always noted, in field research it is often difficult to disentangle the different sorts of advance instructions. Therefore, especially when engaged in international comparison and analysis of the social practice in which these documents play a key role (based on the existing empirical literature), I will sometimes use the general label 'advance directive'. In the empirical part concerning the Netherlands, where I present the results of my own surveys, sometimes some flexibility in the use of terms was necessary. Behavior connected with the social practice of treatment directives is not always actually separable from other forms of medical instructions given in advance. At the beginning of each empirical chapter, I will make explicit the terminological problems I encountered and the solution I adopted in order to minimize

[9] The only countries which explicitly give legal status to advance written requests for euthanasia are the Netherlands and Belgium (respectively available on www.nvve.nl/assets/nvve/info/euthanasiewet.pdf, and www.gbs-vbs.org/wetgeving/2002009590.asp, accessed on 2.6.2005). Several commentators on these laws have held that euthanasia for incompetent patients on the basis of an advance written request would nevertheless be unlawful, failing to fulfill the other requirements stated in the legislation legalizing euthanasia. See van Delden 2003; Wind et al. 2002.

ambiguity. The following figure summarizes the relationship among the various labels I will use.

Figure 1. Conceptual scheme of the labels used in the book



3. The ethical perspective: Autonomy for incompetent patients

If it is the autonomy of a competent patient on which the right to give or withhold informed consent rests, one might suppose that the same principle could be applied in the case of consent or non-consent expressed in advance. In fact, advance consent is regularly asked of patients about to undergo an operation, regarding decisions the doctor may have to make while the patient is anaesthetized. At first glance, there would seem no reason why the same principle would not apply to expressions of consent – or withholding of consent – concerning possible future treatment, should the patient be non-competent at the time. Advance directives[10] are in effect an extension of the principle of respect of autonomy of incompetent patients, permitting people prospectively to express their autonomous choices about medical treatment.

Support for the ethical and practical value of advance directives can be found in the book of Norman Cantor, *Advance Directives and the Pursuit of Death with Dignity* (1993). Cantor argues that autonomy can be seen as a fundamental aspect of personal liberty, both under common and constitutional law (he refers to the American

[10] In this paragraph, I generally use the lable 'advance directive', since it is common in the ethical literature.

situation), and the same applies to prospective autonomy, that is the exercise of autonomy by a competent person for a future situation of incompetence.[11] Cantor recognizes that there are practical difficulties connected with the prospective exercise of autonomy by means of advance directives, but he argues that these difficulties should not stand in the way of acceptance of the instrument.

Beauchamp and Childress, in their influential book on biomedical ethics, take generally the same position. Although they recognize that autonomy is not an absolute value which should determine all medical decisions, they do accept the argument that it should include prospective autonomy, stating that:

> *[…] we respect the previously expressed autonomous wishes of the now severely demented incompetent person because of our respect for the autonomy of the person who made the decision, as well as our own interest in securing control over our lives prior to becoming incompetent. Interventions against autonomous advance directives infringe the principle of respect for autonomy […]. (page 132)*

Nonetheless, several authors take a more critical position. Two main groups of criticisms can be distinguished: the first concerns practical problems that make the implementation of advance directives difficult, and the second concerns the nature of prospective autonomy. Both criticisms are connected with the temporal span between the drafting and the implementation of a directive.

The first group of criticisms are synthesized by Cantor as problems connected with the complexity of medical decisions in a broad range of possible future situations, and problems due to the "distance of the competent person looking toward future events."[12] In both cases, the author concludes that these difficulties can be overcome and argues that:

> *while a comprehensive directive anticipating all possible situations might not be possible (given the limits of human imagination), every competent person is capable of addressing a few precepts or guidelines regarding future medical care. […] The difficulties of remoteness and perspective in making future-oriented death-and-dying decisions ought not to preclude giving binding effect to advance medical directives.*[13]

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[11] As Cantor notes, prospective autonomy has found legal recognition in case of post-mortem dispositions (for example organ donation or use of the body for research purposes). Also in the case of refusal of treatment on the basis of religious beliefs (for example, Jehovah's Witnesses refusing blood transfusions), the prospective autonomous decision of the currently incompetent patient is unambiguously accepted. The same can be said, as already noted in the text, of the everyday situations in routine medical practice where the problems that prospective autonomy can give rise to are latent but in practice no objection is made.

[12] Cantor 1993: 25-26.

[13] *Idem*: pp.25-27.

Cantor concludes, in short, that practical concerns, although important, do not undermine the idea of prospective autonomy. There are no fundamental reasons to think that stating one's preferences and wishes in advance concerning health-care is any less possible than accepted practices of giving similar prospective instructions in many other fields of life.

The second group of criticisms appears to be more fundamental. It addresses the philosophical question of personal identity and continuity of the self. Some authors argue that the incompetent person (in particular, a demented patient) is so different from the person who was once competent that it is possible to talk of different selves.[14] It is therefore not ethically acceptable to base medical decisions for non-competent patients (especially decisions that potentially shorten their life) on previously stated wishes and preferences. Care-givers and families should decide on the basis of the present best interests of the incompetent patient. One of the most influential supporters of this position, Rebecca Dresser, considering also the practical problems mentioned before, concludes:

> *these shortcomings of advance decision-making are reasons to assign less moral authority to precedent autonomy than to contemporaneous autonomy.*[15]

An elegant rejection of this argument is given by Ronald Dworkin, who underlines the importance of the *integrity of a person's life as a whole*, a value that overrides the current welfare of the non-competent person as assessed by others. In his words, the best argument on which to found the right to autonomy of incompetent persons

> *emphasizes the integrity rather than the welfare of the choosing agent; the value of autonomy on this view, derives from the capacity it protects: the capacity to express one's own character – values, commitments, convictions, and critical as well as experiential interests – in the life one leads.*[16]

For Dworkin, therefore, promotion of the current welfare of the person is not a sufficient reason to frustrate the wishes and priorities he stated when competent. Respect for autonomy entails respect for a person's choices concerning the character of his life as a whole, and how he chooses to be remembered is a crucial aspect of autonomy, supporting "a genuine doctrine of precedent autonomy".

Summing up, although there are certainly problems concerning the practical implementation of advance directives, there is enough philosophical ground to accept respect for prospective autonomy as a legitimate principle on which to base decision-making for incompetent patients. I will assume this position in my study and I will not

[14] Especially Dresser and Robertson 1989. Based on the philosophical premises of Parfit 1984.
[15] Dresser 1995.
[16] Dworkin 1993: 224.

go further into this discussion. I am aware of the complexity of the arguments and of the interconnection between practical and substantial criticisms concerning advance directives, but the purpose of this book is not to take part in this debate. For my purposes, the ethical debate has been definitively settled in the form of legal decisions (cases and statutes) recognizing the legal force of treatment directives. In the coming chapters I will focus on the legal answers that the problem of autonomy for incompetent patients has received and on the consequences that these choices have had on the actual practices connected with the decision-making process of the medical shop-floor.

CHAPTER II

THE LEGAL STATUS OF TREATMENT DIRECTIVES: AN INTERNATIONAL SURVEY

In this chapter I present the results of a survey of the legal status of treatment directives in 17 countries, including more than 90 jurisdictions. Almost all western countries where some legal development concerning treatment directives has taken place were included in the survey; a few countries where the situation is still rather underdeveloped were included for purposes of contrast with the rest. For the countries considered I identify common patterns, which allow clustering them in different groups as far as the legal status of treatment directives is concerned. I start the discussion with an analysis of the doctrine of informed consent and its legal recognition in the countries considered, since the acceptance of the principle of informed consent is a prerequisite to legal recognition of treatment directives.

1. Respect for autonomy and informed consent in the medical sphere

The principle of (respect for) autonomy is considered one of the foundational principles of western societies.[1] The situations in which the principle is considered relevant are various, from economic transactions to sexual relations. For example, under Dutch criminal law, the presence of an autonomous authorization of a potential victim to acts in areas such as sexual activities (including those involving violence) and euthanasia, makes these acts not criminal offences.[2]

[1] Beauchamp and Childress 1999: 120-132.
[2] Kelk 2001.

A direct translation of this principle in the area of health-care is the doctrine of informed consent. Generally, informed consent is seen as an absolute pre-condition of medical treatment: no treatment can be performed without the consent of the patient. In other words, doctors have no inherent prerogative to treat just because in their medical judgment treatment is indicated. Put negatively: a competent patient is entitled, for whatever reasons are important to him, to refuse any medical treatment, including treatment necessary to continued life.[3] The fact that withholding consent may shorten a patient's life is not usually considered a sufficient ground for qualifying the right.[4]

The first formulation of the doctrine of informed consent appeared already at the beginning of the twentieth century,[5] and was formulated in terms in which we now understand it in the 1950s in several decisions of US courts.[6] The cultural background of this development was the individualistic bias of American society, in the framework of an abiding suspicion of state power and changes in the relation between doctors and patients.[7] The doctrine quickly received international attention and in a relatively brief period achieved widespread acceptance. Nowadays, the informed consent of the patient is widely regarded as, under normal circumstances, a precondition of any medical treatment and the doctrine is accepted almost everywhere in western countries. Despite this widespread acceptance, the doctrine of informed consent has different consequences depending on the precise way it is understood. For example, the requirements of disclosure of medical information, which is one of the key elements of informed consent as we will see later, can be associated with different standards that reflect substantially different interpretation of the principle. Another point of variability concerns the weight autonomy and informed consent should have in medical decision-making, as against other principles such as beneficence and nonmaleficence.[8]

Because of different views on such matters, it is difficult to find a broadly accepted definition of informed consent. Here, I follow the position expressed in the influential book on informed consent by Faden and Beauchamp.[9] These authors acknowledge a certain level of ambiguity about the concept of informed consent. Therefore, instead of proposing a unique definition, they make a distinction between two common but very

[3] See for example Meisel 1998.
[4] See Cantor 1993: 1, note 2.
[5] Cardozo, J., in Schloendorff v. New York Hospital, 211 N.Y. 127, 129, 105 N.E. 92, 93 (1914), reported in Katz 1972.
[6] See Faden and Beauchamp 1986: 235-273.
[7] For US cultural background of informed consent, see Schuck 2000: 899-959, especially pages 900-901.
[8] Beauchamp and Childress 1999: 128, 146-150.
[9] Faden and Beauchamp 1986: 276 and following.

different conceptions of informed consent: the first, that I will label *ideal* consent, is rooted in moral theory and focuses on the idea of *autonomous* authorization; the second, labeled *effective* consent, reflects a policy-oriented perspective and deals with the cultural and policy rules that together define the requirements for effective consent.

Ideal informed consent is defined as follow: "An informed consent is an autonomous action by […] a patient that authorizes a professional […] to initiate a medical plan for the patient."[10] A necessary condition of the validity of the patient's consent is proper disclosure, which entails that the patient must be properly informed about his situation, the treatment alternatives, the possible outcomes, and the effects of proposed treatment. Consent is autonomous, if the patient:

(1) substantially understands the disclosed information;
(2) is in a situation of substantial absence of control by others;
(3) acts voluntarily.[11]

If these conditions are fulfilled, but the patient withholds authorization, we can speak of *informed refusal*.

Effective informed consent refers to "a legally or institutionally *effective* authorization by a patient." The rules that govern legally-effective exercises of the right to grant or withhold consent focus "on regulating the behavior of the *consent-seeker* and on establishing *procedures and rules* for the context of consent".[12] Ideally, the requirements for *effective* consent should result in an autonomous authorization as defined in the *ideal* definition. But this is in practice not always straightforward, especially because several elements of the *ideal* definition remain abstract and contested, and it is difficult to translate them unambiguously into concrete requirements.[13]

The following paragraph analyses the situation concerning informed consent in several countries from the point of view of the *effective* definition: it identifies the main legal and/or institutional requirements to which informed consent is subjected.

[10] *Idem*: 278.
[11] *Idem*: 278.
[12] *Idem*: 280.
[13] As Schermer notes, the differences between the two conceptions makes the presentation of Faden and Beauchamp problematic: they acknowledge the distinction between the two conceptions of informed consent, but focus mostly on the moral requirements derived from the *ideal* definition without specifically discussing the practical requirements required to implement it. Schermer 2001: 47.

2. Informed consent in several countries

Some requirements concerning informed consent are common to all the countries surveyed (if we exclude Japan, where the principle is not recognized at all). In all countries, the doctrine of informed consent is qualified by the condition that the patient who expresses it must be competent and not subject by law to restrictive measures (e.g. mentally ill persons under guardianship). A minor who is competent at the time he gives or withholds consent is generally regarded as falling within the scope of the right. The most frequent solution is to identify a specific age (the lowest is 12, in the Netherlands) above which a minor patient is considered competent to express a legally binding consent or refusal.

Another important qualification of the principle concerns situations of emergency. In all the countries surveyed, if a person is in a condition threatening his life and temporarily incompetent to express consent, and no representative is available as a surrogate decision-maker, a doctor is expected to make treatment decisions in the person's best interests. This exception does not apply if the doctor knows of the patient's rejection of a particular form of treatment. The typical case of such knowledge is objection to blood transfusions for religious reasons.

Leaving aside these generally accepted qualifications, we can distinguish three groups of countries as far as implementation in law of the requirement of informed consent is concerned:

- a first group, consisting of the Anglo-American countries (USA, England, Canada, Australia, New Zealand) together with the Netherlands, Belgium, and Denmark, exhibit a relatively unqualified commitment to the requirement;
- a second group, including the other European countries (Germany, Switzerland, Austria, France, Norway, Sweden, Italy, Spain, France), accept the requirement in principle;
- a third group, of which Japan is the only example in our survey, rejects the requirement of informed consent.

In countries of the first group, the requirement of informed consent is explicitly recognized at common law and/or by statute. In the common-law countries, many judicial decisions affirm the almost absolute character of the requirement and its priority over the principle of the sanctity of life. The patient's granting or withholding of consent does not have to be grounded in rational considerations and no reasons have to be given to justify a particular choice. The right to refuse treatment is explicitly accepted even when death is the likely effect of the decision, including the situation in which this is the patient's reason for refusing consent. A doctor who performs treatment without consent is potentially liable both criminally and civilly. The three continental European countries included in this group (the Netherlands, Belgium, and

Denmark) have enacted specific statutes on patient's rights. These statutes exhibit a strong commitment to the autonomy of the patient, comparable to that seen in common-law countries. In the Netherlands and Belgium, for example, consent must in principle always be secured and a patient is presumed to be competent.

The countries belonging to the second group do recognize the requirement of informed consent, usually through official statements of national medical associations or in codes of medical ethics. In principle this recognition is more or less unqualified, but the legal status of the recognition is not entirely clear and in practice a more paternalistic approach seems to be widely accepted. The possibilities of legal enforcement are unclear.

Japan alone represents the legal situation where the requirement of informed consent is not officially recognised and medical practice is still rooted in a paternalist approach. Information concerning his condition is said rarely to be supplied to a dying patient and decisions are taken by doctors and the family in the supposed best interests of the patient.

This brief classification suggests how varied is the translation of the doctrine of informed consent into specific legal rules. Especially the difference between the first and second groups is of interest. The countries belonging to both groups subscribe to the doctrine of informed consent in some official way. However in the countries of the first group, the legal recognition of the doctrine at the level of common law or statute includes the possibility of enforcing it, at least in civil proceedings. In the countries of the second group, the possibility of enforcement is much more dubious. Despite a rather general adherence to the idea of informed consent, implementation in specific legal rules is problematic. For this reason it is often possible to speak of a 'rhetoric of informed consent', whereby the doctrine is strongly asserted in abstract declarations, while its legal status is unclear and compliance by the medical profession uncertain. My hypothesis is that this situation has an influence on the legal recognition of treatment directives in the sense that in jurisdictions where the legal status of informed consent is strong, we can expect the chance to be greater that there will be provision for the exercise of prospective autonomy.[14]

[14] Nys 1997 comes to the same conclusion. From a bioethical perspective, applying the logic of Faden and Beauchamp to the case of treatment directives, it should be considered wrong, in jurisdictions that fully accept the requirement of informed consent, to deny a person the fundamental right to refuse treatment just because he is not capable of exercising the right at the critical time (Faden and Beauchamp 1986: 285). From their position, it follows that the situation of a set of rules requiring doctors to honor treatment directives is morally preferable to one in which such documents are not recognized.

3. Autonomy for incompetent patients: the legal status of treatment directives

The legal recognition of treatment directives is a practical answer to the question whether incompetent people can retain some autonomy in the medical sphere, despite their being currently unable to give informed consent. Since the 1970s, treatment directives have become accepted in many countries as a way in which a person who anticipates incapacity can prospectively exercise his right to informed consent. But because the legal recognition of the underlying doctrine of informed consent is a relatively recent matter in all countries, some still interpret the principle of informed consent in a restrictive or qualified way, as applicable – at least in full force – only to a competent patient with respect to a current situation.

An additional distinction concerning the legal status of treatment directives can be made on the basis of the nature of the legal rules dealing with them. The law recognising treatment directives can *require* a doctor to follow a valid one ('must' rules) or it can *allow* him to do so ('may' rules). In the latter case legal recognition protects a doctor against possible civil or penal sanction when the death of the patient is the result of following an advance directive.

Moreover, in the legal and medical literature, the possibility to appoint a representative in advance is seen as a reinforcement of the prospective autonomy of an individual, since a person selected by the author can warrant a more accurate and reliable implementation of the instructions contained in the document. Therefore, the existence of a legal provision allowing the appointment of a representative for health-care (proxy directives) will be considered as a strengthening of the legal status of treatment directives.

In the following paragraphs, we give an overview of the legal status of treatment directives in the countries surveyed. For each country considered, the legal status of treatment directives is assessed on the basis of the following elements:

- the existence of specific legislation or common-law rules recognizing treatment directives;
- the binding nature of the rules ('must' rather that 'may');
- the absence of substantial limitations on the right to give instructions in advance;
- the absence of substantial formal requirements;
- the possibility of appointing a representative for health-care decision-making.

The details for each country based on these elements are available from the author. Here I present a comprehensive table that summarizes the main results. To simplify the

discussion, I have divided the countries surveyed into three groups, depending on the strength of the legal status of treatment directives. The composition of the three groups is similar to that of the three groups identified above in connection with the recognition of the requirement of informed consent, but some adjustments are needed, as shown on Table 1 and Table 2.

Group 1 contains the Anglo-American countries (USA, England and Wales, Canada, Australia, New Zealand)[15] plus the Netherlands, Denmark, Spain, and Belgium. The countries in this group are characterised by a strong legal status of treatment directives, which are recognised by statute and/or at common law.

Group 2 includes the German-speaking countries (Germany, Austria, Switzerland), Norway and Sweden. In these countries some official steps (mainly by the national medical associations) have been taken in the direction of the recognition of treatment directives and debate on the subject is currently active. But the legal status of treatment directives remains uncertain and there is no clear indication that legislation will be enacted soon.

Group 3 includes France, Italy and Japan. These countries do not (explicitly) recognize the legal validity of treatment directives and public discussion of the subject is characterised by a high degree of vagueness.

[15] For USA, Canada and Australia it is not always possible to give a uniform picture of the situation due to the differences between various jurisdictions (states, provinces or territories). Where important for the discussion, these differences will be mentioned.

Table 1. Summary of the legal status of treatment directives (TD) across countries where the legal status is strong

	USA (a)	Canada (b)	Australia (b)	New Zealand	England and Wales	Netherlands	Belgium	Spain	Denmark
Acceptance of Informed consent	Strong	Strong	Strong	Strong	Strong	Strong	Strong	Dubious	Strong
Legal status of treatment directives	Strong	Strong (variable)	Strong	Strong	Strong	Strong	Strong	Strong	Strong
Coverage of legal regulation	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives	TD and Proxy directives
Source of legal status	Statute + common law + constitutional	Statute	Statute + common law	Statute	Common law + statute (d)	Statute	Statute	Statute	Statute
Limitations	Extensive but doubtful	Medium (variable)	Extensive	None	Medium	Mild	Mild	Medium	Mild
Competent author	X	X	X		X	X	X		x
Age	Majority	Usually majority	Majority		Majorty	Always over 16 12-16 if competent	Always over 16 12-16 if competent	Majority	Majority
Specific treatment excluded	Artificial feeding and hydration (c)		Palliative care		Basic care				
Condition of applicability	Terminal phase (?)		Terminal phase or current condition					Terminal illness	Terminal illness
Pregnancy	X		X		X				
Formal requirements	Extensive	Medium (variable)	Medium	Minimal	Medium	Minimal	Minimal	Minimal	Mild
Legal force accorded to treatment directives (kind of rules)	Must	Must	Must	Must	Must	Must	Must	Must	Must

(a) In USA the situation varies among the states. Table 1 gives the most common situation. Despite the variability, the federal constitutional rights of the patient afford a fairly homogenous framework in all states.
(b) In Canada and Australia the situation differs slightly between the various jurisdictions. Table 1 therefore gives only a rough picture of the situation.
(c) Only in few States, and the status of such limitation is unclear.
(d) In England the legal binding force of treatment directives has recently been recognized by statute. See following note 1, page 30.

Table 2. Summary of the legal status of treatment directives (TD) across countries where the legal status is weak or none

	Germany	Switzerland	Austria	Norway	Sweden	France	Italy	Japan
Acceptance of Informed consent	Dubious	Dubious	Dubious	Dubious	Dubious	Dubious	Dubious	Absent
Legal status of treatment directives	Weak	Weak	Weak	Weak	Weak	None	None	None
Coverage of legal regulation	Proxy directives	Proxy directives (analogy)	None	None	Proxy directives	None	None	None
Source of legal status	Medical association	Medical association	Legal literature	Legal literature	Governmental papers	None	None	None
Limitations	Not well-defined	Mild	Not defined	Not defined	Not defined	Not defined	Not defined	Not defined
Competent author	X	X						
Age		Competent minors >=14						
Binding request for treatment explicitly not included	X	X						
Specific treatment excluded		No						
Condition of applicability	Terminal illness or PVS							
Pregnancy								
Formal requirements	Minimal	Minimal	Minimal	Minimal	None	None	None	None
Legal force accorded to treatment directives (kind of rules)	May	May	May	May	May	None	None	None

Group 1: Strong legal status

In the countries belonging to this group, the legal rules designed to protect the autonomy of the patient should he become incompetent are binding on doctors: the refusal of treatment in a valid treatment directive must be respected. The following description is based on the information reported on Table 1.

The Anglo-American countries, members of a single common-law family, are easily located in this group. In most of these countries statutes also deal with treatment directives, but the common law gives a sufficient basis and may even supersede statutory limitations. In England, where the legal status of treatment directives is rather strong, until 2004 there was no statute dealing with them and the Government stated that it did not regard such a statute as desirable since the regulation at common law was considered to be sufficiently clear and had the advantage of flexibility.[1] Nonetheless, a bill providing for negative treatment directives was passed in June 2004. The act does not fundamentally change the legal status of treatment directives, although the source of legitimation became more secure.[2] In some provinces of Australia and Canada and in a few states of the United States, the situation is comparable to the previous situation in England, that is, there is no statutory recognition of treatment directives. Where statutes impose conditions, limitations or formal requirements, the courts often regard treatment directives not fulfilling these constraints as nevertheless binding at common law.[3]

As far as continental Europe is concerned, treatment directives have a particularly strong legal status in the Netherlands, Belgium, Denmark and Spain. Except for Spain, my hypothesis that there is an increasing chance of a strong legal status for treatment directives, given a strong commitment to the principle of autonomy of the patient, is confirmed. As far as Spain is concerned, the process of legal recognition presents some peculiarities. Before the enactment of a national statute, treatment directives were legally recognised at a regional level, the regional parliaments of Catalonia, Extremadura and Galicia having enacted laws that explicitly provide for both treatment directives and appointment of a representative. Legal recognition of treatment directives was strongly backed by the Catholic church, which sees in treatment directives an acceptable alternative to euthanasia.[4] Thus the legal recognition

[1] This was in the past the position held by the Lord Chancellor's Department, *Making Decisions – The Government's Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults* (1999).

[2] See Mental Capacity Act, June 2004, www.publications.parliament.uk/pa/cm200304/cmbills/120/2004120.htm, accessed on 6/4/2005.

[3] See Cantor 1993.

[4] The strong opposition of the Spanish church to any form of legalization of euthanasia is depicted in a recent movie of Alejandro Amenábar (*Mar adentro*, 2003), inspired by the real story of Ramon Sampedro, a Spanish quadriplegic man after an accident in his youth, who undertook a cultural and legal battle for acknowledgement of his right to die (and ultimately was helped by a friend to commit suicide).

of treatment directives has been not only a logical consequence of the recognition of a patient's right to autonomy, but sometimes also the expression of the local assertion of self-determination, and supported by local ideological concerns.

With the sole exception of Denmark, all the countries belonging to this group have also recognised the appointment of a representative for health-care decision-making, often in the same statute recognising treatment directives. In these countries the coverage of legal regulation is therefore complete. The powers of the appointed representative are generally as extensive as those of a competent patient, but his decisions are constrained if there is also a treatment directive.

The conditions of validity differ in minor ways among the various jurisdictions. In general, only a competent patient, adequately informed and free from undue pressure can make a valid treatment directive. Concerning the age of the author, statutes providing for treatment directives are sometimes more restrictive than for informed consent. Generally the author must have reached the age of majority. The doctrine of 'competent minor' holds only in New Zealand, in one province of Canada (Manitoba) and in the Netherlands. In the Netherlands, the low age limitation for informed consent apparently also holds in the case of a treatment directive: patients 12 years or older are presumed competent to make medical decisions.[5]

The degree to which a patient can express instructions in a treatment directive can be affected by a variety of limitations (see Table 1). A typical case of such limitations is represented by various states in the USA, where the three most common limitations provided for in statutes concern the medical state of the patient (a directive is only effective in the case of terminal illness or a permanent vegetative state), the treatment that can be refused (artificial nutrition and hydration sometimes being excluded or limited), and pregnancy.[6] Despite such restrictive legislation, however, non-statutory treatment directives are usually considered by American courts to be a valid expression of the wishes of the patient and therefore binding on doctors because of the common law requirement of informed consent. Moreover, the validity conditions specified in a statute can be overruled by the constitutional 'right of privacy'. Thus references to terminal illness or permanent unconsciousness are not necessarily considered by the courts as exhausting the conditions under which a treatment directive can be valid. Similarly, restrictions on the treatment that can be refused are constitutionally dubious. The exclusion of pregnant women has been held unconstitutional, at least before the foetus is viable.[7]

[5] However, the age of majority (18) is required to make a valid appointment of a representative; below that age the person's parents are his representatives.
[6] Thus in some statutes, the previously written request of an incompetent pregnant woman should not be fulfilled if the consequence of such a course of action will endanger the development of the fetus.
[7] See Meisel 1998.

A case similar to the USA is represented by Australia, where the legislation in the jurisdictions that have enacted statutes on treatment directives includes quite extensive limitations, but the appeal to common law serves to weaken the statutory limitations. In effect, once the right to consent to or refuse medical treatment in advance is recognised, it seems to be difficult for common-law legal systems to subject this right to limitations that do not apply to a competent patient in a current situation.

In some other countries belonging to the first group there are potentially serious limitations on patient autonomy. For example, in Spain the only instructions binding on doctors are those which conform to good medical practice. Clearly, if taken at face value, such a provision significantly weakens the force of the right to refuse medical treatment in advance. In Denmark a doctor is obliged to comply with a treatment directive only if the patient is terminally ill; if the patient's condition is one of serious impairment causing grave invalidity but not terminal,[8] a treatment directive only guides but does not bind a doctor.

At the opposite end of the spectrum are New Zealand, the Netherlands and Belgium, where there are no limitations on the validity of a treatment directive, except the general requirement of identity and competence of the author. In these countries the right to express instructions in advance is extensive and unconstrained. However, in the Netherlands, an escape provision is offered: a doctor can deviate from the instructions contained in a treatment directive if he has "well-founded reasons" (in Dutch: *gegronde redenen*) to do so. A broad interpretation of this provision could undermine the force of treatment directives. However, the provision is interpreted in a restrictive way, and seems not to undermine the legal strength of treatment directives.[9]

As far as formal requirements are concerned, the differences among jurisdictions run parallel to the situation concerning limitations: on the one hand is the USA, where state statutes often impose extensive formal requirements;[10] on the other hand is New Zealand, where no formal requirements are specified. There seems to be a common denominator underlying the differences: some documentation of a treatment directive (not necessarily writing) and at least one witness is generally required. Interestingly, a requirement of periodic renewal is usually not imposed, despite the common expert opinion that regular renewal is highly desirable.

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[8] E.g. dementia; more examples are described in guidelines issued by the National Health Care Directorate. See Hybel 2000.

[9] See more details in Chapter 4, specifically dedicated to the legal situation in the Netherlands.

[10] As an example of a set of formal requirements, we can refer to the West Virginia Living Will Law (1994): "A living will (...) shall be : in writing; executed by the declarant or by another person in the declarant's presence at the declarant's express direction if the declarant is physically unable to do so; dated; signed in the presence of two or more witnesses at least eighteen years of age; and signed and attested by such witnesses". This is followed by the conditions for being a valid witness. Reported in Zucker 1999: 77.

Group 2: Weak legal status

This group is characterized by a rather uncertain and weak legal status of treatment directives. Nonetheless, discussion of the issue is active and some steps toward legal recognition have been taken. In these countries, the main point of discussion concerns the binding nature of the directives. The usual position, held especially by the medical associations, is that a treatment directive gives relevant information on which a doctor can determine the presumed will of an incompetent patient, but in itself is insufficient to bind a doctor's hands. A certain degree of freedom remains, within which a doctor can decide whether the instructions given in advance by a patient should be followed or not. It is clearly accepted, on the other hand, that a doctor may legally carry out a treatment directive without fear of civil or criminal liability ('may' rule).

A common argument used in these countries against giving treatment directives binding legal force is that they are necessarily expressed in such general terms that they can hardly be decisive in a concrete situation. This can indeed be a serious problem in the implementation of treatment directives.[11] However, this does not seem to afford a sufficient reason for a categorical rejection of their binding force when they are clearly applicable. Moreover, considerable improvement in the interpretation of treatment directives can be obtained by coupling them with the appointment of a representative. Appointment of a representative for health-care decision-making is legally recognized in three of the five countries: in Germany by a specific law and in Switzerland and Sweden by analogy with the appointment of a representative for financial matters.[12]

The role played by the arguments against binding force differs among the countries belonging to this group. On the one hand we have Germany, Sweden and Norway, where the arguments are seen as insurmountable objections to giving treatment directives binding force and the medical associations and/or the governments concerned have officially declared that such a legal development would be undesirable. On the other hand, Switzerland and Austria seem to exhibit a more pragmatic approach and legislative change to give treatment directives binding force appears more likely.

Something more should be said about Germany, where the literature takes the position that treatment directives apply in only two cases: when the incompetent patient is in a terminal phase and treatment can only prolong the process of dying, and when a patient is in a permanent vegetative state. A treatment directive refusing treatment if the author becomes incompetent due to a disease such as Alzheimers would apparently

[11] See Chapter 3, paragraph 4.

[12] Despite this official recognition, in Sweden the legal status of an appointed representative is weak and the binding force of his decision is far from certain. See Westerhall 2000: 877-949.

not be considered binding, because German law emphasises the welfare and current will of the patient above prior written expressions of the patient's will. However, given the weak legal status of treatment directives, the meaning of limitations on what a patient can request in advance is unclear. This is the crucial point of difference with the countries of Group 1, where similar limitations draw the line between binding and non-binding treatment directives.

Group 3: No legal status

The countries belonging to this group do not legally recognize either treatment directives or the appointment of a representative. Together with two European countries, we find Japan in this group. The strong opposition of the medical profession may help explain the legal situation in these countries. However the situation is not uniform in the group. Japan does not recognize the principle of informed consent at all, while France and Italy do so at least in theory, and in both countries bills to recognize treatment directives have been introduced in the legislature. Recognition of the requirement of informed consent is weakened in these countries by the context of a paternalistic medical profession.

4. Summary

The question whether incompetent people have a right to respect for their autonomy has not been answered positively from a legal point of view in many of the countries surveyed. For those countries that do give legal recognition to treatment directives, formal legal support for the doctrine of informed consent seems almost always to be a prerequisite. For countries where informed consent has a weaker legal status (mostly through being mentioned in ethical codes of the medical profession), the legal status of treatment directives is, at best, weak.

Even in the countries with strong legal status of treatment directives, several differences exist in the translation of the principle of autonomy into actual rules. In some countries, like New Zealand, the right to express informed refusal in advance is almost unconditional: there are no constraints on the contents of a treatment directive and such a document is binding on care-givers. In other countries, a number of limitations and formal requirements are imposed on valid treatment directives.

The next step in my research will be to evaluate how such legal arrangements work in practice. This will be done in the following chapter, analysing the existent empirical literature on the subject. In the second part of the book (chapters 5 to 8), I will report on the results of my surveys on the working of treatment directives in the Netherlands.

CHAPTER III

THE SOCIAL PRACTICE OF TREATMENT DIRECTIVES: ANALYSIS OF THE EMPIRICAL LITERATURE AND DEVELOPMENT OF A SYSTEMATIC ANALYTIC FRAMEWORK

1. The development of the debate on treatment directives

After Kutner's proposal of 1969, interest in treatment directives passed through several phases. After a few years in which the idea remained in a state of latency, the proponents gained momentum and, from the late 1970s, legislation brought the legal recognition of treatment directives in several American states, beginning with the passage of the California Natural Death Act in 1976. As discussed in the previous chapter, the main reasons for the popularity of treatment directives, especially in legal and ethical circles, resided in a growing concern about medical decision-making for incompetent people and increased attention to the principle of (respect for) autonomy. This first wave of enthusiasm for treatment directives was largely ideological, since empirical knowledge on the subject was almost non-existent. Only in the mid 80s did articles begin to appear in medical journals, but these reflected a predominantly normative approach, taking for granted the presumed positive effects of treatment directives on medical decision-making.[1] However, doubts about the effectiveness of treatment directives were growing: these *first generation* treatment directives (as they are sometimes referred to) were considered too simplistic and vague in their formulation, and ultimately not helpful in the decision-making process.[2] Some authors made attempts to develop more elaborate documents that they considered potentially

[1] Schneiderman et al. 1985.
[2] Lynn 1991.

more effective. Emanuel, for example, proposed what she called a *medical directive*, including four scenarios, representing the conditions in which the directive should be applied, and twelve different treatments that the author of the directive could consent to or refuse depending on the scenario.[3] However, so far as is known, no study was ever done of the effectiveness of such directives.

In the meantime, as a consequence of a few controversial judicial decisions, increasing doubts were raised with regard to the idea of 'substituted judgment' as a criterion for decision-making for incompetent patients,[4] especially concerning its moral and practical validity when reliable evidence of the patient's wishes is lacking.[5] These doubts further increased interest in treatment directives, a process that culminated with the enactment of the Patient Self Determination Act (1990), a federal law intended to encourage the completion of treatment directives and contribute to their effectiveness, and hence to improve care at the end-of-life.[6] As far as treatment directives are concerned, the main provision of the PSDA is that all health-care institutions funded by the federal Medicare and Medicaid programs must inform incoming patients of their right to complete a treatment directive. But once again, this very ambitious policy was based on no empirical evidence of any net advantage of having patients informed about treatment directives. Already at the time of enactment, there were many critics of the choice made by the federal legislator: although they agreed on the importance of the objectives of the act, the critics saw the PSDA as premature, and ineffective in form (mandatory federal law)[7] or target (hospitalized patients, forgetting outpatients).[8] Despite such doubts about its effectiveness, the new law did prompt a series of empirical researches that, for the first time, brought concrete evidence into the debate.[9] Among these, the most significant effort to understand care at the end-of-life and possibly to improve it (as the principal investigators hoped) was the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments (SUPPORT).[10] This study, consisting of a controlled trial on >9000 hospitalized patients, was divided in two phases, one before the enactment of PSDA and one after it, and was aimed at understanding end-of-life communication between patients and

[3] Emanuel and Emanuel 1989.
[4] The 'substituted judgment' standard for decision-making for an incompetent patient implies that the surrogate of the incompetent patient would take a decision in his behalf by answering the question: What would the patient want in these circumstances? The limits of such an approach are discussed by Beauchamp and Childress 1999: 170-173.
[5] Cruzan v. Director, Missouri Dep't of Health, 110 S. Ct. 2841, 2858-59 (1990); In re Claire C. Convoy, 98 NJ 321 1985; In re Nacy Ellen Jobes, 108 NJ394 1987; In re Mary Moe 385 Mass. 555 1982. See generally Emanuel 1988.
[6] Greco et al. 1990; La Puma et al. 1990.
[7] Capron 1990.
[8] Greco et al. 1991.
[9] Some examples of these studies are Danis et al. 1991, and Schneiderman et al. 1992. More details concerning these studies will be given later in this chapter.
[10] SUPPORT Principal Investigators 1995.

doctors. Specific attention was dedicated to the use and effects of treatment directives. Unfortunately, the results of SUPPORT were rather frustrating, showing no effects of interventions devoted to improving communication, and no effects of treatment directives.[11] These findings put in jeopardy the support for treatment directives, at least in the form they then had, and promoted reflection on the possible reasons for such poor results. The most influential researchers in the field began to carry out critical evaluations of the knowledge acquired until that point and to question what had gone wrong in the practice of treatment directives.[12] The disillusioned climate also encouraged the critics of treatment directives, who raised once again the well-known arguments about the supposed impossibility of planning decisions in advance and advocated a revival of the "substituted judgment" approach in medical decision-making for incompetent patients.[13]

On the other hand, the reaction to the apparent lack of effectiveness of treatment directives that gained more support was not to abandon them completely, but to put them in a broader perspective. The shortcomings of a formal document divorced from the ongoing doctor-patient relationship were recognized. The innovation proposed was in the direction of setting treatment directives in the framework of a strengthened relationship. The idea of *advance care planning* (ACP) was therefore introduced.[14] The main idea behind the concept of ACP is that care at the end of life should be planned far in advance of the critical moment. Doctors should engage more often in end-of-life discussions with their patients, and patients should be better educated on their rights. In this light, treatment directives represent an instrument to promote and structure communication but not a goal per se. After the introduction of the concept of ACP, some empirical studies have shown that education of patients and increased communication on end-of-life issues with physicians increases the rate of completion of treatment directives and of patient satisfaction, and has some effect on treatment.[15]

In recent years, interest in how legislation on treatment directives actually works in practice has grown in other countries.[16] Nonetheless, the leading opinions remain those coming from the US, and they are rather critical. As an example, I cite a recent editorial by Teno, appearing in the *Annals of Internal Medicine* under the evocative title "Advance directives: time to move on".[17] Reacting to an interesting study of a colleague,[18] she concludes that focus on the single issue of advance directives to

[11] Teno et al. 1997a and Teno et al. 1997b.
[12] Lynn and Teno 1993, Emanuel 1993, Pearlman 1994.
[13] Tonelli 1996, Dresser 1995.
[14] Pearlman et al. 1995, Teno and Lynn 1996, Martin et al. 2000.
[15] Molloy et al. 2000a, Ho et al. 2000, Tierney et al. 2001
[16] To date, only few studies have been published, and so far they have not added much to the debate, remaining sparse and unsystematic. Schiff et al. 2000, Van der Heide et al. 2003.
[17] Teno 2004.
[18] Degenholtz et al. 2004.

improve care at the end-of-life would be wrong. To support her point, she quotes a clever sentence of H.L. Mencken (1917):

> *There is always an easy solution to every human problem – neat, plausible, and wrong.*

Teno says that focusing on treatment directives would be "to ignore the wisdom in Mencken's injunction against simple solutions to complex problems". Some opinions on the failure of treatment directives are even more drastic. Influential commentators, like Fagerlin and Schneider in the *Hasting Center Report*, expressed their judgment of the practice in a single word: enough![19] They argue that the idea of treatment directives is flawed from the outset, because it is based on wrong premises (for example, that patients value autonomy at the end of life).[20]

However, at least two cautious observations can be set against these critical positions. First, the empirical evidence currently available does not seem to be conclusive, and in many respects it is still far from providing a falsification of the hypothesis that treatment directives can improve care at the end of life. Secondly, it is important to keep in mind that almost all the empirical data on the practice of treatment directives was collected in North America. Given the ambivalent result of the research to date, further study aimed at a better understanding of the practical functioning of treatment directives is necessary. In particular, more systematic empirical research is urgently needed in all those countries outside North America where treatment directives have already been given a strong legal status. Serious studies in several countries of the working of these documents and of the pre-conditions that favour their effectiveness could represent an opportunity to test the results obtained in the corpus of the North American literature, and also to increase our understanding of the social practice of treatment directives, since the North American literature is generally very global and gives no insight into most of the concrete, detailed aspects of the social practice. If treatment directives are or are not effective, we still do not know *why* this is so.

By way of preparation to the sort of study just suggested, I present in the next section a systematic analysis of all the elements involved in the social practice of treatment directives. I will incorporate in the analysis what we already know from the literature and formulate a schematic overview of the social practice of treatment directives. As we will see, despite widespread public, medical and legal interest in treatment directives, little or no reliable information exists on many important questions. Such an analysis of the social practice of treatment directives lays the groundwork for the systematic collection of information in the empirical part of my research.

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[19] Fagerlin and Schneider 2004.
[20] Tonelli 1996, Dresser 1995, Fagerlin and Schneider 2004.

The leading questions in the analysis of the social practice will be as follows:

- What is the **demand** for treatment directives?
- What are the factors influencing the **completion** of treatment directives?
- What is involved in the social process by which treatment directives are **drafted**?
- Where are advance directives kept, once they have been drafted? Are they **available** when needed?
- Do treatment directives **affect care** at the end of life?
- What are the **general social effects** of the use of treatment directives?

2. Demand for treatment directives

Treatment directives are a facility the law makes available to persons wishing to exercise their right to give or withhold informed consent in advance. The legal recognition of treatment directives would be of little social importance if no one wanted to use them. The first empirical question to be asked about the social practice of treatment directives, therefore, concerns the level of potential and actual demand under different conditions (legal, cultural, health-care system). Since treatment directives are a relatively *new* legal facility (and in some countries are not yet available at all), the question of potential demand cannot be answered only by looking at the level of actual use. I therefore consider two other sorts of indicators of potential demand: the size of the population most likely to be interested in treatment directives (demographic demand), and the degree to which treatment directives are socially accepted and actively promoted (social demand). I will then consider the actual frequency of treatment directives among the population (actual demand), as it appears from several empirical studies.

2.1. Demographic demand

If we consider that treatment directives are meant for people who face the possibility of incompetence, a large potential demographic demand seems to exist. The most important source of potential demand for treatment directives is represented by the elderly, particularly those who anticipate being afflicted by conditions such as senile dementia. Available demographic and medical information indicates that this population is large, and expected to continue to increase in the foreseeable future. Together with the decline in fertility, the dominant factor in the aging of the population, at least in developed countries, is the decline of mortality and the consequent increase in life expectancy.[21] The decline in mortality is strongly affected

[21] Gavrilov and Heuveline 2003; Preston et al. 1989.

by improvements in medical technology that allow an increasing number of patients to be kept alive who would previously have died as a result of their pathology.

Aging of the population affects both the proportion and the absolute number of elderly in society. The United Nations forecast for Europe predicts a rise in the proportion of the population aged 65 years or over from 15% in 2000 to 29% in 2050.[22] Even more dramatic is the increase of the population of people 80 years old or over.[23] In the whole world, they will increase from 69 million to 377 million, a more than 5-fold growth (see Table 3).

Table 3. Dynamics of population aging in the modern world: percentage of elderly (65+) in selected areas and countries

Major Area, and country	1950	2000	2050
World	5%	7%	19%
Europe	8%	15%	29%
U.S.A.	8%	12%	21%
Japan	5%	17%	36%
Africa	3%	3%	7%
Latin America and the Caribbean	4%	5%	17%
China	5%	7%	23%

Source: United Nation, 2001

We can also expect an increase in the numbers of people facing incompetence at the end of life. For the US, a recent study appearing in the *Archives of Neurology* gives an estimate of 4.5 million American suffering from Alzheimer's disease, the most common neurological degenerative condition; the study forecasts a continuous increase in the number of persons with Alzheimer's unless new discoveries are made in the field of prevention.[24] In the Netherlands, a total of 172,600 people 65 or older were estimated to suffer from some form of dementia in the year 2000; in the same year, more than 5000 people died as a consequence of dementia (being this the third largest cause of death for women).[25] In short, the very large population of elderly people, and in particular those with some reason for anticipating dementia, could be

[22] UN 2002: 16. In the Netherlands, the population 65 years or over is expected to grows from 14% in 2005 to 22% in 2050.
[23] People 80 years or over are considered by United Nation as the 'oldest old' (UN 2001).
[24] Herbert et al. 2003. Although these estimates are controversial (see for example Grant 2004), the unquestioned fact remains that in the coming years, due to the aging of the population, there will be a substantial growth in the number of persons affected by Alzheimer's in particular, and dementia in general.
[25] Van den Berg et al. 2004: pp.146-147. Available also by www.nationaalkompas.nl, accessed 27.7.2005.

potentially interested in having a treatment directive to retain some decision-making power once incompetent.

The frequency of death due to stopping or not initiating life-prolonging treatment in populations where the rate of dementia is high gives another indication of the magnitude of potential demand. Eight percent of all deaths in the Netherlands, and 23% of all deaths in nursing homes – many of which involve persons suffering from Alzheimer's Disease - follow upon a decision not to administer artificial feeding and hydration to a patient who spontaneously stops eating and drinking (at present, of course, there is probably no advance directive in most of these cases) .[26]

Other populations representing a potential demand for treatment directives include chronically and terminally ill patients. Many studies of treatment directives focus on cancer patients, HIV/AIDS patients, ALS patients, and patients on dialysis.[27] Although not always terminal, all of these diseases involve serious impairment, and often lead to a state of (irreversible) unconsciousness in the last phases before death.[28] In all cases in which the progress of a disease can be expected to lead ultimately to incompetence, a treatment directive can be of use to try to maintain autonomous control over the decision-making process.

Another important (although often ignored) group of people potentially interested in treatment directives is represented by patients undergoing serious surgery. Among elderly people, the incidence of cognitive deterioration after serious surgery is high: one in ten for general surgery,[29] one in four for cardiac surgery.[30] There also other groups of potential users. For example, even relatively young persons concerned about the risk of suffering from a persistent vegetative state might be interested in the possibilities afforded by treatment directives.[31] Unfortunately, we have no quantitative information concerning this group, but impressionistic information suggests that the numbers are relatively small and there seems no reason to anticipate a significant increase.

In summary, if treatment directives are thought to permit a person to retain his autonomy with respect to decision-making concerning medical treatment, it seems that

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[26] See Griffiths, Bood and Weyers 1998: p. 216, note 49. More generally between 1990 and 1995 there was a striking increase in the frequency in nursing homes of abstinence with the express purpose of hastening the death of the patient, ibid. p. 45.

[27] Note the considerable literature on decision-making at the end of life of patients with HIV/AIDS: see for instance Wenger et al. 2001, Ho et al. 2000, Kohut et al. 1997.

[28] In the last phases of cancer, for example, a patient may experience a state of confusion or complete inability to make competent decisions; the same can be true for persons suffering from AIDS.

[29] Moller et al. 1998.

[30] Newman 2001.

[31] See for instance Teno and Lynn 1996, Miller et al. 1999. The recent Schiavo case in the US is an obvious example. On this last case, see Quill 2005.

a potentially very large number of people might want to make use of them. The question remains however whether those in the population of potential users in fact want to state their wishes about heath-care in advance.

2.2. Social demand

With the expression 'social demand' I refer to the level of acceptance of and concrete interest in treatment directives among the population as a whole and among specific categories, in particular the elderly. Very little information is available on this, but the results of public opinion research in various European countries gives some indication. On the whole,[32] there seems to be strong social support for the principle of patient autonomy and in particular for the right of a person to specify in advance which medical treatments he does not want to undergo should he become incompetent.[33]

Public support for treatment directives is probably connected with growing awareness of the emotional and physical suffering associated with senile dementia, particularly when, in its later stages, it involves confinement in a psycho-geriatric institution. Anticipation of such a fate is a common reason given in public discourse for the choice to forego life-prolonging treatment (or, in the Netherlands, to request euthanasia).[34] The low opinion of the public concerning the quality of life that demented people can expect in medical institutions finds support in the medical literature. A study by Morrison and Siu (2000), for example, shows that in a large hospital in New York elderly people afflicted by end-stage senile dementia and hospitalized for severe pneumonia or a hip fracture rarely receive adequate pain relief; the researchers also found no evidence that medical decision-making took care to minimize burdensome interventions.

Sensitivity to end-of-life issues, and consequent interest in treatment directives, can be also indicated by the existence of public support for right-to-die organizations. In all the countries surveyed, at least one right-to die association is present. The main objective of these associations is to promote the autonomy of dying patients. The most

[32] There are some exceptions. For example, in two otherwise very different countries, Italy and Japan, similar family structure and culture may stand in the way of social acceptance of advance directives. Care of a dying person is a family matter and decisions are taken by the family, not the patient. See Kimura 1998, Buzzi et al. 2001.

[33] See, for example, a survey conducted in France, published on the site http://perso.club-internet.fr/admd/fenetre.htm; Trappenburg and Holsteyn, 2001. The idea of patient autonomy seems, among ordinary people, not to follow the fault lines of the ideological differences typical of modern society. The high level of public support also applies, albeit to a lesser extent, to euthanasia – for which there is, of course, far less widespread political support. See, for example, a survey published on the site of the French Right to Die association (http://www.admd.net/sondage.htm, accessed 23.2.2005).

[34] The Previous Dutch Minister of Health, Mrs. Borst, has repeatedly argued on precisely these grounds for the right to request euthanasia in an advance directive, a right incorporated in the recently enacted law that gives legislative recognition to the legalization of euthanasia in the Netherlands.

prominent aspect of their commitment is usually represented by their explicit support for the legalization of euthanasia. But they also usually promote legalization and use of treatment directives. The Dutch right-to-die organization (NVVE) is very active, and its membership exceeds 100,000.[35] Among the members, interest in treatment directives is high, as documented in the yearly panel study among the members of the organization.[36] In other countries, such organizations are apparently much smaller; their activity seems usually to take a number of forms: supplying standard forms and information to members and others interested in making a treatment directive, addressing the relevant institutions (legislative bodies, governments, medical associations) in order to obtain recognition of treatment directives, seeking to mobilize public opinion on the subject, etc. The emphasis varies depending on the local legal status of treatment directives: where this is strong, concrete service to members predominates; where it is weak, the focus is on urging the need for less limited recognition; where treatment directives have no legal status at all, the attitude of these associations can vary, according to the social and political situation, from the presentation of concrete proposals for reform where legal recognition is likely in the near future to a more symbolic position-taking where the possibility of legal development is remote.[37]

Also among patients, interest in treatment directives is rather high. Research in Australia, for example, shows that more than half of the interviewees (hospitalized patients, N=152) would like to express their wishes concerning cardio-pulmonary resuscitation in writing.[38] Even higher percentages were found in an English study of elderly hospitalized patients: three quarter of a (very small) sample expressed interest in writing a treatment directive.[39] The most common reason mentioned was to make their views concerning treatment known; the next most frequent reason was relieving the burden on their families.

2.3. Frequency of treatment directives

Two critics of treatment directives come to the following conclusion: "despite the millions of dollars lavished on propaganda, most people do not have treatment directives [*living wills* in the original]."[40] The authors base their conclusion on a quick review of the literature on the subject. However a more careful look at the empirical literature on treatment directives suggests that more caution is in order. First of all, few of the empirical studies on treatment directives are based on representative samples of large populations (e.g. nursing home residents, hospice patients, HIV-infected adults);

[35] Information available on the site of the organization: http://www.nvve.nl/, accessed 9.2.2005.
[36] NVVE 2002, 2003.
[37] The internet site of the World Federation of Right To Die Societies (http://www.worldrtd.net/) gives an extended list of national right-to-die societies.
[38] Kerridge 1998.
[39] Schiff 2000.
[40] Fagerlin and Schneider 2004.

others utilize convenience samples or data coming from one or just a few institutions. The first group give reliable estimates of the frequency of treatment directives in the studied populations; the second group gives only an indication of the prevalence of treatment directives among small, specific population groups.

All the studies based on representative samples were conducted in the US. The table below gives the prevalence of treatment directives in the populations studied, and some information about the characteristics of the research. Before commenting on these studies, it is important to note that comparing such empirical studies is not an easy matter, and often problems rise as far as the definitions are concerned, since the terms used to indicate the documents whose frequency is at stake are not always consistent. In the literature I consider, two main terms are used: 'living wills' and 'advance directives'. The first usually seems to coincide with what I call 'treatment directives', that is, documents containing a refusal of treatment. 'Advance directive' is more vague. When it is used in the American literature, the document referred to may contain either a treatment directive and/or the appointment of a representative (proxy directive). But sometimes 'living will' and 'advance directive' are used as synonyms. The unfortunate common denominator of almost all the articles on the subject (especially those concerning the frequency of the documents) is that a clear definition of what the authors were counting is missing. Consequently, the comparisons remain indicative and some ambiguity cannot be excluded. As a rule, I will use the label 'treatment directive' and I will indicate when ambiguity in the terms used can give rise to problems in the interpretation of the results.

Table 4. Frequency of treatment directives detected in representative samples in the US

Study*	Frequency of treatment directives	Label used in the article	Year	Specific population	N
Teno et al. 2000	71%	Advance directives	2000	people who died with chronic illness	1578
Degenholtz et al.2004†	40%	Living wills	1993	elderly people (>70) living in the community in 1993 who died between 1993 and 1995	539
Wenger et al. 2001	38%	Advance directives	1996	HIV-infected adults	2864
Buchanan et al. 2003	27%	Living wills	1998-2000	Hospice patients in nursing home (at admission)	40622
SUPPORT – Phase 2 (Teno et al. 1997)	18%	Living wills	1992-1994	Seriously ill hospitalized patients, post-PSDA	1705
Mitchell et al. 2003	17%	Living wills	1999	Nursing home residents, cognitively impaired	186835
SUPPORT – Phase 1 (Teno et al. 1997)	13%	Living wills	1989-1991	Seriously ill hospitalized patients, pre-PSDA	3056

* All the studies are based on USA samples, except † which was limited to the state of Michigan.

As Table 4 shows, the range of variation in the frequency of treatment directives is very high. Comparison of the two extremes might suggest that the frequency of treatment directives increased from 13% to 71% in one decade (1990 to 2000). Are the two figures comparable? The first comes from the first phase of the SUPPORT study carried out before the enactment of the PSDA in 1989-1991. It concerns seriously ill, hospitalized patients, considered to be in the advanced stages of at least one of nine potentially terminal illnesses.[41] The second figure comes from a study of informants representing patients who died of a chronic illness in 2000. The two populations are different and this fact can partly account for the differences in the results. Thus, chronicity could be of some importance for the decision to draft a treatment directive, since we can expect that people affected for a long time by an irreversible disease will be more aware of their condition, will have more time to reflect on their treatment preferences, and hence may more often complete treatment directives. The two populations are also different in age: for the SUPPORT study, the median age is 65, while for the second study the mean age is 75. The different settings could have also influenced the results, as SUPPORT was carried out only with hospitalized patients.[42] Finally, the more recent study considered 'advance directives' in general and not only treatment directives. Thus also proxy directives with no additional medical instructions may have been included in the count. But even after taking all these cautionary remarks into account, the magnitude of the difference in the frequency of written directives in the two studies still seems to indicate that, in the decade considered, there was an increase in the use of treatment directives. Such a trend was already visible in the second phase of the SUPPORT study, although the differences between phase I and phase II (13 to 18%) were not statistically significant.

The other studies in Table 4, although dealing with different sub-populations, also consistently show an increase in the frequency of treatment directives during the 1990s. Wenger's study (2001) is representative of the population of American HIV-infected adults, and for 1996 reports a frequency of written directives of 38%. This population is of special interest because the age of its members is much lower than that of the usual populations interested in treatment directives (dying or chronically ill patients, nursing home patients): 89% of the subjects interviewed were less than fifty years old. This finding suggests that the effect of age on drafting a treatment directive may not be independent from health condition, and that relatively young people affected by a chronic and/or terminal disease can show a high rate of completion. Degenholtz (2004) focuses on elderly people (>70). This recent study is of particular interest because previous researches had almost exclusively considered inpatients (hospitalized or in nursing-homes), while this study includes elderly people living in

[41] SUPPORT Principal Investigators 1995: 1592.

[42] Even if we look at the data disaggregated for last place of care in Teno et al. (2004), the frequency of directives among the subjects remains far higher than in SUPPORT: an impressive 60% of the patients who died in hospital had some advance treatment preference expressed in a written form.

the community. The number of treatment directives among them was already high at the beginning of the 1990s. Finally, two studies based on representative samples concern nursing-home patients. However, they consider very different groups: Mitchell (2003) deals with cognitively impaired residents; Buchanan (2003) considers nursing home patients admitted for hospice care but still competent at the time of admission (57% were admitted with cancer). This seems to explain the difference between the frequencies reported in the studies: among incompetent nursing home residents, the frequency of treatment directives is 17%, while in the group of competent patients it is 27%. This suggests once again that a person's medical condition strongly affects the likelihood of completion of treatment directive.[43]

Concerning nursing homes, data from the Health Care Financing Administration database covering all nursing home residents in the US,[44] supplies some useful information. Unfortunately, these data suffer from the usual lack of lack of specification, reporting the frequency of 'formal advance directives' in general, but they are interesting for their comprehensiveness. The data for 1999 and 2000 given in Table 5 seem to reflect a situation of stability, but they do tend to confirm that the use of advance directives increased during the 1990s. The data also show that the frequency of advance directives is highest among terminally ill inpatients.

Table 5. Frequency of advance directives among nursing home patients in the US

	Year	
	1999	2000
Formal advance directives in all nursing home residents	37%	36%
Formal advance directives in terminally ill nursing home residents	42%	45%
Formal advance directives in persons with severe cognitive impairment	38%	37%

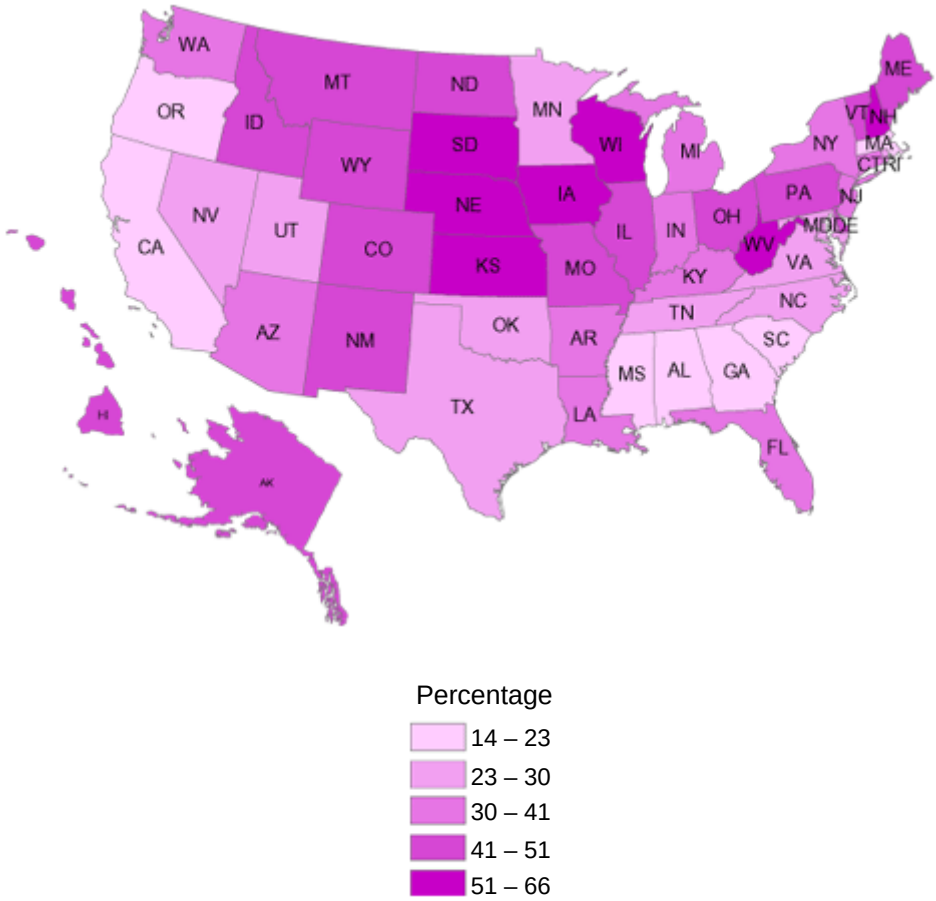
Source: www.chcr.brown.edu/dying/factsondying.htm, visited on November 1st, 2004.

If we consider a disaggregated picture of the US in 2000 (Figure 2), it appears that the frequency of 'formal advance directives' among nursing home residents is always above 13%, and in some states is above 50% (Kansas: 66%, New Hampshire: 65%, Wisconsin: 60%, Nebraska: 56%, Iowa: 55%, South Dakota: 54%, Wyoming: 51%).

[43] There may be two reasons for this: early-stage cognitive impairment may reduce the frequency of treatment directives; and cancer - involving a long-term intensive doctor-patient relationship in which what amounts to 'advance care planning' is common – seems to increase their frequency. See Anderson 2005.

[44] Minimum Data Set (MDS), see Hawes et al. 1995; Health Care Financing Administration, Medicare and Medicaid 1997.

Figure 2. Frequency of formal advance directives among all US nursing home residents in 2000



Source: Brown Medical School – Center for Gerontology & Health Care research
(www.chcr.brown.edu/dying/factsondying.htm, visited on November 1st, 2004)

Some tentative conclusions can be drawn from this discussion of the quantitative studies based on representative samples of specific US populations:

- the frequency of treatment directives seems to have increased during the 1990s;
- the frequency differs greatly between different groups of patients;
- a person's health condition seems to be an important factor influencing completion of treatment directives;
- the effect of age on completion of treatment directives probably reflects at least in part the kind and seriousness of the underlying medical condition: groups of relatively young people (HIV-infected adults and cancer patients) can have high rates of treatment directives;
- cognitive impairment due to a degenerative disease is associated with a lower completion of treatment directives.

It is now interesting to check if the tentative conclusions drawn from the studies based on representative samples are confirmed by the findings of the other group of studies dealing with small non-representative groups of patients. The results of these studies are presented on Table 6.

Table 6. Frequency of treatment directives detected in non-representative empirical studies in the US and Canada

Study	Frequency of treatment directives	Label used in the article	Year	Specific population	N	Country
Morrison and Siu 2000	44%	Advance directives	1996-1998	elderly people (>70) hospitalized patients with pneumonia or hip fracture	216	USA (NY)
Bradley et al. 1998	35%	Advance directives	1994	nursing home residents, after PSDA	300	USA (Connecticut
Dendaas et al. 2000	34%	Advance directives	1996-1997	hospitalized cancer patients who died	100	USA (Wis.)
Molloy et al. 2000	18%	Living wills	1994-1998	nursing home residents	606	CA (Ont.)
Ho et al. 2000	16%	Living wills	1995	HIV/AIDS outpatients [home care and clinic]	140	CA (Tor.)
Gross 1998	14%	Living wills	1994	Patients admitted to a hospital	31693	USA (Illinois)
Bradley et al. 1998	5%	Advance directives	1990	nursing home residents, before PSDA	300	USA (Connecticut

If we arrange the studies chronologically (from bottom to top), the tentative conclusion that in the decade between 1990 and 2000 an increase in the frequency of treatment directives was under way seems to be confirmed. It is particularly interesting to compare the results of Bradley et al. (1998) in 1990 and 1994, that is, before and after the enactment of the PSDA. The 7 fold increase (5% to 35%) in use is much more dramatic than that found in the other pre and post PSDA study (Teno et al. 1997a). However, the methodology may have influenced the results. The authors of the study based their data on patients' records in the nursing homes included in the research. This means that the data for 1990 may have underestimated the frequency of treatment directives, since one of the few certain effects of the PSDA is an increased probability that treatment directives are documented in patients' files (Teno et al. 1997a). Moreover, use of the label 'advance directives', without distinction between treatment and proxy directives, impedes a secure interpretation of the results. Nonetheless, the fact remains that the frequency of advance directives generally seemed to be increasing since the beginning of the 1990s.

The effect of a person's medical condition on the likelihood of completion of a treatment directive is also reflected in the non-representative studies. For example, Gross (1998) considers all admissions to an academic hospital in Illinois, while

Dendaas 2000 considers only hospitalized cancer patients who died. The frequency of directives in the two groups is very different, with terminal cancer patients far more often having written instructions (14% vs. 34%).[45]

As far as nursing homes are concerned, the results of Molloy et al. (2000) are very similar to those of Mitchell (2003) based on a representative sample, although they are obtained from Canadian patients. They confirm that the prevalence of treatment directives is relatively low in such institutions. Bradley (1998) gives higher figures, but, as we have already mentioned, she considers 'advance directives' in general and it seems plausible to suppose that proxy directives are particularly likely to be found in a population of demented persons. What is the reason for low completion in the nursing home setting? As we have previously noted, cognitively impairing diseases seem to be associated with a lower completion rate. This may well reflect postponement of consultation of end-of-life issues until it is too late: the course of the disease is already too advanced for the patient to be able to express his wishes in a competent way.[46] The effect of cognitive impairment is also confirmed by Morrison and Siu (2000), who found that cognitively intact patients have a much higher rate of completion compared with demented ones (56% vs. 33%). The fact that nursing homes include a large number of demented persons among their patients thus probably keeps the number of treatment directives there relatively low.

Finally, the study by Ho et al. (2000) seems to suggest a lower frequency of treatment directives among HIV infected patients than that found by Wenger (2001). The two studies were carried out in two different countries (Canada and US) and this could account for some difference. But a more relevant difference seems to be the health condition of the subjects: in the Canadian study, reporting a lower frequency of instruction directives (16%), only 39% of the subjects had AIDS and 88% considered their health between good and excellent; in the American study, where 38% of the subjects had a treatment directive, most of the population had symptomatic HIV disease, 59% had AIDS and only 10% were asymptomatic. This difference, besides accounting for the different results of the two studies, also tends to confirm the hypothesis that completion of treatment directives is influenced by the health condition of the subjects.

Interpretation of the studies based on non–representative samples is made difficult by the fact that all of them suffer from lack of precision in specifying the sort of written instructions involved – even more so than the studies based on representative samples. In a few studies some reference to treatment directives is made, although the term is not explicitly used (Molloy, Ho and Gross). In the others, the term 'advance directive'

[45] Some caution is necessary because the two studies are not clear about the exact definition of the documents they were looking for.
[46] Reisemberg 2000.

is left completely unspecified. From better documented studies (Teno et al. 1997), it seems that, in the majority of cases, an 'advance directive' will include a treatment directive. This somewhat reduces the problem of interpretation. But it is important for future research that the distinction between the different sorts of directives be absolutely clear, since treatment directives and proxy directives have completely different implications for medical decision-making for incompetent patients. In fact, some critics of treatment directives consider proxy directives useful and they conclude in favour of policies promoting only the latter.

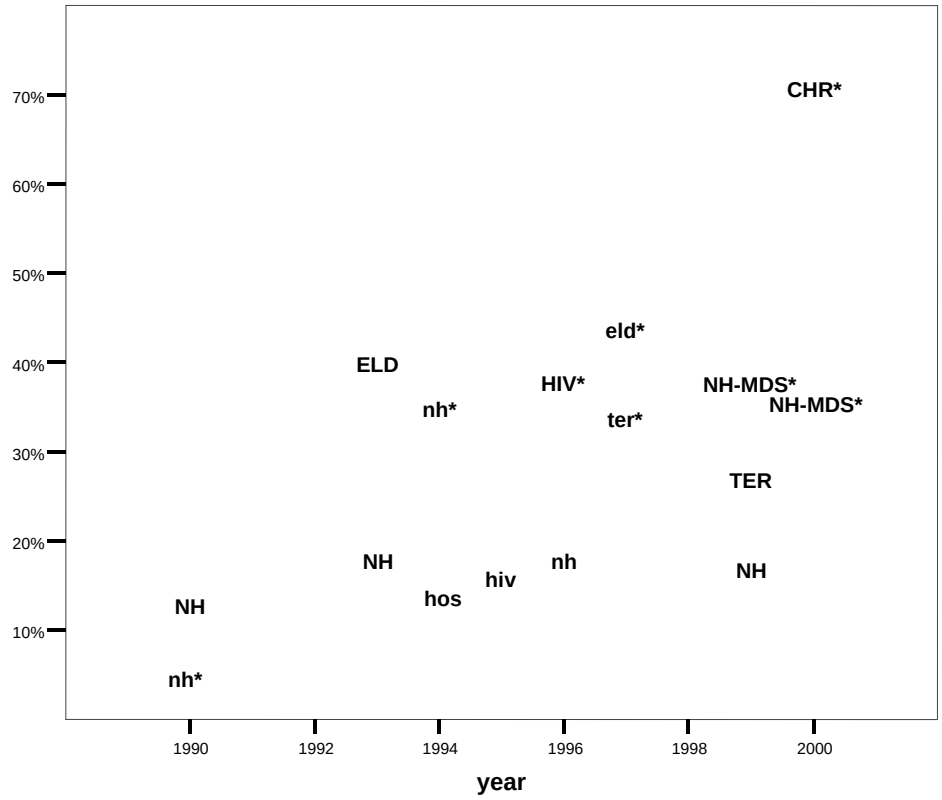
To summarize the forgoing analysis of the literature on completion of treatment directives, it is useful to represent the two main variables (frequency of advance/treatment directive and year) on a scatterplot. With the use of different labels, uppercases and asterisks, I will be able to distinguish the groups of patients included in the studies, whether the studies were based on representative samples, and whether the studies gave specific data for treatment directives, or generically referred to 'advance directives'.

The main findings that can be drawn from the forgoing analysis of the empirical literature on the frequency of treatment directives can be summarized as follow. A first glance at Figure 3 shows that, in the last decade, a general increase in the frequency of treatment directives can be observed. If we exclude the study of Teno et al. (2004), that refers to 'advance directives' in general and gives an impressive, but highly deviant, 71% frequency among chronically ill patients who died, the range seems to vary between 15 and 40%. Some critics interpret these results negatively, saying that "despite decades of urging, most Americans lack [treatment directives]."[47] It is true that most people even in highly relevant populations do not currently have treatment directives, but this does not seem to warrant the conclusion that, quantitatively, the use of treatment directives is insignificant. Especially if we consider elderly people, chronic patients and terminally ill patients, the frequency of treatment directives is rather high: in North America, roughly 1 in 3 of these patients has a document giving some kind of treatment instruction. In nursing homes, the picture is rather different: although there has been a growth from the beginning of the 1990s, the frequency of treatment directives among residents does not seem to exceed 20% (studies where higher percentages were detected considered either 'advance directives' in general, or involved a special group of patients, namely hospice patients). In this respect, it should be kept in mind that cognitive impairment seems to be a factor diminishing the chances of having a treatment directive. Although persons affected by senile dementia are, in the public discussion, often thought of as a group for whom treatment directives are particularly relevant, the specific traits of the disease and the reluctance of doctors and patients to talk about end-of-life issues early enough in the progress of the disease

[47] Fagerlin and Schneider 2004

(before impairment is so serious that the patient is no longer able to make decisions) seem to result in a lower level of completion precisely in this group. However this may be, 1 resident in 5 with a treatment directive is not a negligible frequency, especially for a facility that both legally and culturally is of very recent vintage.

Figure 3. Percentage of the population studied with a treatment directive or an advance directive, by year, in several empirical studies carried out in North America



Legenda

CHR: chronically ill patients
ELD, **eld**: elderly patients (>70)
HIV, **hiv**: HIV-infected patients
hos: hospitalized patients in general
NH, **nh**: nursing home patients
NH-MDS: nursing homes, data from Minimum Data Set
TER, **ter**: terminally ill patients

***** = the study refers to advance directives in general

Nota bene:
UPPERCASE: studies based on representative samples
LOWERCASE: studies based on non-representative samples

The studies discussed so far were all carried out in North America, and the majority of them (all but two) were carried out in the US, where the requirement of the PSDA that patients be told at admission of their right to complete a treatment directive seems to have played a key role. Therefore the picture presented in the literature cannot be generalized to other western countries. Only a handful of studies deals with the

frequency of treatment directives in Europe. A comparative survey of end-of-life medical decision-making in Europe offers some global data on the frequency of treatment directives in six countries.[48] The survey, a retrospective death certificate study, is representative for patients who died between June 2001 and January 2002 with some kind of end-of-life decision taken (non-treatment decision, alleviation of symptoms with possible life-shortening effects, euthanasia or doctor-assisted suicide). In the Netherlands, among these patients, the frequency of treatment directives (referred to as 'living wills') is reported to be 13%.[49] In all other countries the frequency of treatment directives in this population is below 5%. This is interesting to note, because the other countries surveyed are not homogeneous as far as the legal status of treatment directives is concerned: in Denmark treatment directives are legally binding, while in Sweden and Switzerland their legal status is weak, and in Italy and Belgium[50] they have none; the result seems to suggest that 5% is a rough baseline figure for the frequency of treatment directives among persons who die as a result of and end-of-life decision. Of course, the frequency among all persons who die, and even more so in the general population, would be much smaller. Another interesting result comes from an English study,[51] where, among a non-representative sample of hospitalized elderly people, not a single one had a treatment directive.

A final source of information on the use of treatment directives in European countries is data from the panel study that the Dutch Euthanasia Society (NVVE) carries out every six months among its members. Clearly the population is very biased, consisting of persons particularly sensitive to end-of-life issues. However in this specific group of people between 60 and 65% have a treatment directive. Since the membership numbers approximately 100,000, the total number of NVVE treatment directive is easily estimable.

[48] Van der Heide et al 2003. The six countries considered are: Denmark, Sweden, Switzerland, Belgium, Italy and the Netherlands.

[49] From other Dutch studies we know that the total population of deaths following an end-of-life decision is roughly 60000 per year: about 44% of all deaths in the Netherlands. See Van der Wal 2003: 67. It should be noted that the research referred to in the text concerns the frequency of treatment directives among deceased patients and not the frequency of deaths following upon implementation of a treatment directive.

[50] In Belgium, the enactment of the new law on patient's rights (see Chapter 2) was posterior to the collection of data for the research.

[51] Schiff et al. 2000.

Table 7. Frequency of treatment directives detected in European empirical studies

Study	Frequency of treatment directives*	Year	Population	N	Country
NVVE 2002 (1)	65%	2002	NVVE members (103.000)	500	NL
NVVE 2002 (2)	62%	2002	NVVE members (104.000)	429	NL
Heide et al. 2003	13%	2001-2002	Deaths where an end-of-life decision was taken	2763	NL
Heide et al. 2003	<5%	2001-2002	Deaths where an end-of-life decision was taken	6551	5 European countries
Schiff et al. 2000	0%	2000	Elderly (>65) in hospital	74	UK (London)

* All the studies refer to treatment directives

3. Factors influencing the completion of treatment directives

From the findings discussed in the previous paragraph, it is possible to suggest some factors that influence the rate of completion of treatment directives. The specific health condition of the person concerned is a relevant factor, with terminally ill and chronically ill patients more often drafting treatment directives. Also the setting (nursing home, hospital, outpatients) seems to have an influence, although the confounding factors of age and cognitive condition and the specific influence in the US data of the PSDA preclude a firm conclusion from the existing data.

Few researches have directly addressed the subject. Bradley (1998) observed that older age, higher level of education (more than high school), and private payment for care are factors predicting a higher presence of documented advance treatment directives among nursing home residents. Also patients admitted directly from hospital were more likely to have a directive in their file.

Presumably a key variable in influencing completion is the availability of information about treatment directives. The level of (legal and medical) knowledge among patients seems to be very different depending on the country concerned. An interview study conducted in Great Britain for example found that only 4 out of a sample of 74 elderly people knew what a treatment directive is.[52] The situation in the US is very different: more than 60% of competent nursing home residents say they know about treatment directives.[53]

Where do people potentially interested in treatment directives get information? We can note here six obvious possibilities: their physicians, governmental programs, specific

[52] Schiff et al. 2000.
[53] Teno et al 1997a.

interventions (such as information programs aimed at specific populations), right-to-die and other associations, the media, and their immediate social surroundings (family, friends, etc.). Some reflections on and empirical evidence concerning these six sources of information follow.

Doctors are an important source of information for their patients, and the nature of the relationship between doctor and patient can therefore be a factor of importance both for the completion of treatment directives and the planning of end-of-life care.[54] If we regard a treatment directive as an extension of a person's right to give or withhold consent to medical treatment, it is clear that participation of the doctor in the process by which it comes into being will often be important. One of the reasons for the low effectiveness of treatment directives is imputed to their lack of specificity, resulting from a failure to discuss them with a doctor. In practice, it seems that barriers to initiating such discussions exist on both the physician's and patient's side.[55] Failure to discuss end-of-life care persists, despite the fact that no adverse emotional or attitudinal responses on the part of patients have been documented in empirical studies.[56] Among HIV-infected adults, Wenger (2001) found that half of them had discussed some aspect of end-of-life care with their physician.[57] The same study found that the most important predictors of treatment directive completion were previous discussion with a physician and the length of the doctor-patient relationship.

Governmental programs aimed at increasing patients' knowledge concerning treatment directives can be a relevant factor. Federal legislation in the US on treatment directives concerned precisely this aspect of the social practice. The PSDA made it compulsory for institutions funded by Medicare or Medicaid to inform patients at the time of admission about their right to complete a treatment directive. Despite the high level of expectation, the SUPPORT study found no substantial increase in the completion rate of treatment directives following the enactment of the law.[58] On the other hand, Bradley (1998), who also made a pre/post-PSDA comparison, did find otherwise a significant difference in the number of directives documented in medical records, although this might reflect more a change in the rate of documentation than a genuine increase of treatment directives. The limited effects in the short term of this federal law may be attributed to a wrong judgment about the effectiveness of information

[54] This idea represents the basis for the literature promoting advance care planning (ACP), where discussion with the physician is generally recognized as an important factor improving end-of-life care generally and the effectiveness of treatment directives in particular.
[55] Larson and Tobin 2000.
[56] Song 2004 (literature survey).
[57] Negative factors connected with a lower chance of discussing end-of-life care with a physician were: being Latino or black, male, having being infected via injection drug use. Positive factors were: presence of children in the household, higher education, longer doctor-patient relation, more positive attitude toward coping with the disease.
[58] Teno 1997a.

given to patients upon admission to a nursing home. This was anticipated by commentators on the law before its enactment.[59] At admission, patients are confronted with a huge amount of paper work presented to them by a bureaucrat, and information about treatment directives may not register under these conditions. A possible solution to this problem might be to identify other opportunities, before or after the admission to deal with the subject of treatment directives.

More promising results were found in studies of information programs aimed at potential users of treatment directives. For instance, a pair-matched study conducted in Canada in six Canadian nursing homes shows that the systematic supply of information on treatment directives can dramatically increase the rate of use (from 57% to 70%).[60] The quality of treatment directives also improved: the vast majority of those who after participation completed a directive gave detailed instructions taking into account different situations and a number of possible treatments. By contrast, in the nursing homes where no specific information was given, more than two thirds of the directives simply requested 'no resuscitation'. In another study, the same author observed a similar effect of an educational program implemented among community-dwelling veterans: 42 of 67 veterans who received information completed a directive (63%), and almost all of them reported that the information program was helpful.[61] In another Canadian study of HIV/AIDS patients in Toronto,[62] the systematic supply of information in the context of 'advance care planning' increased the completion rate of advance directives from 16% to 41% in the space of six months.[63] But Teno et al (1997), in the framework of the SUPPORT investigation, did not find any significant effects of a special intervention (additional to the standard information under the PSDA) aimed at increasing the rate of completion of advance directives. Even among patients who indicated that they did not want resuscitation, the intervention did not increase the frequency of documented patient-doctor discussion about resuscitation, let alone the rate of completion of directives including a refusal of resuscitation.

Another source of information about treatment directives is represented by right-to-die associations. In some countries (in particular the Netherlands), they probably fulfil an important role in this regard. But their activity seems rather marginal in most countries, primarily reaching a fairly small group of persons already aware of their rights.

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[59] Capron 1990.
[60] Molloy et al. 2000a.
[61] Molloy et al. 2000b.
[62] Ho et al. 2000.
[63] On the other hand, despite an increase in the rate of completion of treatment directives after the specific informational program, the legal quality of directives remained low: a quarter of them were invalid under Ontario law.

The media are possibly better able to reach the general public. Especially in the United States, media attention to cases in which a prominent person makes use of a treatment directive, or in which such a person dies an undignified death due to the absence of one, probably convey basic information to a large public.[64]

Finally, a person's immediate social surroundings (family, friends, neighbours, colleagues, etc.) could be an important source of information about, or a stimulus to complete, a treatment directives. Among the reasons given for completing a directive, Bradley (1998) found that the first one mentioned is the experience of witnessing the prolonged death of a friend or a family member.

Summing up, several factors seem to influence a person's decision to complete a treatment directive. Specific kinds of disease (namely chronic or terminal conditions) clearly increase the chances of having a directive. Information is surely important. However, the professionals representing the first source of information on medical issues in general, and on treatment directives in specific, seem reluctant to initiate discussions with patients on end-of-life matters. The lack of doctor-patient communication has so far not been corrected by the implementation of general governmental programs aimed at persons being admitted to hospitals or nursing homes. Intervention targeted at specific groups of patients, who are potentially interested in treatment directives, seems to be more successful. The development of a comprehensive practice of advance care planning may also be promising. But despite the undoubted desirability of 'advance care planning', the question remains whether its implementation on a large scale is realistic. It seems rather dubious that policies assuming considerably increased investment in communication between doctors and patients will be feasible, given the current budget and time constraints in health-care systems.

4. Drafting a treatment directive

The drafting phase starts the moment a person decides to make a treatment directive. It is an obvious but not a trivial truth that the will to make a treatment directive does not suffice to produce a valid and effective one. Problems of legal validity can largely be dealt with in fairly simple ways, such as the dissemination of standard forms that match the legal requirements. In fact, where treatment directives are legally

[64] Both Jaqueline Kennedy and Richard Nixon were reported to have signed a living will; their example is often mentioned by the supporters of advance directives in order to promote the use of these documents. See for example, Hospital Ethics 1994, Kelley 1995. See also Udall, 1999, about the death of congressman Morris K. Udall.

recognized, standard forms usually exist.[65] Incidental evidence suggests that the role of legal advisors in drafting treatment directives is sometimes important, but how often they are involved and under what circumstances – and how much difference their involvement makes to the quality and effectiveness of a treatment directive – is uncharted territory.

The medical quality of treatment directives is a more difficult problem. It has often been observed that the clarity of the medical instructions in treatment directives is often so low that they cannot effectively contribute to medical decision-making.[66] It is widely supposed that the medical quality of a directive is directly affected by the relationship between doctor and patient (how long-term and encompassing it has been) and their communication concerning the patient's future treatment wishes (how openly, extensively and repeatedly they discuss the matter).[67] Several efforts to improve the medical quality of treatment directives in order to render them more effective at the time of implementation seem to have had some effect.[68]

Relevant in connection with the communication between doctor and patient, is the question of timing. Ideally, the instructions in a treatment directive should be formulated neither too late nor too early: long enough before the point of implementation that the communication can take place in an unhurried way, but not so long before that the directive deals with an abstract, unknowable future situation. It is difficult to define these temporal constrains *a priori*. Empirical research suggests that the majority of treatment directives were written between 2 and 5 years before the death of the author.[69]

Related to timing (but also to matters discussed earlier, in particular access to legal information) is the question, who takes the initiative for discussing a treatment directive: the doctor or the patient (or a family member)? The aspect of timing and initiative is particularly important for patients diagnosed with some form of deteriorating dementia. Such patients can expect to be fully competent for only a limited period. Postponement involves the risk of being overtaken by incompetence. It has been suggested that if there is no initiative from the patient or his family, the

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[65] Several US state statutes on treatment directives include forms for a valid directive. In the Netherlands, the best and most common form is that of the NVVE.

[66] Teno et al. 1997b; Schneiderman et al. 1992; Tonelli 1996; Fagerlin and Schneider 2004.

[67] Wenger et al 2001; Teno and Lynn 1996.

[68] For example the "Let Me Decide" advance directives developed in the framework of a complete educational program by William Molloy at McMaster University, Ontario, Canada (*http://www.newgrangepress.com/LMD.html)*. See Molloy et al. 2000c.

[69] Teno (1997b) found that, although the majority of directives were written before admission to an institution, only 2% of the directives detected were more than 5 years old. On the other hand, Degenholtz (2004) observed that 84% of the directives presented at the time of admission to hospital were at least 2 years old. If we integrate the two data, we can infer that the treatment directives involved were between 2 and 5 years old.

doctor himself should raise the possibility that the patient might want to express his wishes or instructions in advance of the period when he has become incompetent. Commenting on research on elderly people hospitalized for hip fracture or pneumonia, an editorial in the *Journal of the American Medical Association* gives this advice to doctors:

> *Introduce the topic of advance directives sooner rather than later. The unpredictable events of hip fracture and pneumonia […] drive home the point that the discussion should take place before the crisis occurs. […] The topic should be an agenda item in every encounter with patients with dementia, much like nutrition or safety. There is no time like the present to begin planning future approaches to care. A few minutes spent can save a world of suffering.*[70]

Unfortunately, also on the question of initiative we have essentially no information.

5. Availability of treatment directives: the latency phase

The effectiveness of a treatment directive obviously depends on its availability at the moment the doctor or the patient's family or representative must make medical decisions for the incompetent author. I call the phase from the drafting of a treatment directive to the time when the directive is intended to be implemented the *latency* phase. Availability for implementation is not always easy to accomplish, above all in the case of emergency treatment by medical staff who do not know the patient. In this regard, in a ethical discussion reported in *Medical Economics* (October 1999), one of the participants observed:

> *[…] typically, by the time somebody says, "I think the patient has a DNR order," the EMS (emergency staff) people have already started to intubate her. The patient ends up in the emergency room, and somebody says, "I have documentation that this patient was supposed to be DNR." Now what do we do?*

But the problem of the availability of a treatment directive does not end with emergency cases. For instance, one US study found major difficulties in the transmission of treatment directives to accompany nursing home residents being admitted to hospital.[71] The situation is supposed to have improved in the last few years, as the increased number of treatment directives documented in the medical files of the patients seems to be one of the few incontestably positive effects of the implementation of the PSDA.[72]

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[70] Riesenberg 2000.
[71] Danis et al. 1991.
[72] Bradley et al. 1998, Teno et al. 1997a.

In the Netherlands, the organizations that distribute large numbers of standard-form treatment directives urge those who use them to discuss their treatment directive with their family doctor and to have a copy on file with him. However, it is not known how many authors of treatment directives actually do this. To assure that the existence of a treatment directive is known when needed, cards and necklace hangers are also sometimes recommended.

The Danish Health Care Ministry has tried to overcome the problem of availability by instituting a Living Will Data Bank (*Livstestamentregistret*). Registration of treatment directives is supposed to improve their availability to doctors. To achieve this end the law requires that doctors consult the register when considering life-prolonging treatment for an incompetent patient. In practice, however, this provision is apparently ignored.[73]

6. Effects of treatment directives on care at the end-of-life

"If living wills [treatment directives] do not affect treatment, they do not work." This is the harsh test put forward by Fagerlin and Schneider for evaluating the effectiveness of treatment directives. Based on evidence mostly derived from Teno et al. 1997, they conclude that no such effect can be shown. The reasons for such a failure, in their view, are the following: a) the instructions in a treatment directives are always difficult to apply to a concrete situation, even when they are clearly stated; b) treatment directives are taken into consideration too late in the decision-making process: "by the time doctors and families finally conclude the patient is dying, the patient's condition is already so dire that treatment looks pointless quite apart from any living will"; c) doctors prefer to listen to the wishes of patients' families, and families usually do not follow treatment directives.[74] From these observations, they conclude:

> *The program [of promoting treatment directives] has failed, and indeed is impossible. […] Not only are we awash in evidence that the prerequisites for a successful living will policy are unachievable, but there is direct evidence that living wills regularly fail to have their intended effect.*

Although the arguments of Fagerlin and Schneider are powerful, they are not conclusive. The fact that treatment directives are difficult to apply to a concrete situation depends greatly on their contents. Surely, specific conditions exist that can be clearly stated in a treatment directive and unhesitatingly implemented, for example the

[73] Vestergaard 2001.

[74] The fact that, despite the strong legal status of the documents, doctors tend to respect the wishes of the family more than the advance written instructions of their patient has also been documented in the case of organ donation. See Nowenstein 2005.

refusal of any curative treatment in the case of persistent vegetative state (PVS). This condition has a clear medical definition[75] and refusal of curative treatment in that situation has no particularly complicated implications. In other cases, treatment directives often clearly apply to the situation of the patients who drafted them: Dagenholtz (2004) found that to be the case in 86% of the cases he studied among elderly people above 70. Farlingen and Schneider would reply that the imprecision of treatment directives enables doctors to interpret them in the light of their own preferences. To support this contention they quote the following results of Mower and Baraff (1993):

> *Even with the therapy-specific advance directives accompanied by the designation of a proxy and prior patient-physician discussion, the proportion of physicians who were willing to withhold therapies was quite variable: cardiopulmonary resuscitation, 100%; administration of artificial nutrition and hydration, 82%; administration of antibiotics, 70%; simple tests, 70%; and administration of pain medication, 13%.*

If we leave aside the withholding of pain medication, whose status as treatment *tout court* is questionable (and which also is rarely refused), the other situations present quite high percentages of implementation by doctors, and do not seem to afford support to the argument of the irrelevance of treatment directives.

As far as the late consideration of treatment directives is concerned, this seems more a fault imputable to doctors than a shortcoming intrinsic to the nature of treatment directives. The same could be said of the fact that doctors prefer to deal with the family instead of implementing the advance written instructions of the now incompetent patient.[76] Both criticisms point to the fact that the general attitude among medical professionals and the personal attitude of a given doctor toward treatment directives may have a strong influence on the chances of implementation. A doctor who profoundly disagrees with the idea of having his hands bound by written instructions of a patient who has become incompetent can use the generic nature of many advance directives to justify treatment decisions the patient probably did not want, arguing that the treatment directive does not unambiguously apply in the situation at hand. He is more likely to do this if his personal attitude reflects a widely-shared professional norm, or if the author's family vigorously objects to implementation. But it has not been shown that doctors always have a negative attitude concerning treatment directives, and even if such attitudes are predominant in the profession, it is not clear why attitudes could not change. In this light, education of health-care providers may well be an important factor in fostering a more successful use of treatment directives. However such interventions were not considered in the PSDA, and this affected also the later studies, that regularly neglected the attitudes of

[75] See, for example, Jennet 2002.
[76] See previous note 74.

doctors. The implementation of treatment directives can also be influenced by the knowledge medical staff possess concerning the legal status of such instructions. In countries like the USA and the Netherlands, where the social practice of treatment directives has become quite common and medical journals regularly publish articles on the subject, we might expect such legal knowledge to be fairly widely diffused. However, there seems to be no empirical information supporting this idea. Nor have I found any indication in the literature of the development of standards or protocols for the treatment of an incompetent patient with a treatment directive.

The contents of treatment directives are undoubtedly one of the most important factors influencing their successful implementation. If the instructions in a treatment directive are expressed in vague forms, it can be a problem for the doctor and the patient's representatives to interpret correctly the treatment wishes will of the patient. Doubts in this regard seem to be well-founded, as empirical research has shown that the interpretation of both representatives and doctors often do not coincide with the wishes of the patients who drafted the directives.[77] Possibly this is a general problem connected with the formulation of complex preferences; in fact a study by Schneiderman shows that there is a discrepancy between the instructions put into writing and the actual preferences of the authors.[78] Several proposals have been made to formulate more exhaustive and less ambiguous directives.[79] However, to date empirical research has not confirmed the potential improvement obtainable by more precise instructions.

If we look directly at the effects of treatment directives on treatment at the end-of-life, the situation does not appear to be positive. The SUPPORT investigation,[80] possibly the most systematic attempt to understand the effect of treatment directives, concluded that only a very small number of the treatment directives in seriously ill hospitalized patients were detailed enough to provide concrete guidance in the decision-making process, and even if they were, they were regularly (approximately half of the time) overruled by the doctors. However, while the study underlines the shortcomings of treatment directives and the failure of the PSDA to solve the problems of decision-making for incompetent persons, the authors acknowledge that their results cannot be generalized, since their data come only from seriously ill hospitalized patients.[81]

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[77] Schneiderman et al. 1993; Fagerlin and Schneider 2001.
[78] Schneiderman et al. 1992: the author interviewed patients who wrote a treatment directive on their real wishes concerning end-of-life treatment.
[79] Emanuel and Emanuel 1990, Cantor 1993.
[80] Teno et al. 1997a.
[81] The same limitations apply to the study of Morrison and Siu 2000, who found no effects connected to the presence of treatment directives in the treatment of elderly people hospitalized for pneumonia or hip fracture.

An important shortcoming of the empirical studies to date is that they focus on *inpatients*, that is, patients already admitted to a hospital or nursing home. That means that one of the potential effects of treatment directives (avoidance of admission) has been missed. A recent study has pointed to this bias, showing that the presence of a treatment directive is associated with a lower probability of dying in a hospital for both nursing home residents and elderly people still leaving at home.[82] If such a result is confirmed, assessment of the impact of treatment directives on end-of-life treatment will have to be reconsidered.

7. General social effects of the use of treatment directives

A final question about the social practice of treatment directives on which one would want to have information concerns the general social effects connected with an active social practice, including widespread use and substantial effects on end-of-life care.

First of all, one might expect some changes in the experience of the end of life on the part of users and potential users. An active social practice, about which the general population is well informed, could be expected to lighten the psychological burden for those patients – particularly those with diseases such as Alzheimers disease – who are anguished by the prospect of becoming incompetent and losing control over what happens to them. A greater sense of control may also make it easier for such patients to talk about and plan for end-of-life issues with their doctors and their families.

There might also be some effects on the health-care system. There is some empirical evidence that when patients decide for themselves, they choose for less aggressive and less expensive treatment than doctors would otherwise give.[83] If this is true, increased use of treatment directives would lead to a decrease in the costs for health-care as a whole. However, this implication (more treatment directives → lower health-care costs) is problematic. Firstly, it has not been proven. Secondly, if it were the case, this might be the result of (or lead to) patients feeling pressured to complete treatment directives as a way of sparing themselves or their families or society as a whole the high costs of end-of-life treatment.[84] To avoid such a risk, policies promoting treatment directives should include measures to ensure the voluntary and informed decision of a patient who decides to have such a document. But supplying education, consultation and support to potential users of treatment directives requires spending money. Therefore, even if treatment directives would result in fewer resources spent

[82] Dagenholtz et al. 2004. The probability of in-hospital death decreased from 65% to 52% for people living in the community, while for nursing home residents the probability decreased from 35% to 13%.
[83] Gross 2003.
[84] Loewy 1998.

for treatment at the end of life, some or all of the saved resources would already have been invested in the implementation of policy promoting a sound use of the facility.

Apart from such theoretical arguments, the fact remains that it is very difficult to establish whether the use of treatment directives leads to a reduction of the costs of treatment for incompetent patients. The empirical results are rather discordant on this issue. Molloy et al. (2000) show that one of the main consequences of the increased number of treatment directives after the implementation of an information program in three Canadian nursing homes was a significant reduction of hospitalization of the residents, with a consequent reduction of medical expenditure per patient. The authors are confident that despite profound differences in health care systems, such a program would have similar effects in the USA and Northern Europe. Such optimism must, however, be critically considered because, as Teno observes, the authors fail to analyze whether the cost reduction was the consequence of honoring the requests contained in the treatment directives of the nursing home residents, or rather simply the result of generalized under-treatment of patients with a treatment directive. In general, the economic effects of treatment directives are unclear, and whether there would be much saving seems to be dubious.[85]

8. Summary

The forgoing overview of the social practice of treatment directives allows us to synthesize the evidence collected in earlier studies and to construct an analytical structure that will afford the basis for the empirical part of this book, dealing with the situation in the Netherlands.

As we have seen, the potential demand for treatment directives seems rather high in Western societies where the proportion and absolute number of elderly persons is increasing. In connection with the aging of the population, the prevalence of cognitively degenerative diseases is growing, giving an increasing urgency to the necessity of acknowledging the right to autonomy of the incompetent elderly. Since treatment directives implement their right, demand for them should increase in the coming years. However, empirical evidence concerning the actual demand for treatment directives is mixed. If we consider North America, the last decade saw an increase in the use of the documents, but not homogeneously among the relevant population: seriously ill people (terminal or chronic patients) show a higher frequency of treatment directives than nursing homes patients, especially those who eventually

[85] Emanuel and Emanuel 1994, Teno 1997c.

became cognitively impaired. It is difficult to give an overall evaluation of the situation, but the metaphor of a glass being half empty or half full depending on how you look at it could be used. The harshest critics of treatment directives hold that the policy promoting them has failed because only a minority in the relevant populations have such documents: they see the glass half empty. On the other hand, the occurrence of directives at a rate of 1 in 3 to 1 in 5 patients, depending on the kind of group considered (for disease and/or setting), does not appear to be particularly disappointing: the glass could be looked at as half full.

In the rest of the world the situation seems much different, with an extremely low frequency of treatment directives. From the data available, the only country where these documents are present in a frequency even remotely comparable to the US or Canada is the Netherlands. In other Western countries, even when treatment directives are legally recognized, the quantitative presence of these documents seems to be negligible.

In order better to assess the data, it is necessary to understand the factors connected with completion of treatment directives. As we have seen, a person's specific medical condition appears to have a significant effect on the rate of completion. Progressive conditions that involve intensive contact over a long period with one's doctor (e.g. example cancer, ALS and HIV) are associated with a higher frequency of treatment directives. Suffering from (early stage) dementia, on the other hand, is a diminishing factor, and the effect of this is visible in nursing homes where the frequency of treatment directives never exceeds 20%.

Beside a person's particular health condition, another important factor responsible for differences in the rate of completion seems to be the amount of information concerning treatment directives available to potential users. The situation concerning this aspect is very different in North America, where the majority of the population is aware of the meaning of treatment directives,[86] from the rest of the world, where only a minority have an idea of what such a document is. This difference could at least partly account for the higher frequency of treatment directives in the US and Canada than elsewhere.

Several sources of information are available to a person potentially interested in a treatment directive. First of all, the opinion of the most influential researchers in the field is that the doctor-patient relationship is the best place to inform patients about

[86] See Teno et al. 1997a.

end-of-life issues, among them the possibility of giving written instructions about health-care applicable if the author becomes incompetent. But doctors are reluctant to begin such conversations, although no negative affective outcomes on patients have been documented in the literature. Another source of information for potential users is government programs directed to a general public or specific information programs targeted at potential users of treatment directives (for example, educational intervention in hospitals and nursing homes as required by the PSDA in the US). While general governmental programs like the PSDA seem to be of relatively low efficacy in increasing discussion of and completion of treatment directives, specific educational intervention targeted at specific groups have given more promising results.

Once a patient has decided to draft a treatment directive, he confronts the question how to do that in an effective way. In fact, an average person rarely has the legal and medical skills to draft a directive that will turn out to be valid and effective when it is needed. The problem of legal validity can be tackled by making standard forms that fulfil the formal legal requirements generally available. The down-side of standard forms, however, is that they are often not very flexible and also quite general, being therefore rather poor on the other important element influencing the success of a treatment directive: its medical quality. From a medical point of view, the quality of a directive can be improved by having a doctor (optimally, the treating doctor) involved in the drafting, but this seems in practice not to happen very often as most treatment directives present a low medical quality. The consequences of low medical quality appear at the time of implementation, when the written instructions can only give a vague or uncertain idea of the actual wishes of the author, and therefore cannot be a decisive factor in the medical decision-making for an incompetent patient.

As a consequence of the way most directives are formulated, the few studies that have analyzed the effects of treatment directives on actual treatment have given rather disappointing results. But up till now, these results are not strong enough to justify the conclusion that treatment directives cannot be successful. Moreover, all the empirical evidence comes from North America, and very little is known about Europe.

Finally the general social effects connected with the use of treatment directives are still unclear, and most of what has been said in this connection remains at the level of speculation. One of the most common arguments in favor of treatment directives is that an increase in their use will have the positive side effect of saving resources in the health-care system. However, the empirical evidence on the matter is far from conclusive.

To conclude this chapter, I summarize the elements that make up the social practice of treatment directives in a synthetic analytic scheme, which I will use from now on as the theoretical framework within which my own empirical research concerning treatment directives in the Netherlands must be understood. The scheme is presented in Box 1.

Box 1. Schematic overview of the social practice of treatment directives (TD = treatment directives)

Demand

- *Potential demand*: proportion of elderly people in population and prevalence of degenerative diseases such as senile dementia, HIV/AIDS, ALS
- *Social demand*: the level of acceptance and concrete interest in treatment directives among the population as a whole and among specific categories and, in particular, the elderly; the presence of interest groups, organizations or political parties demanding the legal recognition of TDs
- *Actual demand (frequency):* numbers of TDs in the population and the proportion of people with TDs in the most important categories, specifically the elderly and those with degenerative diseases

Factors influencing decision to complete a treatment directive

- *Medical condition and setting*
- *Level of legal and practical knowledge among potential users*
- *Availability of information and suppliers of information*: doctor-patient relationship, governmental programs, specific interventions, right-to-die associations, family, media
- *Social surroundings of potential users*

Preparation/drafting

- *Assistance*: discussion with family, fellow patients and others, doctors (how do doctors respond to inquiries?), lawyers, organizations
- *Timing*: when is an TD considered? when is it completed?

Latency

- *Archiving*: where do people register, deposit or otherwise make known their TDs?
- *Validity through time*: do people renew their TDs? how often? Do they change their instructions?

Implementation

- *Factual knowledge* of the existence of a TD and of the existence of the specified conditions
- *Contents:* conditions, treatments, proxy decision-maker
- *Legal knowledge* and sources of legal information
- *Attitudes* among health care professionals toward TDs
- *Acceptance by the family*
- *Social organization of decision-making*

General social effects of the social practice

- *Effects on the population of (potential) users*, in particular the elderly (e.g. on well being, health care and other end-of-life planning)
- *Effects on health care at the end of life* (timing and nature of dying)
- *Effects on families and intimates of authors (economic, emotional)*
- *Effects on the health care system* (e.g. saving of resources; availability of organs for donation)

CHAPTER IV

TREATMENT DIRECTIVES IN THE NETHERLANDS

In this chapter I present the legal situation concerning treatment directives in the Netherlands and describe the results of existing empirical studies that have dealt with the subject. This information forms the background for the empirical surveys presented in the second part of the book.

1. Treatment directives in Dutch Law

In the Netherlands, (negative) treatment directives received legal recognition in 1995, in the framework of the Law on Contracts for Medical Treatment (Wet op de Geneeskundige Behandelingsovereenkomst, WGBO 1995). One of the grounds on which the law rests is article 11 of the Constitution, which states the right of all persons to the inviolability of the body.[1] To implement this right, the law provides that any medical treatment requires the informed consent of the patient. If a patient refuses to give consent for a treatment, the doctor must comply with the refusal, no matter what the reasons may be underlying the refusal and however dire its consequences. The WGBO provides that a refusal of consent can also be given in advance.[2] Under Article 450, if a patient is no longer competent, refusal of consent can take the form of

[1] Grondwet, Art. 11: 'Ieder heeft, behoudens bij of krachtens de wet te stellen beperkingen, recht op onaantastbaarheid van zijn lichaam.'
[2] Positive treatment directives, demanding particular treatment in a specific situation, are not included in the WGBO.

a treatment directive written while he was still competent. The relevant passage (Art. 450.3) reads in part as follow:

> *In case a patient sixteen years of age or older cannot be considered capable of a reasonable assessment of his relevant interests, the health care provider and [the personal representative] shall follow the patient's apparent views laid down in writing when he was still capable of such reasonable assessment and containing a refusal of consent […]. The health care provider may depart herefrom if he considers that there are well-founded reasons for doing so.*[3]

In principle, such a directive, if valid, has the same force as the current refusal of a competent patient. What are the requirements for a treatment directive to be valid?

First of all the document must be in writing[4] and the identity of the author must be certain. There should be no doubts about the authenticity of the document. Secondly, the author must be older than sixteen and competent (capable of a reasonable assessment of his interests) at the time of drafting the document. Thirdly, the patient must no longer be competent at the time of implementation. There are no other requirements for a valid treatment directive.

A treatment directive binds all care providers. The law only allows deviation only if there are "well-founded reasons" [*gegronde redenen*] to do so. This formulation is vague.[5] It is generally accepted that a doctor's personal views concerning the instructions expressed in a treatment directive cannot amount to a "well-founded reason" to depart from it. The same should be said for conflicts between the professional medical standard and the instructions in the document. The fact that following a treatment directive will cause or hasten the death of the patient is not a sufficient reason not to comply with it.[6]

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[3] "In het geval waarin een patiënt van zestien jaren of ouder niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, worden door de hulpverlener en een persoon als bedoeld in de leden 2 of 3 van artikel 465 [de persoon die daartoe door de patiënt schriftelijk is gemachtigd in zijn plaats op te treden], de kennelijke opvattingen van de patiënt, geuit in schriftelijke vorm toen deze tot bedoelde redelijke waardering nog in staat was en inhoudende een weigering van toestemming als bedoeld in lid 1 [voor verrichtingen ter uitvoering van een behandelingsovereenkomst is de toestemming van de patiënt vereist], opgevolgd. De hulpverlener kan hiervan afwijken indien hij daartoe gegronde redenen aanwezig acht." Translation partly based on Hondius et al. 1996.

[4] One can doubt whether the statutory requirement of a directive in writing excludes the force of an oral advance refusal by a patient that is competent at the time of the advance refusal. The following considerations suggest such a refusal would also be binding: (a) it it excludes the possibility of a resumption of consent; (b) surrogate decison-makers as a doctor or a representative are required, in the absence of written instructions, to implement the patient's views to the extent these are known; (c) in everyday medical practice, oral instructions (e.g. of a person about to undergo total anesthesia) are surely binding within the context of the implied contract for medical treatment.

[5] Compare De Jong 1997: 206.

[6] Doubts can exist on this point when the patient has a high chance of a good recovery after the intervention. For example, it is not clear if, confronted with a patient who has written a do-not-

Van Veen[7] suggests that the situations where a 'well-founded reason' can be said to exist are those in which there is uncertainty with regard to:

- the identity of the author of the directive;
- his competence at the time of the drafting;
- the correspondence between the directive and the wishes of the author when he drafted the directive;
- the correspondence between the conditions of applicability in the directive and the current situation of the (now incompetent) author.[8]

If one of the situations above occurs, caregivers can consider not complying with the wishes expressed in a treatment directive. In order to reduce the possibility of such doubts a number of precautions can be considered, although these are not required by the WGBO.

The *presence of witnesses* to the drafting of a treatment directive can minimize doubts about the identity and competence of the author. Evidence of the competence of the author can be a matter of concern for at least two reasons: it is in general difficult to decide if a person is or is not competent for such a task,[9] and it often happens that, between the moment of drafting and that of implementation, there has been a change of treating doctor. In the case of a patient with a written treatment directive who is admitted to a nursing home, for example, the doctor who is supposed to implement the directive did not know the patient at the time of drafting. The existence of witnesses and their availability at the time of implementation can give the necessary confidence that the author was competent at the time he drafted the treatment directive.

Notarial authentication of the document would be another way to resolve doubts about the identity and the competence of the author. Moreover the assistance of a notary in the drafting phase should assure the document meets all the legal requirements.[10]

Although the law does not set a time requirement for the validity of a treatment directive, a *recently drafted or renewed document* can avoid problems concerning the

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resuscitate directive but who could easily recover from his underlying condition after resuscitation, the doctor should or should not resuscitate. For an impressionistic example, see Kleijer 2005.

[7] In Legemaate 1995: 48.

[8] The last two points can be partly traced back to the category of 'interpretation problems' mentioned by De Jong 1997: 214-216.

[9] For a more general discussion about the assessment of competence under the WGBO, see Van Veen 1995: 43-46.

[10] In Chapter 6, I will present empirical evidence on the involvement of notaries in the drafting of treatment directives.

correspondence between the instructions in the directive and the current wishes of the author. In fact, a common reason given in the literature for disregarding treatment directives is that the request expressed no longer reflects the real wishes of the patient, for example in the case of a demented person whose treatment directive rejects any kind of treatment if he can no longer recognize his loved ones, but who now appears smiling, happy and demented. To neutralize this argument against following a directive, the Dutch Society for Voluntary Euthanasia suggests including in a treatment directive a statement that the patient accepts this risk.

The *assistance of a medical expert* (for example, the patient's family doctor or, later on, the treating doctor) in the drafting phase might help to assure more effective implementation, given the fact that achieving concreteness and specificity is not a simple task for a person who lacks medical knowledge.

Finally, perhaps the most important thing that can be done to ease the process of interpretation of a directive is to include in the directive the *appointment of a representative*. This possibility is provided for under the WGBO, as we will see in the next paragraph.

Since the legislator chose to put the law on patient's rights in the civil code, and to give the relationship between doctor and patients a contractual nature, a treatment directive is in effect a part of the contract between the two parties. It follows that sanctions for infringement are primarily civil (prospective and retrospective). However, a serious violation of the requirement of informed consent could also give rise to liability in tort and to penal sanctions, the patient's denial of informed consent removing the justification for an invasion of bodily integrity. Disciplinary sanctions are presumably also a possibility. All of this remains largely speculative: only one relevant case has been published, and it was decided prior to the enactment of the WGBO.[11]

Summing up, we can say that treatment directives have a strong legal status in the Netherlands. The relevant provisions are contained in the WGBO. The explicit legal requirements for a valid treatment directive concern the written form of the document, the author's age (above sixteen), the identity of the author and his competence at the time of drafting.

[11] TvGR 1990/63 and 1993/66. A woman who attempted to commit suicide left a unsigned and undated note stating that she did not want any attempt made to resuscitate her, should she be found still alive. A criminal case was brought against the doctor who reanimated her, but the doctor was acquitted because there was insufficient ground to determine whether the request of the woman was authentic.

A valid treatment directive is binding on all caregivers, unless there are "well-founded reasons" to depart from it. In order to keep the grounds on which "well-founded reason" could be based to a minimum, a number of elementary precautions can be suggested; the presence of witnesses, notarial authentication, recent drafting or updating, inclusion of an explicit provision by which the author accepts the risk he might have changed his mind, the assistance of a doctor in the formulation of the instructions, and the inclusion of a provision appointing a representative to interpret and supervise the implementation of the author's instructions.

Table 8. Summary of the requirements for a valid treatment directive under Dutch law

Requirements explicitly mentioned in the WGBO	Precautions in order to increase chances of a valid treatment directive
• in writing • identity of the author • competence of the author at the time of drafting the treatment directive • current incompetence of the author	• witnesses • recent drafting or renewal • provision that the author accepts the risk of changing his mind • assistance of a medical expert in drafting • written appointment of a representative

2. Other kinds of advance directives under Dutch law

Although they are not the subject of this book, we should remember that, under Dutch law, two other kinds of advance directive are recognized: the appointment of a representative (proxy directive) and a written advance request for euthanasia (*euthanasieverklaring)*. Positive treatment directives have no independent legal status in the Netherlands, although they may of course be relevant in connection with treatment decisions, for example when 'quality of life' considerations play a substantial role in deciding whether to withdraw or withhold treatment on 'quality of life' grounds.

2.1. Appointment of a representative

The WGBO provides for the appointment in writing of a representative for health-care decision-making, should the person doing so become incompetent (Art. 465.3). The relevant passage states:

> *If an adult patient cannot be considered capable of a reasonable assessment of his relevant interests and he has not been placed under guardianship or had a mentor*[12] *appointed for his benefit, then the obligations on the part of the health care provider towards the patient arising from the WGBO, shall be fulfilled towards the person authorized in writing by the patient to act on his behalf. […]*[13]

Except where a legal guardian or a mentor has been appointed by a court, a representative appointed by the patient takes precedence over the family members provided for as default representatives in the WGBO itself. The representative must behave as a "conscientious representative" (Art. 465.5), he must try to involve the patient as much as possible in the decision-making, and decisions should reflect the patient's wishes (again Art. 465.5). If the behavior of a representative is "not compatible with the level of care expected from a conscientious care provider" (Art. 465.4), a health care provider can refuse to comply with the representative's instructions. In this sense, the strength of a refusal of treatment by a representative is qualified in a way that refusal by a competent patient is not.[14]

2.2. Written advance request for euthanasia (euthanasieverklaring)

The euthanasia law enacted in 2002 provides for the possibility of a positive directive requesting euthanasia under specific conditions, should the author become incompetent. The relevant article reads (Art. 2.2):

> *If a patient aged sixteen years or older is no longer capable of expressing his will, but prior to being in this condition was considered capable of a reasonable assessment of his relevant interests, and has made a written statement containing a request for termination of life, then the physician may carry out this request. The requirements of due care [referred in the preceding paragraph of the law] are applicable in such a case.*[15]

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[12] "The mentor is a natural person, appointed by a judge, who represents a person who has reached the age of majority but cannot be considered capable of evaluating his non-material interests because of mental or physical deficiency." Quoted from Hondius et al. 1996: 15, note 24

[13] "Indien een meerderjarige patiënt die niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, niet onder curatele staat of ten behoeve van hem niet het mentorschap is ingesteld, worden de verplichtingen die voor de hulpverlener uit deze afdeling jegens de patiënt voortvloeien, door de hulpverlener nagekomen jegens de persoon die daartoe door de patiënt schriftelijk is gemachtigd in zijn plaats op te treden. […]". Translation partly based on Hondius et al. 1996

[14] The autonomy of the incompetent patient is further protected by the provision that, despite the consent of the representative, a treatment cannot be performed if the patient strongly resists it. The only exception is if the treatment "is clearly necessary to avoid serious harm for the patient's health" (Art.465.6).

[15] *"Indien de patiënt van zestien jaren of ouder niet langer in staat is zijn wil te uiten, maar voordat hij in die staat geraakte tot een redelijke waardering van zijn belangen terzake in staat werd geacht, en een schriftelijke verklaring, inhoudende een verzoek om levensbeëindiging, heeft afgelegd, dan kan de arts aan dit verzoek gevolg geven. De zorgvuldigheidseisen, bedoeld in het eerste lid, zijn van overeenkomstige toepassing." Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding [valid since: 01-04-2002], Art. 2.2. Translation by Kim Goossens.*

An *euthanasieverklaring* is not the same as a current written request of a competent patient to receive euthanasia. In the latter case, the document only provides a proof that the patient actually requested euthanasia. Such a document will be included in the dossier which accompanies the doctor's formal report on the case. However, in such a case the patient is still able to communicate and can at any time - orally or otherwise - reaffirm or withdraw his request. In the case of an *euthanasieverklaring*, the patient has become incompetent and it is the document itself that is the basis on which the termination of life takes place.

Although *euthanasieverklaringen* are unambiguously recognized in the euthanasia law, many doubts persist about the actual possibility of performing euthanasia in the case of an incompetent patient on the basis of a previously written request. In this study, I do not deal with *eutanasieverklaringen* because the problems that they raise are very different from those related to negative treatment directives. However, in practice, a request for euthanasia is often included in an advance directive together with a negative treatment directive, and sometimes, as we will see in the following chapters, it proved in field research practically impossible to distinguish between the two kinds of documents.

3. The existing empirical data for the Netherlands

By contrast with euthanasia, actual practice connected with the making and implementation of treatment directives has received little attention in the Netherlands. In 1999 a large-scale evaluation study of the WGBO took place, but nothing is reported as far as treatment directives are concerned.[16] Some tangential information can be obtained from the national studies of euthanasia and from two academic studies. Data coming from the member-panel of the NVVE are also relevant. The following paragraphs present the main findings of these studies that provide some indication concerning the social practice of treatment directives in the Netherlands.

3.1. The national studies of euthanasia

In 1990, 1995 and 2001, three large national studies took place concerning end of life practices in the Netherlands, especially focusing on euthanasia.[17] Some information was produced concerning previously written instructions to caregivers, but unfortunately the data do not distinguish the kind of instructions involved and the condition of the patient as far as competence is concerned. Only in 2001 do the data explicitly concern the presence of a treatment directive in the case of withholding or

[16] Dute et al. 2000.
[17] See Van der Maas 1991, Van der Wal et al. 1996 and Van der Wal et al. 2003.

withdrawing treatment without discussion with the patient: in only 1,3% of such cases was a treatment directive present.[18]

The research of 2001 paid specific attention to the situation where a demented patient (who subsequently died) had made written request for euthanasia.[19] The researchers estimate that for the whole of the Netherlands there are in approximately 2200 such cases per year. Twenty-nine percent of the interviewed doctors had ever experienced such a situation, while 13% had experienced it in the preceding two years. These percentages are much higher in the case of nursing home doctors (66% and 50% respectively). Despite the apparently relative high frequency of demented persons who have completed a written request for euthanasia, doctors are not keen to fulfill these requests. Only 3% of them have ever performed euthanasia for a demented patient on the basis of a written request. Of the remaining doctors who have not done so, 44% consider it at least conceivable, while 54% do not. Specific questions were addressed only to nursing home doctors who had had a patient with a *euthanasieverklaring*. Although in 67% of these cases the patient had arrived at the situation he had specified in the document, euthanasia was actually performed in only 7% of the cases. Much more often (88%), there was some decision to withhold or withdraw treatment. However, the main element that influenced such decisions was the medical situation of the patient (76%), followed by the personal opinion of the doctor (60%). The presence of a *euthanasieverklaring* had much less influence (31%).

3.2. Two other studies

As far as the frequency of treatment directives is concerned, a European comparative study on end-of-life medical behavior, already mentioned in chapter 3, reports for the Netherlands that in 13% of cases where an end-of-life decision was taken a treatment directive (referred to as a 'written living-will') was present.[20] The frequency in the Netherlands is the highest among the six countries considered, being for all other countries less then 5%. However the study remains very vague on the precise sort of document involved and it does not give any details on their actual contents nor on the nature of the end-of-life decision.

In 2002, an ethnographic study on withholding artificial administration of food and fluids from elderly people with dementia in Dutch nursing homes was published.[21] The study was carried out in two nursing homes and analyzed the decision-making process for a total of 35 patients. Once again, the study fails to distinguish among different sorts of directives, in this case between treatment directives and *euthanasieverklaringen*. Nonetheless, and despite the very small size of the sample,

[18] Computation based on CBS 2003: 23.
[19] See Van der Wal et al. 2003: 110-117.
[20] Van der Heide et al. 2003.
[21] See The et al. 2002.

the study gives some tentative indications. First of all, very few patients (the precise number is not given) had any kind of written directive. When a directive was present, it appeared to influence the decision to withhold life-prolonging treatment. However the final decision was mainly based on the medical condition of the patient, the wishes of the family, and the quality of life of the patient as judged by his care providers. At the end of the day, the role of written directives seemed of limited importance in Dutch nursing home practice.

3.3. NVVE member panel

In the Netherlands, one of the most important promoters of treatment directives is the national right-to-die association (NVVE). The NVVE has developed a standard form for advance directives that contains all three kinds of instructions: a treatment directive, a proxy directive and a *euthanasieverklaring*. The form is available only for members (although an unknown number of others, including some professionals such as doctors and notaries, make use of it as a model in advising patients or clients).

The NVVE carries out a regular panel study among its members. A few of the questions concern the completion of written advance directives using the form supplied by the organization. In the most recent panel study (Autumn 2002), 64% of the 429 panel members said that they had completed the advance directive form, and 20% had received the form but had not yet completed it. It is interesting to note that among the members who had completed the form, almost everyone had included a refusal of treatment. If these results are representative for all members of the NVVE (approximately 104.000 people), then quite a large number of these treatment directives are present in the Dutch population, especially among older patients exposed to end-of-life decision- making, the large majority of members of NVVE being above 55 years old.[22]

[22] See NVVE 2002.

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.[1] 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.

[1] 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').[2]

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

[2] 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.

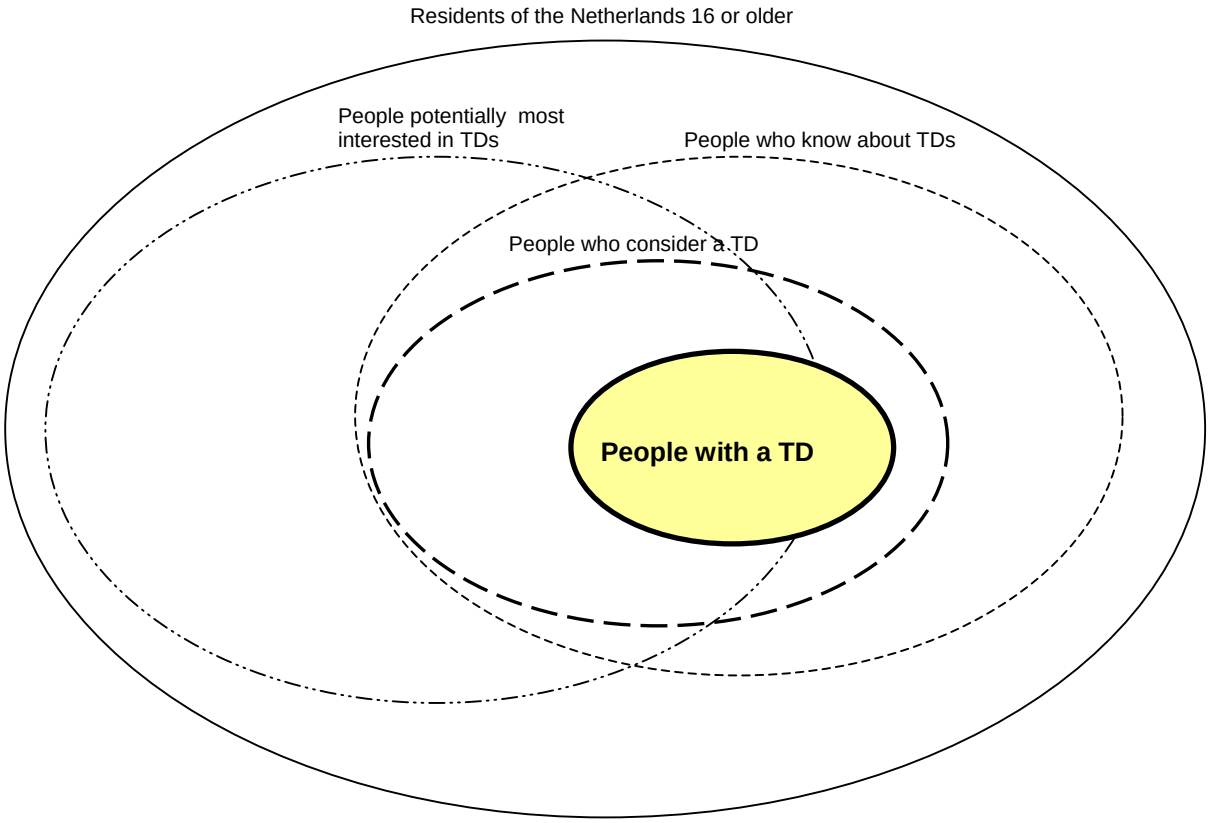
We can identify some groups that have a higher potential level of interest in treatment directives. Elderly people, persons affected by degenerative diseases and people with chronic or terminal conditions may be particularly interested. However, not all of them know about the possibility of drafting 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 knows 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.[3] 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 of 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

[3] 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 make to use only doctors as sources of information. This was because the authors of treatment directives are difficult to locate and to approach[4] 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.[5]

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.[6] 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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[4] 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.

[5] Details on the construction of the samples will be presented in the chapters concerning each study.

[6] 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.[7] 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.[8] 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.[9] Only impressionistic information and ethnographic studies of the use of such

[7] 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.

[8] 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).

[9] 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[10] administered through CATI (computer assisted telephone interviews).[11] 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.

[10] 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.

[11] 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 homogenously 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.[12]

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

[12] 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.[13,14]

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

[13] Classification of the grounds for medical decision-making from The et al. 2002.
[14] 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.

CHAPTER VI

THE ROLE OF NOTARIES IN THE SOCIAL PRACTICE OF TREATMENT DIRECTIVES

1. Introduction

The statutory recognition of treatment directives in the law on patient's rights (WGBO),[1] does not require the involvement of notaries or any other expert in drafting such documents. In practice, however, a patient rarely will have the legal and medical knowledge required to produce an effective treatment directive. The problem can potentially be remedied by securing counsel and assistance from an expert. One such expert, to whom some people in the Netherlands are known to turn, is the notary.[2] Commentaries on the Dutch law refer to this option[3] and a preliminary qualitative study carried out in connection with my research[4] made clear that notaries do regularly assist clients who want to have a treatment directive and/or an advance request for euthanasia. The Royal Dutch Notarial Association (KNB) initially supported this practice, supplying its members with a model document containing both an advance refusal of treatment and a request for euthanasia. However, the KNB has recently withdrawn the model as inadequate to fulfill the needs of clients and now encourages its members not to engage in a practice that demands a number of skills not generally

[1] See Chapter 4.
[2] Notaries are specialist in drafting legal documents such as wills, deeds, articles of incorporation, etc. In fact, in the Netherlands, the most popular source for legal advice concerning treatment directives is probably the NVVE.
[3] De Jong 1997.
[4] Hofman 2002.

possessed by notaries.[5] However, this decision by the KNB took place in the absence of reliable information concerning the actual extent and character of the involvement of notaries in drafting treatment directives or their views on the usefulness of their involvement.

The aim of the study reported here is to shed light on the frequency of the involvement of notaries in drafting treatment directives, the nature of their involvement and the quality of the treatment directives they produce. Based on these results, I will consider the implications of notarial intervention for the effectiveness of treatment directives, that is, for assuring that the wishes of the author are known, correctly understood and implemented at the time of his incompetence.

Before proceeding with the presentation of the study, a linguistic note is necessary to clarify the terminology I will use in this chapter. My research deals with the social practice of treatment directives. However, in the case of notaries, it proved difficult to find a label that was both precise for purposes of the study, and usable in communication with the interviewees. When notaries refer to documents containing medical instructions to be applied should the author become incompetent, they almost always use the term *euthanasieverklaring* (euthanasia declaration). The standard forms they use (including the model supplied by the KNB) carry this title. This does not mean that these forms contain only an advance request for euthanasia. The KNB model, for example, contains a refusal of life-prolonging treatment in case of "a physical or mental condition due to disease, accident or any other cause, in which there is no prospect of recovery to a dignified condition of living," and a request for euthanasia, if, under the same circumstances, the withholding of treatment would not lead to death. Sometimes, the model used in a particular office also includes the appointment of a representative. In practice, notaries do not draw clear distinctions among the different sorts of documents. In the questionnaire used for this part of my research, I was more or less forced to use the term currently used by notaries, despite its imprecision for my purposes.[6] On the other hand, since the KNB model includes refusal of treatment and this model is practically always used by notaries to assist clients in drafting directives (as my data show), for purposes of my research, I can reasonably assume that a document that a notary calls a *euthanasieverklaring* will include a treatment directive. Consequently, in reporting the results of the study, I use

[5] *Notariaat Magazine*, 'Euthanasiemodel uit KNB-bestand.' Issue 2, February 2002. This decision was based primarily on criticism of the KNB model, especially from the Dutch Association for Voluntary Euthanasia (NVVE). Although discussion concerning the role of notaries in the drafting of *euthansasieverklaringen* was already going on at the time of our research, the KNB's decision came after our survey was completed, in February 2002.

[6] Where the distinction between different sorts of advance instructions was easy to make clear and did not create confusion (for example in questions concerning treatments most often refused in advance), I specifically referred to treatment directives, explaining the term to the notaries by means of an introduction to the question.

the term ‘treatment directive’ to denote what in the administration of the research was called a *euthanasieverklaring*. This choice is consistent with the rest of the book. But the reader should always keep in mind that practically every document containing advance medical instructions drafted with the assistance of a notary also contains a request for euthanasia.

2. The research questions

The first aim of my study was to estimate how many notaries provide assistance in drafting treatment directives, and how many of these documents they produce each year. Next I was interested in the opinions of notaries concerning the basic principles underlying the law (patient autonomy and the requirement of informed consent), their judgment concerning the importance of treatment directives in the medical decision-making process, and their views concerning the importance of their role in drafting these documents. Finally, I assessed the legal and medical quality of the treatment directives they draft, in an attempt to evaluate the potential influence of these documents on medical decisions concerning the author of the document. These three main groups of questions can be further specified as follows.

Frequency
- How many notaries have experience with treatment directives?
- How many treatment directives did the notaries in the sample draft in the previous year?
- How many treatment directives can we estimate to have been drafted by all Dutch notaries during the last year?

The answers to these questions are important both in connection with the question of the extent of the use of treatment directives in the population and also with the question whether the involvement of notaries is a significant part of the social practice of treatment directives.

Opinions
- What is the opinion of notaries about the principles underlying the WGBO provision giving binding legal force to treatment directives?
- How important do notaries consider their involvement in drafting treatment directives?
- What is the opinion of notaries concerning the impact of treatment directives on medical decision-making for incompetent patients?

What I sought to understand with these questions is whether notaries consider safeguarding the autonomy of a person in medical matters important, whether they

consider a treatment directive a potentially adequate means to do this, and whether they are committed to the task of supporting their clients in the fulfillments of this objective. A skeptical position of notaries toward the principle of autonomy and the usefulness of treatment directives would presumably justify in their minds a low investment in time and care in drafting the documents. On the other hand, a positive opinion of such legal tool should imply a serious effort to assure its effectiveness.

Effectiveness: legal and medical quality
- Do treatment directives drafted by notaries fulfill the legal requirements under Dutch law?
- What is their technical quality as legal documents?
- How is their availability at the time of implementation assured?
- Do they contain a provision for a personal representative?
- What is their medical quality: how are the treatment refused and the conditions of applicability specified?

These questions relate directly to the way notaries actually behave in drafting treatment directives and the potential effectiveness of the directives they draft. We can also compare the results here with the answers to the previous questions on opinions to see whether notaries behave consistently with their beliefs.

3. Methods

A telephone questionnaire was administered to notaries working in a sample of Dutch notarial offices. The interviews were carried out in the period November 2001 – January 2002. The sample of offices was randomly selected from a list of addresses supplied by the KNB.[7] The number of offices selected was 129 from a total of 880 Dutch notarial offices (15%). Seven offices were ineligible for the survey (3 of the offices selected had been involved in the pilot study to try out the questionnaire, 4 proved to be impossible to contact), bringing the total number of offices approached to 122.

Before the first telephone contact, a letter was sent to the office, briefly presenting the research and asking the office to identify the notary most acquainted with the practice of drafting treatment directives. Two or three days after sending this letter, the interviewer called the office, asking to speak with the notary considered to be the 'office expert' on treatment directives, and made an appointment for the interview. This procedure produced a quite high response rate: 93 of 122 offices agreed to co-operate (76%). This number represents approximately 10% of all Dutch notarial

[7] I used a proportionate stratified sample: that is for each geographical group the same proportion of offices was selected.

offices. Of the 93 respondents reached in this way, 34 stated that they had no experience at all with treatment directives and that the same was true for their colleagues. In this case the interview was limited to background information. Table 10 gives an overview of the distribution of notarial offices in the Netherlands and in the sample, and distinguishing within the sample between offices that collaborated (although sometimes none of their notaries had experience with treatment directives) and offices that refused. [8]

Table 10. Distribution of notaries by region and size of city (absolute values and percent in brackets)

	Region					Size of city			
	Population	Sample	Response	Refusal		Population	Sample	Response	Refusal
West	401 (46)	54 (44)	41 (44)	13 (44)	Big cities	413 (47)	57 (47)	44 (47)	13 (45)
South	197 (22)	27 (22)	23 (25)	4 (14)	Small cities	467 (53)	65 (53)	49 (53)	16 (55)
East	167 (19)	25 (20)	15 (16)	10 (35)					
North	115 (13)	16 (13)	14 (15)	2 (7)					
Total	880	122	93	29	Total	880	122	93	29

The request to identify the notary with most experience in treatment directives was intended to maximize the chance of contacting notaries with some experience in drafting these documents. However it also imposes a limitation on the interpretation of the results because once we had sampled an office, we had no further control over the selection of the respondent (except, of course, in the few cases of offices with only one notary). Furthermore, the data concern only the one member of the office we interviewed. These limitations will have to be kept in mind when I try to estimate the total number of treatment directives drafted by Dutch notaries.

4. Results

4.1. Experience with treatment directives

Although I explicitly asked to speak with the notary with the most experience with treatment directives, as noted already 34 of the 93 notaries who participated in the survey had no such experience. These 34 notaries do not significantly differ from the rest as far as individual characteristics are concerned (specialization and years of experience in the profession). They are significantly more concentrated in the West of

[8] The sample is representative of the Netherlands for both regional and city-size distribution (first and second columns of each sub-table, Table 1). Among non-respondents, the notaries from the Eastern region are overrepresented (fourth column, Table 1).

the country, in urban areas, especially in the four biggest Dutch cities,[9] and in offices with only one notary.

As far as geographical location is concerned, the outcome is rather unexpected in light of the general opinion that people in the West of the country, and especially in the big cities that are concentrated there, are more assertive about end-of-life issues. Our expectation was to find more treatment directives in that part of the country. In fact, notaries in the West are less familiar with treatment directives than those in the rest of the country. A greater availability in the West of other sources of assistance for drafting such documents may be responsible for this.

Concerning the effect of office size, it appears that notaries in solo practice are usually not involved in drafting treatment directives. In our sample we had 14 notaries working alone: 11 had never drafted a treatment directive, while the other 3 had done so but not in the last year. We can suppose that the smaller number of clients in a one-notary office decreases the chances of the office experiencing a request to draft a treatment directive.

When an office has more than one notary, drafting treatment directives is generally not limited to one specialist. Often all the notaries in an office do so, as is shown on Table 11 (squared cells). Apparently, drafting treatment directives is not a practice thought to require special expertise.

Table 11 – Notaries per office by number of notaries involved in drafting treatment directives

Notaries involved in drafting treatment directives	Notaries in the office					Total
	1	2	3	4	>4	
1	3	6	2	2	2	15
2		9	4	7		20
3			7	2	3	12
4				3		3
>4					9	9
Total	3	15	13	14	14	59

Squared cells: all notaries in the office are involved

4.2. Frequency

Seventeen of the 59 notaries who had some experience with drafting treatment directives had nevertheless not done so within the last year (see Table 12). The remaining 42 notaries had drafted between 1 and 18 treatment directives in the last

[9] Amsterdam, The Hague, Rotterdam and Utrecht.

year (18 being an isolated case), with a modal value of 2. None of the descriptive variables except office size (lower frequencies in small offices) appeared to have a significant effect on the number of treatment directives drafted in the last year.

Using these data, we can attempt to estimate roughly how many treatment directives were drafted by notaries in the last year, first in the offices in our sample and then in all Dutch notarial offices. If we sum up all the treatment directives detected among our respondents, we obtain a total of 136. To estimate the total number of treatment directives in the offices involved in the study, I take the total number of treatment directives detected per interviewed notary and multiply this by 2 if the interviewed notary declared that other notaries in the office also drafted treatment directives. If more than one other notary was involved in making treatment directives, this estimate could be conservative, but this is counterbalanced by the fact that I asked to speak with the notary in the office with the most experience in drafting treatment directives, so that we can expect that the respondent was usually the one making the most treatment directives. In this way, I conservatively estimate a total of 237 treatment directives for the offices in the sample (see Table 12). The sample covered approximately 10% of all Dutch notarial offices. We can therefore reasonably deduce that in the Netherlands in the year before my research (2001), roughly 2000 treatment directives were drafted by Dutch notaries. This would mean that a total of between 9,000 and 11,000 treatment directives have been drafted by notaries in the period since the WGBO became effective (1995) up to and including 2001. Of these treatment directives, 6000 to 7000 can be supposed to be still in effect in the Netherlands, while 3000 to 4000 will have been drafted for people who have since died.[10] Given the rough method of estimation, the actual numbers may be several hundreds more or less than these. It does, however, seem safe to conclude that while the involvement of notaries in drafting treatment directives is fairly limited, on the other hand treatment directives drafted by notaries are not rare. Supporting this impression, the data from the study on the nursing homes (next chapter) show that approximately 8% of the treatment directives among nursing home patients are notarial documents.

[10] These estimates are based on the plausible assumptions that: a) the number of notarial treatment directives proportionally increased until 2001 (each year, 200 new treatment directives were drafted); b) in 2001, the yearly total reached 2000 (see previous note); c) people who make treatment directives die at a constant rate of 10 % per year (that is, in 10 years, all of them will be dead). This last assumption is consistent with the results of the preliminary qualitative study (Hofman 2002), where notaries said that the typical client asking to draft a treatment directive is old, living alone and without strong social relations. For each estimate I give a lower and upper boundary; the lower one is computed under the assumption that notaries began to draft treatment directives in 1996, one year after the enactment of the WGBO, while the upper one assume a practice developing in the last 10 years, with a starting point in 1992. Changes in the basic assumptions, as for example a different death-rate, do not produce dramatic changes in the estimates.

Table 12 – Number of treatment directives drafted by each notary in the last year

	Number of treatment directives							
	0	1	2	3	4	5	More than 5	Total
Frequency	17	8	15	7	5	2	5	59
Total treatment directives per interviewed notaries	0	8	30	21	20	10	48	136
Expected treatment directives per offices	0	14	56	36	40	15	76	237

Since notaries do draft treatment directives with some regularity, it is interesting to note that they seldom take the initiative to inform their clients about this possibility (only 11 out of 59, or a little less than one fifth, say they ever do so). The idea of drafting a treatment directive thus usually originates with a client, who often goes to the notary with the specific purpose of having such a document made. Indeed, 39 of the 59 interviewed notaries said that clients regularly approach them just to make a treatment directive. The informal supposition with which I began the research, that notarial involvement in drafting treatment directives would usually be an adjunct to their (legally required) involvement in drafting wills, was apparently unfounded.

When notaries are asked to draft a treatment directive, they normally do so. Only a few notaries refer a client to another specialist, such as a doctor or the NVVE, for assistance in preparing the document (8 to a doctor, and 6 to the NVVE). On the other hand, 17 notaries said that they had experience with clients being referred to them by a doctor, suggesting that some doctors consider legal expertise important.[11]

4.3. Opinions

The notaries to whom I administered the questionnaire were asked to indicate their agreement with four statements concerning the right to refuse treatment, the possibility to do so in advance by means of a treatment directive, the role of such instructions in guiding medical decisions, and the importance of the involvement of a notary in drafting them. The results are shown on Table 13.

More than 90% of the interviewed notaries agree that a patient should be able to refuse any treatment, even if this decision may lead to his death (item 1) and that a refusal in advance should be as binding as a contemporaneous refusal (item 2). All of them think that a well-drafted treatment directive "can have a major influence on medical decision-making" (46 express complete agreement). Finally, many notaries consider it important that a person considering drafting a treatment directive have the assistance

[11] This idea is also suggested by De Jong 1997.

of a notary, although more differentiation can be seen in the answers to this item: 22 and 21 respectively agree completely or partly with the statement, while 11 and 5 disagree partly or completely.

In summary: most of the interviewed notaries recognize the right of patients to refuse treatment, contemporaneously and in advance, they believe in the effectiveness of treatment directives, and many of them consider notarial involvement in drafting treatment directives important.

Table 13 – Opinion of notaries

ITEMS	Completely agree	Partly agree	Partly disagree	Completely disagree	No answer
1. A patient should be able to refuse a treatment even when this refusal will result in death.	45	9	3	-	2
2. A refusal of treatment in a treatment directive should be as binding on a doctor as the refusal of a competent patient.	31	22	6	-	-
3. A carefully-drafted treatment directive can have a major influence on medical decision-making regarding the end of life.	46	8	-	-	5
4. It is important that people considering drafting a treatment directive have the assistance of a notary.	22	21	11	5	-

4.4. The legal quality of treatment directives

Legal requirements

The involvement of a notary deals effectively with problems connected with the identity of the author of a treatment directive, since in authenticating a document a notary assures the author's identity.

Dutch law further requires voluntariness and the competence of the author. In my data, only information about competence is available, but we can probably assume that the situation for voluntariness is similar. Legally, a person is presumed competent in the absence of evidence to the contrary.[12] Notaries rarely doubt the competence of their clients in connection with the drafting of a treatment directive (5 respondents regularly have doubts, while 53 seldom or never do). I asked them what they would do in a case where they doubted the competence of the client: half of the notaries would consult the client's doctor, the other half expressed confidence that they would be able to deal with the situation in further conversation with the client. In either case, all notaries will

[12] Van Veen 1998: page 44.

eventually proceed with the drafting of the document. It seems that the involvement of a notary does little to guarantee the competence of the author of a treatment directive. In effect, a doctor confronted by such a document must simply have faith in the notary's power of discernment.

Technical quality

The technical quality of a notarial treatment directive is highly dependent on the formulations used in the office models notaries generally use to draft such documents (57 of 59 say they use a model). These models are almost always taken directly or in slightly modified form from the model formerly supplied by the notarial association (KNB). Analyzing these models we can conclude that they exhibit several flaws. The most important are:

a) failure to distinguish between fundamentally different kinds of advance medical instructions;
b) use of imprecise terminology, not consistent with the law.

a) Notaries scarcely distinguish between an advance refusal of treatment and a request for euthanasia. The fact that the KNB model is entitled a '*euthanasieverklaring*' ('request for euthanasia'), although it includes both kinds of instructions, reflects and probably adds to the confusion. Such confusion is a rather serious matter since a written refusal of treatment and an advance request for euthanasia are regulated by different laws and have a completely different legal status. The right to refuse treatment in advance is provided for in the law on patient's rights (WGBO), while an advance request for euthanasia is regulated in the new Dutch law on euthanasia. The legal force of a written refusal of treatment is unquestioned, whereas an advance request for euthanasia has a doubtful legal status and is certainly not binding.[13] Notaries appear to be unaware of these fundamental distinctions and, in the documents they draft, they combine rules taken from the different laws and apply them to both kinds of instructions. For example, a passage in the KNB model that applies to both treatment refusals and euthanasia requests says that if the attending doctor refuses to comply with the instructions, the author requests transfer to another doctor. However, while a doctor is entitled to refuse to perform euthanasia, this is not the case for a refusal of treatment.

b) The time when the treatment directive comes into effect is described in the KNB model as follows: "this document takes effect when […] the author is unable to express himself".[14] However, the relevant legal criterion in the WGBO is that the

[13] See chapter 4, paragraph 2.2.
[14] The complete formulation in the KBN document is: "De comparant verklaarde dat deze wilsverklaring eerst aan de orde is, voor zover deze door hem op enig tijdstip niet bevestigd,

author "cannot be considered able to make a reasonable assessment of his interests [concerning medical treatment]".[15] A moment's reflection makes plain that the inability to express oneself can quite be a different matter from an inability reasonably to assess one's interests. Even though such use of imprecise terminology may not often give rise to problems of interpretation, since in many cases either formulation would suffice, the incorrect phrasing does reflect a lack of familiarity with the relevant legislation.

Availability

Availability is, as we have seen in chapter 3, a necessary condition for the effectiveness of the instructions contained in a treatment directive. Unlike legislation in some other countries (see Chapter 3, paragraph 5), the WGBO contains no specific provisions in this regard. As a practical matter, it seems that the most effective way to make sure that an advance directive will be available in case of need is to inform the relevant people, such as close family members and the family doctor, of its existence[16] and where possible to take further steps to ensure that the advance directive will be close at hand at the time of the decision-making.

Dutch notaries seem to be aware of this: 51 of the 59 say that they advise their clients to inform other people of the existence of their treatment directive.[17] Asked about the persons to inform and in which order, 40 notaries mentioned the family doctor (in 26 cases, as the most important person to inform). Notaries also mentioned the partner (29 cases, 21 times in first place) and the children (18 answers, but only once in first place). The preponderance of answers indicating the family doctor as the most important person to inform reflects the fact that the family doctor will often be the person responsible for implementing a treatment directive, and also in a position to inform other doctors (e.g. if the patient is taken to hospital). Recognition of the importance of the availability of a treatment directive is also evident in the statement by 38 notaries that they advise clients to have their directive included in their medical file (30 do so often or always, 8 regularly).

Renewal

As we have seen, a common argument against giving advance instructions binding

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gewijzigd, aangevuld of herroepen kan worden op grond van onvoldoende bewustzijn of onvermogen uit andere hoofde om zich te uiten."

[15] "In het geval waarin een patiënt […] niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, …" Art. 7:450, lid 3 BW.

[16] In the Netherlands, the main organization that distribute standard-form treatment directives (NVVE) urge those who use them to discuss their advance directive with their family doctor and to have a copy on file with him.

[17] The office models we received always include a provision that the notary has permission to inform the client's treating doctor about the existence of the document.

force concerns the possible difference between the current wishes of an incompetent patient and the instructions he expressed when he was still able to make decisions. Those who make this argument question whether the person who drafted the instructions and the impaired person who has to bear the consequences of its implementation are really the same 'person'.[18] Whatever force this argument may have is obviously greatest when the temporal interval between drafting and implementation of a treatment directive is long; a long time gap taken together with other intervening developments (e.g. new treatment possibilities) might even amount to a 'well-founded' reason for disregarding the instructions given.[19] It is therefore reasonable to assume that doctors are more likely to implement recently drafted or updated instructions. Notaries are aware of this: 51 of 59 notaries consider it important to renew a treatment directive from time to time, and 40 say they always advise their clients to do so.[20] Moreover, a validity of five years is specified in the office models normally used by notaries. However, these models do not include a provision such as that of the NVVE forms to the effect that the author is aware of and accept the risk that his wishes might change.

Appointment of a representative

The appointment of a representative can play an important role in the effectiveness of a treatment directive. Because of his personal knowledge of the author and his wishes, the representative is in a position to take decisions on behalf of the patient in situations not covered, or only partly covered, by the treatment directive. The representative can provide important information concerning its interpretation and can supply supplementary information to the doctor if the latter doubts whether the treatment directive is consistent with the current will of the patient.[21] The last circumstance is important because inconsistency between advance instructions and the author's actual wishes is considered to be one of the 'well-founded reasons' that permit a doctor to refuse to follow a treatment directive.[22] Finally, a representative can insist that the treatment directive be followed and take the necessary steps to enforce it.

Although I did not collect direct information from the notaries concerning the frequency with which they include the appointment of a representative in a treatment directive, I did analyze the models they use. The KNB model includes the appointment of a representative. However only 5 of the 18 office models we received contained

[18] See e.g. Tonelli 1996.
[19] The law provides that a doctor can decline to follow a treatment directive if he has "well-founded reasons" to do so. See Chapter 4.
[20] When the notaries who consider it important to renew a treatment directive were asked how often this should happen, 34 answered every 5 years, 9 said more frequently than 5 years and 2 said less frequently. Six of them did not answer the question.
[21] Van Veen 1998: 46-47.
[22] *Ibid.*: 48-49.

such a provision. We can therefore suspect that such a provision is often not included when a notary drafts a treatment directive.[23]

4.5. The medical quality of treatment directives

A refusal of treatment expressed in a treatment directive will be ineffective if the doctor cannot use it as a secure guide to decision-making. Clear specification of the conditions of applicability and the treatments refused are key to the success of a treatment directive in influencing a doctor's actions. Unfortunately, neither element is regularly present in the treatment directives drafted by a notary.

The office models notaries use to draft treatment directives do not usually specify the conditions of applicability[24] and never explicitly mention any refused treatment. The majority of the models simply read as follows:

> *If at any time I am permanently in a physical or mental condition due to disease, accident or any other cause, in which there is no prospect of recovery to a dignified condition of living, I explicitly declare it my wish that no life-prolonging treatment be applied to me and that I be allowed to die while receiving comfort and palliative care.*

Empirical research has repeatedly shown that such general instructions fail adequately to communicate the preferences of the author concerning medical treatment at the end of life. In particular, a study by Schneiderman et al. (1992) found that patients whose treatment directives contained similar generic instructions (namely, "I do not want life-sustaining treatment to be provided or continued if the burdens of the treatment overweigh the expected benefits") in fact had preferences that were rather different from what they actually received.[25]

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[23] The same indication emerged from the qualitative pilot study conducted before our research. See Hofman 2002.

[24] The KNB model does specify some situations where the medical instructions are applicable, but such provisions are included in only 5 of the 18 office models we received. The KNB list is as follows: a condition of severe and/or prolonged terminal suffering; an irreversible coma; the permanent and (nearly) complete loss of the capacity for mental activity, communication and the ability to take care of oneself.

[25] Schneiderman et al. 1992.

Table 14 – Are conditions of applicability and treatments refused specified in the treatment directives drafted by notaries?

	Condition		Treatment refused	
	Freq	Percent	Freq	Percent
Yes	11	18.6	8	13.8
No	48	81.4	50	86.2
Total	59	100.0	58*	100.0

* 1 missing case

Actual notarial practice may improve on the vagueness of the models but, as Table 14 shows, only 11 interviewed notaries said they specify the conditions of applicability of the instructions.[26] Dementia does not appear at all among the conditions specified by notaries. Even fewer notaries (8) said that the directives they make specify the treatment the client refuses.[27]

In the qualitative study that preceded our survey,[28] the notaries seemed to attribute the lack of specificity of the treatment directives they draft to their clients. They perceive their role to be limited to recording of the will the client without interfering with his opinions or wishes. They do not believe that they should try to influence the substance of a directive, seeing this as the personal business of the client. The plausibility of this belief would be severely weakened if notaries actually use the models analyzed above. Moreover, notaries are involved in the process of drafting treatment directives because they are considered experts. Presumably, they should at least be aware of the fact that generic instructions risk being ineffective and advise their clients accordingly. Their own view that involvement of a notary is important certainly requires no less.

From the above findings we can conclude that actual notarial practice concerning treatment directives reveals a fundamental lack of competence. This may be partially explained by the fact that notaries get their information mostly from legal publications (KNB, law books and journals). None of them mentioned medical publications as a source of information about treatment directives or advance requests for euthanasia, and only two said they get information from family doctors. Of even greater concern is the fact that six notaries (one tenth) had never consulted any source of information at all (see Table 15). Notaries seem in practice to be primarily concerned with the formal aspects of treatment directives, and to pay little attention to the practicalities of implementation.

[26] The most frequently-mentioned condition of applicability being an incurable disease such as cancer or AIDS (3 notaries).
[27] The most frequently mentioned treatment specifically refused is artificial ventilation (3 notaries).
[28] Hofman 2002.

Table 15 – Source of information about treatment directives

Source	Frequency*
Legal publications	45
NVVE	13
Internet	6
Family doctors	2
Other sources not specified	2
No sources	6

* more than one answer possible

As a possible remedy to low level of medical knowledge on the notary's side, it might help if the client's family doctor were involved in the process of drafting the document. However only 19 notaries said that the doctor of the client is involved in the drafting of a treatment directive, and of these, only 4 said that this occurs often or always.

5. Discussion

Our results indicate that a significant number of Dutch notaries are regularly but not frequently involved in drafting treatment directives: in a random sample of 93 offices, we found at least 59 notaries [29] with some experience in this regard. Forty-two of them had drafted at least one directive in the past year. Extrapolating from our sample, we estimate that in 2001 some 2000 treatment directives were written by notaries, while another 6000 to 7000 notarial treatment directives written in the preceding years were in existence circulating in the Netherlands in 2001.

The initiative to draft a treatment directive usually originates with the client, who goes to a notary specifically for assistance in drafting the document. This gives rise to the following question: Why would a person invest energy and money to have his treatment directive drafted by a notary? Since the main purpose of the legal recognition of these documents is to effectuate the autonomy of their authors, and assuming that this is also the typical author's main reason for drafting one, we can suppose that a person who seeks the assistance of a notary does so in order to produce a legally valid and practically effective document. For their part, notaries are confident concerning the role of treatment directives in guiding medical decision-making and they consider their involvement in drafting the documents to be important.

Nevertheless from our research, it appears that the added value of the involvement of a notary in the procedure is in fact pretty much limited to affording assurance about the

[29] The total is underestimated because in offices with more notaries it is often the case that more than one of them deals with such documents.

identity of the author and an inexpert check on his competence. Fulfilment of the minimal legal requirements of the Dutch law, which can easily be accomplished with a pre-printed form, does not seem to be a sufficient reason to turn to a notary for help.

The added value of involving a notary might in he first place be sought in the technical quality of the directives they draft. In this regard, the performance of Dutch notaries is disappointing. From their models, we can see that notaries fail to distinguish between fundamentally different kinds of instructions (refusal of treatment and request for euthanasia). The language they use in the documents is confusing and inconsistent with the relevant legislation.

As far as the availability of notarial treatment directives is concerned, if clients follow the suggestions of notaries to inform other people, especially their family doctor, about the existence of the document, this may contribute to the availability of directives when the author is no longer competent and treatment decisions must be made. But notaries themselves take no steps to insure the availability (for example, by involving the patient's doctor in the drafting process).

Notaries consider it important that a treatment directive be regularly renewed, and they do advise clients to do this. This is important, since one reason for doubting the effectiveness of these documents involves the possible inconsistency between instructions previously expressed and the present wishes of an incompetent patient. A recent directive can decrease the force of such concerns.

The added value of the involvement of a notary is particularly dubious as far as the medical quality of directives is concerned. Notaries produce exactly the sort of vague and general documents that have repeatedly been shown in the literature to be incapable of guiding medical decision-making. What are the reasons for such a low medical quality of treatment directives drafted by notaries? One possible explanation, suggested by the notaries themselves, is that notaries consider their task to be limited to recording the will of the client. Therefore, if a client does not have clear and outspoken ideas about precisely what he does not want and merely expresses a general preference for less treatment, a notary is unlikely to press for more specificity.

Another explanation for the poor medical quality of notarial treatment directives is that notaries underestimate the complexities surrounding the practical implementation of a treatment directive and are not aware of the importance of clear and unambiguous instructions.[30] As a consequence, the documents drafted by notaries run the risk of being useless in the implementation process, having a mainly symbolic value, and simply revealing that the author had thought about end-of-life issues and had some

[30] We can suppose that notaries are not aware of the literature on the subject, and the KNB does not provide them with any relevant guidance.

general preference for limited treatment. Although such a directive may ease the difficult position of the family in making end-of-life decisions, and may make it easier for a doctor to stop a treatment which he considers to be futile, it fails to provide a clear guide for medical decision-making. Such generic directives only provide support for medical decision-making in non-problematic cases, where the treating doctor and the family of the patient agree on limitation of life-sustaining treatment. In such a case, the decision-makers need only supplementary support for their choice, and a directive which expresses some wish for limitation of treatment can play this role.[31] In more complex situations, such unspecific documents are unable effectively to guide the decision-making process or to resolve a conflict between different actors, such as doctors and representatives. Precisely where the autonomous preference of the patient himself is needed, it will be largely unknown.

The appointment of a representative to see to the implementation of the wishes expressed in advance could represent a partial remedy to the problems mentioned, leaving the final decision to a person presumably close to the patient and selected by him. However there is no evidence of a widespread practice of including the appointment of a representative in notarial treatment directives.

Summing up, it seems that in the Dutch situation the value of the involvement of a notary in drafting a treatment directive – given current notarial practice – is negligible. Aside from some slight possible influence on the availability and up-to-dateness of treatment directives, and a probable positive symbolic influence at the point of implementation due to unwarranted respect for the formality of a notarial document, it is doubtful that the involvement of notaries significantly increases the effectiveness of treatment directives. Considered cumulatively, these results undermine both the rationale of clients in seeking the counsel of a supposed legal expert and the confidence expressed by notaries in the importance of their role.

In the light of our results, the advice of the Notaries' Association to their members to put a stop to the practice of drafting treatment directives and instead to refer interested clients to the NVVE seems sound. Notaries do draft a small but significant number of treatment directives, but the added value of their involvement is, given current practice, too dubious to justify itself. However, given the current practice of notaries in drafting such documents, we can expect that a number of clients will continue to address their requests to a notary. If, despite the suggestions of their association, these notaries continue to assume the role of expert, the need for a serious effort to improve their practice in several respects cannot be avoided. First, they should improve the office models they use, making them more consistent with the relevant law (WGBO). Second, they should increase their knowledge of the practical working of this kind of

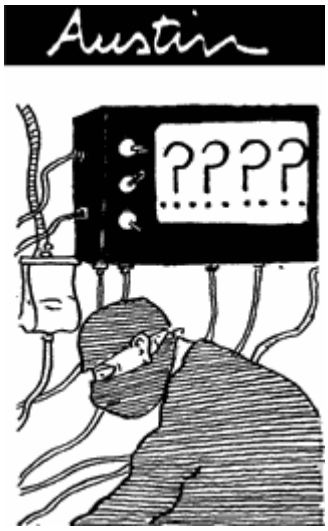
[31] To give an example, consider the situation of an old incompetent patient in the last stages of dementia complicated by an infection that could easily lead to death if left untreated.

written medical instruction. This knowledge will help them to become a reliable source of counselling for their clients and to produce documents that will assure that the author's attempt to continue to control the decision-making process should he become incompetent are as effective as possible. Third, simultaneous involvement of both the notary and the family doctor in the process of drafting a treatment directive could assure a higher level of effectiveness, securing both good legal and good medical quality in the same document. Finally, the standard inclusion in notarial directives of a provision appointing a representative for the client, should he become incompetent, could be of considerable importance in improving effectiveness at the point of implementation.

CHAPTER VII

THE ROLE OF NURSING HOME DOCTORS IN THE SOCIAL PRACTICE OF TREATMENT DIRECTIVES

Nursing homes seem *a priori* a good place to study the social practice of treatment directives. The patients constitute a large group of the potential users of treatment directives, consisting mainly of old people confronted with end-of-life questions. Moreover the cognitive abilities of the patients are often deteriorating, resulting in partial or complete impairment of the capacity to make competent choices. In nursing homes more often than in other medical institutions, a treatment directive could therefore be relevant in the medical decision-making process. In this chapter, I present the findings of a study of the social practice of treatment directives carried out in several Dutch nursing homes.



David Austin, from The Guardian Unlimited 5/11/2004

1. Methods and instruments

1.1. Sample

I selected a sample of 44 institutions from a list of all 305 Dutch nursing homes.[1] The sample was stratified in three groups:

- confessional nursing homes;[2]
- Amsterdam nursing homes;
- the rest (here called 'general nursing homes').

For the first and second group, there are good reasons to suppose that the situation could differ from that in general nursing homes. Confessional nursing homes might differ in respect to institutional regulations and doctors' and patients' behavior related to treatment directives, due to the relevance of specific values derived from religious beliefs. The city of Amsterdam differs historically from the rest of the country concerning euthanasia practice,[3] so it seemed likely that treatment directive practice would also be different there. In these two groups, I over-sampled at the level of 30%, in order to secure more reliable information. In the group of general nursing homes, I selected 15% of the institutions. The result was 10 confessional nursing homes (6 protestant, 4 Roman Catholic), 5 Amsterdam nursing homes and 29 general nursing homes.

The managers of the 45 selected nursing homes were contacted by telephone to obtain their consent to carry out the study in their institutions and to ask for the names and addresses of the doctors working there.[4] With the names received, I built the final list of the doctors to be interviewed. The managers were also asked to answer a semi-structured telephone interview, covering some basic data about their institutions (e.g. number of beds, kind of patients, and so on) and about the institution's policy concerning the practice of treatment directives. After having received the names of the doctors working in the selected institutions and having built the final list of the doctors to be interviewed, I sent them a letter describing my research. The letter included a short written questionnaire dealing mostly with quantitative data (number of patients, number of deaths in the last year, number of advance directives among patients, and so on). The doctors were then approached by telephone and an appointment for an interview was fixed.

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[1] The list was supplied by ARCARES, national association for nursing and care (www.arcares.nl). From the list, we excluded institutions devoted to the care of people belonging to religious orders.

[2] The list received from ARCARES reports whether a nursing home is or is not confessional.

[3] See Van der Wal 1992: 25-26.

[4] Hans Konst, with whom I collaborated in various aspects of the research is nursing home director. He carried out the first telephone contact with the request for consent to participate in the study. After having received consent he also carried out the short interview with the managers.

1.2. Nursing home response rates

Thirty-six of the 44 nursing home managers replied positively to the request to supply the names of the doctors working in their institutions, but, despite this previous agreement, 9 nursing homes withdrew consent at the time of the interviews, mostly for organizational reasons. Eventually, 27 nursing homes entered the final list: 16 general nursing homes, 8 confessional nursing homes (4 catholic, 4 protestant) and 3 nursing homes from Amsterdam. The data concerning the nursing homes in the sample, as far as regional, sub-sector and sampling group distribution are concerned, are presented in Table 16. There also the relative response rates for sub-groups are reported. A comparison with the data concerning the whole list of nursing homes supplied by Arcares is included.

The response rates of the different sorts of nursing homes remain always comparable, except for the confessional nursing homes (higher, 80%) and for the institutions devoted to the care only of somatic patients (none of which participated). This response, connected with the sampling procedures, produced some distortion in the final list of the nursing home participating in the study: confessional nursing homes and Amsterdam nursing homes are overrepresented, while no somatic nursing homes are present in the final list. Complementarily, psycho-geriatric nursing homes are proportionally overrepresented. This last fact is also reflected in the distribution of beds per sub-sector, where the proportion of psycho-geriatric beds is greater in the sample than in the population of Dutch nursing homes (Table 17).

However, the distortions in the sample are not dramatic (for example, the distribution for geographical location is very similar to that for all Dutch nursing homes). Even as far as the average number of beds is concerned, the nursing homes in the final sample do not differ significantly from the rest of the country (Table 17).

Given these results and considering the fact that the institutions included in the study account for approximately 5000 beds (a little less than 10% of all the available nursing home beds in the Netherlands), we can conclude that the final group of nursing homes that participated in the study represents a good picture of the situation in the Netherlands, and the results can be cautiously generalized, although the sample is not strictly speaking representative.

Table 16. Distribution of the nursing homes at the national level, in the sample, and relative response rates

	Netherlands, from Arcares list (N = 305)		Sample (N = 44)		Nursing homes that participated (N=27)		Response rate
	Abs.	%	Abs	%	Abs.	%	.
Total	305		44		27		61%
Per geographical location:							
North	38	12%	5	11%	3	11%	60%
West	150	49%	21	49%	13	48%	62%
East	54	18%	7	16%	4	15%	57%
South	63	21%	11	24%	7	26%	64%
Per sub-sector (3 missing):							
Combined	217	72%	32	73%	20	74%	62%
Psycho-geriatrics	53	18%	10	23%	7	26%	70%
Somatic	32	11%	2	5%	0	0%	0%
Per group of sampling:							
General	256	84%	29	66%	16	60%	55%
Amsterdam	15	5%	5	11%	3	11%	60%
Confessional	34	11%	10	23%	8	29%	80%

* From the list of the Arcares members 2001, excluding the *kloosterbejaardenoord* (institutions devoted to the care of people belonging to religious orders).

Table 17. Number and distribution of nursing home beds at national level and in the sample

	Netherlands* N=328	Netherlands** N=305	Sample N=44	Nursing homes that participated N=27
Total number of beds	59865	51839	7730	5005
Average per nursing home	183	172	176	185
Distribution of beds per sub-sector:				
Combined	80%	75%	70%	72%
Psycho-geriatric	13%	17%	27%	28%
Somatic	7%	8%	3%	0%

* From the list of the Arcares members 2001.
** From the list of the Arcares members 2001, excluding the *kloosterbejaardenoord* (institutions devoted to the care of people belonging to religious orders).

Some other descriptive characteristics of the nursing homes that participated in the study are of interest. Of the 5005 beds they account for, almost two thirds are for psycho-geriatric patients (Table 18). When we consider that 84% of these nursing home patients die inside the institution,[5] we can suppose that the acquaintance of the interviewed doctors with end-of-life decision-making for incompetent patients is rather

[5] Arcares "Grezen verleggen (Jaarverslaag 2003)." Available at www.arcares.nl, accessed on 1/12/2004.

high. This supposition is also supported by the rather high yearly patient turnover (defined as the number of deaths for 100 beds per year).

Table 18. Total number of beds by categories of patients, total number of deaths, and turnover

	Abs. values	%
Total number of beds	5005	
Of which:		
Chronic somatic patients	1328	27
Short term somatic patients	405	8
Psycho-geriatric patients	3144	63
Special categories: Korsakov and others	128	3
Total number of death	2279	
Average annual turnover (deaths per 100 beds)	43	

1.3. Terminological clarification

Before proceeding with the presentation of the instruments used, a terminological note is necessary. My research deals with the social practice of treatment directives, and the main focus of interest is on these specific documents. However, in nursing home practice, the distinction between treatment directives, proxy directives and advance requests for euthanasia is not always recognized. In practice, different sorts of directives are often covered in one document. This reflects the formulation of the most widely available standard forms which include all three sorts of directives in the same document.[6] Since a single document often contains different directives, it is common that in everyday discourse little distinction is made between the different sorts of directives.

Schriftelijke wilsverklaring (written expression of will) is the general term that nursing home doctors use to refer to any document that contains medical instructions for doctors in case the author should become incompetent. In carrying out research, it is often not possible to disentangle behavior related to treatment directives from other behavior, since how doctors deal with a directive is often the same no matter what the content of the directive is (for example, as far as archiving the documents in the latency phase is concerned). As a consequence, many of the questions refer to *schriftelijke wilsverklaringen* in general.

When a clear distinction was possible, I specified that the question referred only to treatment directives (in Dutch, *schriftelijke behandelweigering*, written refusal of treatment). This was the case, for example, for the questions about the contents of

[6] This is as true for the NVVE form as for the notarial model examined in chapter 6, although the NVVE form keeps the three parts separate, gives different titles, and is otherwise much more detailed and precise.

treatment directives (treatment refused and conditions of applicability), about their implementation, and about the opinion of the doctors on the role of treatment directives in the medical decision-making process.

As in the previous chapter, in the following presentation I will use the label 'advance directive' when in the questionnaire the reference was to *schriftelijke wilsverklaringen*, while I will use 'treatment directive' when such specificity is possible. The reader should keep this in mind. Although I have tried to be as clear and precise as possible, it is impossible to avoid completely the ambiguity that exists as a matter of fact in the social practice of treatment directives in the Netherlands.

1.4. The instruments

Three instruments were used to collect information about the social practice of treatment directives in the nursing homes:

- a semi-structured questionnaire for the managers;
- a short written questionnaire for the doctors;
- a telephone interview for the doctors.

The semi-structured questionnaire for managers

During the initial telephone contact with managers, a short questionnaire was administered to get some information about their nursing homes and about the practice of advance directives in their institutions. These questions referred to advance directives in general, since the aim was to collect some general information on how advance written instructions were being handled in the nursing homes in the sample. The managers were asked about local agreements, policies or protocols concerning the management of advance directives; they were asked to estimate the total number of current residents with an advance directive; and they were asked about the way information on advance directives is transferred when a patient is admitted to another institution (hospital or nursing home).

The written questionnaire for doctors

The short written questionnaire for doctors included quantitative questions concerning the patients treated. It was attached to the introductory letter mentioned above. The questionnaire was meant to give the doctors the opportunity to think about these quantitative questions in advance of the interview, possibly checking their files, and thereby to give us figures that would be as reliable as possible. The doctors were requested to send the questionnaires back after the telephone interview. Nonetheless, qualitative information concerning the total numbers of advance directives among their patients was also collected during the interview.

The written questionnaire consisted of two blocks:

- questions asking for quantitative data concerning the practice of the nursing home doctor concerned (number of currently treated patients, categories of patients, number of patients who died in the last year);
- questions referring to the number and kind of advance directives among the current patients and the patients who died in the last year.

The telephone interview with nursing home doctors
The main instrument used to collect the information was a broad structured telephone questionnaire which lasted approximately 25-30 minutes. The interviews were carried out in October-December 2002.

Apart from a few biographical questions on education, training and experience as a nursing home doctor and a battery of items on the doctor-patient relationship, the questionnaire focused on the different phases of the social practice of advance/treatment directives. Some questions dealt with advance directives in general, when making a distinction between different sorts of documents was practically impossible.[7] Otherwise, the doctors were asked specifically about treatment directives. The specific kind of document to which each question referred was always made clear during the interview, in order to avoid any kind of confusion or ambiguity.

Most of the time the doctors were asked questions about their own behavior in connection with the social practice of advance (treatment) directives. However, on a few occasions, I utilized hypothetical questions where too concrete a question might simply have produced a generic answer. An example is the question on the implementation of treatment directives. The process of implementation of the instructions contained in a treatment directive is influenced by several contingent factors and varies from case to case; it is therefore impossible to ask what a doctor usually does. In this case, I presented a hypothetical situation and asked the doctor to give his opinion about it.[8]

1.4. Response rate and description of the sample of nursing home doctors

The managers of the 27 nursing homes that participated in the study supplied the names of 96 doctors. Of these, 77 agreed to answer the questionnaire, while 19 did not. Of these 19, 4 explicitly refused, and 15 were not reachable. The overall response rate

[7] For example: the questions concerning the sources that the doctors utilize to collect information on advance directives, since the professional publications and the courses dedicated to this subject often cover both treatment directives and *euthanasieverklaringen*. See also the terminological clarification above, paragraph 1.2.
[8] The same is true for the questions concerning the role of treatment directives in the decision-making process.

was therefore 80%.[9] Not all doctors who agreed to be interviewed sent back the written questionnaire. As a consequence, complete quantitative data are available only for 38 of the 77 doctors.[10]

Although national data are not available to compare with the characteristic of the doctors in my sample, a comparison is possible with the KNMG evaluation research of 1999 on the implementation of the WGBO.[11] As we can see on Table 19, the values found in that study for nursing home doctors are very similar to those for the nursing home doctors who participated in my study. The proportion of men and women is identical, the average age does not significantly differ, and the same can be said both for the functions the interviewed doctors represent (registered doctors or doctors in training) and for their average years of experience as nursing home doctors. In summary, although the way the group of doctors interviewed in my study was constituted does not permit me to qualify it as a representative sample of the population of Dutch nursing home doctors, it does seem to correspond closely with the samples in similar Dutch research.

Table 19. Biographical characteristics of the interviewed compared with the ones in the KNMG evaluation research

	My sample	KNMG study
	N=77	N=98
Response rate (%)	80%	61%
Sex		
Man	49	49
Woman	51	51
Age		
Mean	43	41
s.d.	8	8
Function		
% registered NH doctor	78	83
% other specialization	9	-
% in training	13	17
Years of experience as NH doctor		
Average	11	10
s.d.	7	7

[9] If we consider all 36 nursing homes whose managers gave in first instance consented to participate, the number of names of doctors received was 125. The 9 homes that later withdrew consent accounted for 29 doctors. In this case, the response rate would be 61% (77 of 125).

[10] The estimates of the number of advance directive among the nursing home patients are therefore partly based only on the answers collected during the telephone interviews. See section 2.2.1 in this chapter.

[11] Dute et al. 2000: 447-462.

2. The social practice of treatment directives in Dutch nursing homes

The following paragraphs present the empirical findings of the study of nursing home doctors. The presentation is organized following the scheme of the questions given in Chapter 5. I begin with a short paragraph reporting the information collected in the semi-structured interviews with the managers.

2.1. The practice of advance directives according to the answers of the managers[12]

All the questions put to the managers referred to advance directives in general. None of the surveyed nursing homes have protocols or policies concerning the practice of advance directives. Apparently, the matter is still treated on a case by case base by individual doctors. Nonetheless, institutional practices connected with advance directives seem to be rather similar.

In 28 of the 36 nursing homes in the sample, on admission of a patient a specific inquiry is made concerning the existence of an advance directive; if an advance directive exists, it is always included in the patient's file (*medisch-* or *zorg-dossier*). The treating doctor is always informed of its existence (usually, all other members of the team which cares for the patient are also informed: 23 nursing homes). In case of hospitalization, 30 of the 36 nursing homes take steps to ensure that the advance directive follows the patient either in a written note calling attention to its existence or by including a copy in the patient's documentation. From the answers received from manages, we can therefore reasonably expect that if a nursing home patient has an advance directive, it will usually be in place when needed.

The supply of information to incoming patients is quite a different matter. Only 2 nursing homes offer standard information about advance directives at the time of admission. We can conclude that in general admission to a nursing home is not an occasion at which an incoming patient (or his family) learns of the possibility to draft an advance directive.

2.2. The practice of advance directives according to the answers of the doctors

2.2.1. Frequency of advance directives

To estimate the frequency of advance directives of all sorts among nursing home patients, I use three different sorts of data collected in my study:

- data from the telephone interviews with nursing home doctors;

[12] I include here all 36 interviews with managers, although in 9 nursing homes there were no further interviews with the doctors.

- additional data collected from a subgroup of the interviewed doctors who agreed to complete a more detailed written questionnaire concerning the frequency and contents of advance directives in their practice;
- estimates made by the managers concerning the number of advance directives among all the patients of their institutions.

These sources lead to very similar conclusions, as shown in Table 20. The questions to doctors about how many of their current patients have an advance directive, produced a total of 168 advance directives (129 drafted before and 29 drafted after admission). The proportion of patients with an advance directive, obtained by dividing the total number of advance directives by the total number of patients, is 4.5 out of 100. In other words, about 1 patient in 20 in Dutch nursing homes has an advance directive. The same proportion of advance directives was reported for patients who died during the last year (4.7%). These results are confirmed from the data additionally collected from the subgroup of doctors who agreed to fill a written questionnaire and from the estimates of the managers (Table 20, column B and C).

Table 20. Number of advance directives (ADs) detected and proportion among patients

	A. From telephone interview (N=77)	B. From written questionnaire (N=38)	C. From estimates of the managers (N=36)
Current patients: ADs before admission	129	70	n.a.
Current patients: ADs after admission	39	25	n.a.
Total ADs among current patients	168	95	290
Total number of current patients	3768	2047	6210
Frequency of ADs per 100 current patients	4.5	4.6	4.7
ADs among patients who died in the last year	68	23*	n.a.
Total number of patients who died in the last year	1434	478*	n.a.
Frequency of ADs per 100 patients who died in the previous year	4.7	5.1	n.a.

* 4 missing cases

Since these results outcomes suggest that, compared with the situation in USA and Canada,[13] advance directives are infrequent among nursing home patients in the Netherlands, we can wonder whether there is an unfulfilled potential demand for advance directives. In the opinion of the doctors who have some competent patients (N=56), this is not really the case: only 3 of them think that many of their competent patients would potentially be interested in advance directives, while half (30) consider only some of their patients interested.

[13] See Chapter 3, paragraph 2.

Table 21. How many competent patients interested in ADs? (N=56)

Patients interested in ADs	Frequency
Many	3
Some	30
Almost none	23

2.2.2. The kind of instructions contained in advance directives

As we have seen, an advance directive can contain a refusal of treatment (treatment directive), the appointment of a representative (proxy directive) and a request for euthanasia. Detailed information concerning the kind of instructions contained in the detected ADs is only available from the written questionnaires, answered by 38 doctors. In these written questionnaires, the doctors were asked to indicate the specific kind of instructions the advance directives of their patients contain. The results are presented in Table 22.

Table 22. Number of ADs, data from written questionnaire (n=38)

	A Current patients	B Patients deceased in the previous year
Total ADs	95	28
Contents specified	84	22
Contents not specified	7	6
When specified, the content was (%):		
1. only a treatment directive	33%	27%
2. only a proxy directive	21%	5%
3. only a euthanasia request	31%	27%
4. a combination of the previous three and specifically:	14%	41%
- treatment dir. + proxy directive	4%	0
- treatment dir. + euth. request	7%	32%
- treatment dir. + proxy dir + euth.	4%	9%
In summary, ADs contained at least (%):		
- a treatment directive	48%	68%
- a proxy directive	29%	14%
- a euthanasia request	42%	68%

Based on the previous table, some observations are possible:

a) About half of the advance directives contain a treatment directive;

b) there is a discrepancy between the advance directives of current patients and those of patients who died in the previous year, the latter more often containing a treatment directive;
c) in almost half of the directives of patients who died in the previous year (32% + 9%), a treatment directive appears together with a request for euthanasia;
d) proxy directives are less common than the other kinds of instructions;
e) treatment directives and euthanasia requests are about equally frequent (48 vs. 42% in current patients, 68% in both uses for deceased patients).

These observations help us to understand some of our other findings. They help to explain the confusion that exists among the doctors between treatment directives and requests for euthanasia, since the two kinds of instructions occur with almost the same frequency and they are often together in the same document. We may also be able to explain the differences between the directives of current patients and those of patients who died in the previous year. In my opinion, the differences between the two categories are not as big as they appear. A doctor only has to focus on the specific content of a directive at the time of its implementation. Before that time, he may have read the directive superficially and may not be able to remember exactly what the instructions listed there are: he knows only that a document exists containing some medical instructions to follow in case the author becomes incompetent. If this is true, his classification of the document within a group defined by its contents is likely to be unreliable, with a tendency to remember rather impressionistically what the document was about. For example, in the case of a directive drafted by the patient with the help of a notary, it is possible that the doctor will remember the title (*euthanasieverklaring*) and will therefore say that that directive contains only a euthanasia request. This supposition might explain the fact that only 14% of the advance directives of current patients are social to contain a combination of instructions, while this is true in 41% of the cases of advance directives of deceased patients. This line of thought seems to be confirmed by the data concerning the forms used to complete these directives. Since almost a half of the advance directives among current patients are drafted using the forms supplied by the NVVE (Table 23) and given that these forms contain all three kinds of instructions, we can suppose that the advance directives of current patients will contain a combination of instructions much more often than the doctors reported. In short, it seems safe to conclude that nursing home doctors' reports concerning the sorts of advance directives among their current patients are not reliable.

The doctors were also asked what, in their experience, are the main reasons for patients to draft an advance directive. The reason that in their view most often moves a patient to draft an advance directive is a terminal illness. This suggests that advance directives in nursing homes are usually not meant for a hypothetical situation, more or less unforeseeable, but for a situation that is highly probable and anticipated in the

near future. Fear of dependence and fear of dementia are also mentioned as reasons to draft advance directives.

Table 23. Kind of forms used to draft the advance directives among current patients

Kind of form	Freq.	%
Selfmade document	35	37
NVVE form	45	47
Notarial document	8	8
Other kind	5	5
Not specified	2	2
Total	95	

Table 24. Reasons to draft an advance directives (row percentage)

Reasons to draft an advance directive	Always or often	Regularly	Seldom or never
Terminal illness	38	36	26
Fear of progressive dependence	31	46	23
Fear for dementia	27	35	38
Serious operation	4	5	91
Old age	3	12	85

2.2.3. The experience of doctors with advance directives

Although only one patient in 20 has an advance directive (see previous paragraph), it is quite common for a nursing home doctor to have a few patients with advance directives. More than three quarters of the doctors interviewed (61) have at least one patient with an advance directive either among their current patients or among the patients who died in the previous year. Only 16 have never experienced any patient with an advance directive (Table 25, column A). The modal frequency of advance directives per doctor is between 2 and 5 (41 doctors fall in this group). The highest frequency of some experience with advance directives is among current patients (column B). Nevertheless, it is interesting to note that almost half of the doctors (36) were recently confronted with an advance directive in a practical situation of decision-making for a patient who died (column C).

Table 25. Frequency of advance directives (AD) among current patients and patients who died in the previous year (N=77)

Experience with advance directives		A Total AD experienced	B Among current patients	C Among patients who died in the previous year
None		16 (21%)	23 (30%)	41 (53%)
At least one		61(79%)	44 (70%)	36 (47%)
How many ADs for doctors with at least one AD				
	1	8	11	17
	2-5	41	36	18
	6-10	9	7	1
	11-20	3	1	0

2.2.4. Nursing home doctors' knowledge concerning advance directives

A good knowledge of the legal and practical aspects connected with advance directives is an important condition for following the applicable legal rules and is presumably associated with behavior that promotes an effective use of these documents. We therefore asked the nursing home doctors what information about advance directives they had received, either written material, lectures or consultation with colleagues. Although a majority of the interviewed doctors have been exposed to some information about advance directives (written material or lectures), one quarter (18) had neither read anything nor been to a lecture on the subject (Table 26). Of these 18 'uninformed' doctors, only a minority (7) had filled the gap by consulting a colleague (Table 27).

As far as written information is concerned, we asked for further specification. Among the 49 doctors who had read something about advance directives, only 4 had read a legal text. The rest of the doctors had read medical publications (books or journals), or publications of the NVVE.[14] That means that doctors rarely have direct knowledge of the legislation on advance directive; they rely on second-hand information, filtered by more or less expert sources.

Table 26. Source of information about ADs (n=77)

Sources of information	Frequency	Percent
Both written and lectures	18	23
Only written	31	40
Only lectures	10	13
None	18	23

[14] This result further confirms the important role of the NVVE as source of information concerning advance directives.

Table 27. Written sources and kind of exchange (n=77)

	Consult colleagues	
Reading and/or lectures	Yes	No
Yes	24	35
No	7	11

2.2.5. Informing patients about advance directives

As we have seen from the information received from managers (see paragraph 3.1), only 2 of the 36 nursing homes included in the study regularly supply material on advance directives to incoming patients. This failure to inform patients is hardly corrected by the doctors. To the question how often they supply information about advance directives on their own initiative, only 4 doctors said that they always or often do so; 8 said they do so regularly. The remaining 58 seldom or never supply information (missing cases = 7). It follows that a patient who is still competent at the time of admission to a nursing home and does not know about the possibility of drafting an advance directive, will probably remain ignorant about this possibility. This idea is confirmed by the fact that only 39 of the 168 advance directives detected among current patients were written after admission to a nursing home (see paragraph 2.2.1 on the frequency of advance directives, Table 20). Only if requested by a patient do doctors seem to supply information about advance directives. Fifty-nine of the interviewed doctors say that they do this, and 27 of them have done so at least once in the previous year.

When these empirical results are presented to nursing home doctors, they may react by saying that, although they do not supply specific information about advance directives, an inquiry into the preferences and wishes of the patient is always carried out at the time of admission and a report is placed in the medical dossier of the patient.[15] It is possible that such a practice contributes to the decision-making process after a patient has become incompetent, affording evidence on which a 'substituted judgment' can be based. But from the point of view of patient autonomy such a report is no substitute for an advance directive, since in itself it has no binding legal force.

2.2.6. Drafting: assistance to the patients

Only a minority of the interviewed doctors help patients to draft advance directives. Less than one third of the sample (20) has ever done so and, of these, only 7 had done so in the previous year. When doctors help their patients to write an advance directive, they usually use the model supplied by the NVVE (12 out of 20).[16] The fact that

[15] I received this comment when presenting preliminary results of my research at the annual meeting of the Nursing Home doctors Association in Utrecht, November 2003.

[16] What doctors do if requested to help to draft an advance directive by a patient whose competence is doubtful was not asked of the nursing home doctors.

doctors are rarely involved in the drafting of advance directives can have important consequences. If they were involved, they could contribute to the effectiveness of the documents, for example by suggesting formulations that can readily be translated into practical decisions, should the patient become incompetent. Moreover, if a doctor has assisted a patient in the drafting phase, his interpretation of the written instructions can be supported with oral information about the preferences and values of the patient: this is indeed the whole idea of advance care planning discussed in chapter 2. As a confirmation of the relevance of the involvement of doctors in the drafting of advance directives, there is the opinion of the doctors themselves concerning the following statement: "It is important that people who consider drafting a treatment directive consult their doctor." Fifty-two of the interviewed doctors completely agree with the statement, 23 partly agree, and only 2 disagree. If most of the doctors are right in this, and it seems reasonable to suppose that they are, then we must conclude that their low level of actual involvement potentially reduces the effectiveness of the advance directives of their patients.

2.2.7. Latency: informing other people and renewing advance directives

Two thirds of the doctors interviewed say they advise a patient with an advance directive to inform other people, especially the available relatives (Table 28). A little more than half (40) advise their patients to renew their advance directives, although only 25 always do so regardless of the patient's specific situation. The remaining 15 advise updating the document only if they consider the situation has changed and a renewal is needed. More than one fifth of the doctors give neither sort of advice (Table 30); on the other hand, almost a third are quite pro-active, and say they give *both* sorts.

Table 28. Do you advise informing other people of the existence of an advance directive? (absolute values)

Informing other people	Frequency				Frequency*
Yes	48	→	Who?	Available family member	44
				Representative	16
				Other	11
No	26				
No answer	3				

* More than one answer possible

Table 29. Do you advise renewing an advance directive? (absolute values)

Renewing Ads	Freq.
No	31
Yes, but only if needed	15
Yes, regardless of the condition of the patient	25
No answer	6

Table 30. Advise informing other persons by advise renewing advance directives (table percentage)

	Advise renewing advance directives		
Advise informing other people	Yes	Only if needed	No
Yes	28%	13%	22%
No	9%	7%	22%

2.2.8. Implementation: the effects of treatment directives on decision-making

In this paragraph we turn specifically to treatment directives, because, as I have noted before, at the time of implementation it is possible to disentangle the different sorts of instructions contained in an advance directive. Although my research did not include any form of direct field observation, an attempt to get some information on the effects of treatment directives in the actual decision-making process for incompetent patients was made by means of a series of questions on the role of treatment directives. A first group of questions referred to the interpretation of the legal rules on treatment directives by the doctors, while a second group concerned the assessment of a hypothetical situation where a treatment directive is present.

Interpretation of the legal rules

Not only knowledge but also the interpretation of the relevant legal rules is a precondition of rule-following behavior. The interpretation of the relevant legal rules by doctors can be tested by asking them to assess a set of statements on the role of treatment directives in the decision-making process for incompetent patients. The doctors were asked to assess in terms of agreement (from complete agreement to complete disagreement) the following statements:

S0. A carefully drafted written refusal of treatment has a major effect on the medical decisions concerning the end-of-life.
S1. A doctor should consider a written refusal of treatment as supplementary information in the medical decision-making.
S2. A written refusal of treatment is as binding for the doctor as the oral refusal of a competent patient.
S3. If the written refusal of treatment and the doctor's medical judgment are in conflict, the written refusal must prevail in the medical decision-making concerning the patient.
S4. A doctor must consider a written refusal of treatment as binding on the medical decision-making.

The first statement is very general while the second is a minimalist interpretation of the legal status of treatment directives. The third to the fifth statements reflect more

precisely the legal rules contained in the WGBO. The results are presented on Table 31.

Almost no one (only 2 doctors) disagrees with the statement that a carefully drafted treatment directive has a major influence on end-of-life decision-making (S0), but 90% completely or partly agree with the statement that a treatment directive is supplementary information in the medical decision-making (S1). About a third of the doctors disagree with the idea that a treatment directive is as binding as a current refusal of a competent patient (S2). Even more (42%) completely or partly disagree with the statement that a treatment directive should prevail in case of conflict between the instructions in the treatment directive and the medical judgment of the doctor (S3). Finally, only 7% completely agree that a treatment directive is binding in the decision-making, while 37% partly agree (S4). More than 50% of the doctors disagree with this statement.

Table 31. Opinion of the interviewed doctors on the following items (percentage)

Statement	Completely agree	Partly agree	Partly disagree	Completely disagree	Missing
S0. Major effect of a treatment directive	64	34	3	0	0
S1. Treatment directive as supplementary information	57	30	9	4	1
S2. Treatment directive and current refusal same strength	29	37	20	14	1
S3. Treatment refusal prevails over medical judgment	15	43	28	14	3
S4. Treatment directive as binding	7	37	21	36	1

It appears that the way doctors see treatment directives does not correspond to their legal status. If these answers of nursing home doctors to the questions asked reflect their operational interpretation of the legal rules involved, one would have to conclude that the effects of treatment directives on the decision-making process for incompetent patients significantly differ from the apparent expectation of the legislator.

Hypothetical questions

This last idea finds support in the assessment by the doctors of hypothetical situations where incompetent patients with a treatment directive are involved. The doctors were asked to state their degree of certitude (answer categories: surely yes, probably yes, probably no, surely no) with regard to the following questions:

1. “Imagine that in your institution there were two groups of incompetent patients, a group with and a group without a written refusal of treatment. Would you

expect the presence of the written refusal of treatment to have any effect on the medical decision-making?"

2. "Imagine the situation where the written treatment refusal of an incompetent patient differs to some extent from your medical judgment. Do you think that you would follow the written refusal?"
3. "Imagine the situation where your medical judgment is completely opposed to the refusal of treatment in the advance directive. Do you think that you would follow the written refusal?"

The results are shown in Table 32. In general, the doctors believe that a treatment directive would have some effect on their medical decision-making (item 1). However, it seems that the medical judgment of the doctor weighs more heavily than a treatment directive. In the hypothetical situation where a treatment directive differs somewhat from their medical judgment (item 2), only 10% of the doctors say they would definitely follow the instructions contained in the document, while 64% consider this probable. If the instructions in the treatment directive differ completely from their medical assessment of the situation (item 3), only 4% say they would definitely follow the treatment directive, 37% think there is some chance they would do so, but more than half consider it probable (46%) or certain (13%) that they would not.

Since these data concern the doctors' opinions about their own behavior in a hypothetical situation where the patient's instructions do not require interpretation, we can probably safely assume (given the human tendency to prefer a convenient interpretation) that their actual behavior would in practice be even less subject to influence by a treatment directive. In short, there is little reason for optimism that the strong legal status of a treatment directive is reflected in medical practice in Dutch nursing homes.

Table 32. Assessment of the degree of certainty for items related to the implementation of treatment directives (percentage)

Item	Surely yes	Probably yes	Probably no	Surely no	N	No answer
Item 1. Treatment directives influence decision-making	38	46	14	1	76	1
Item 2. Would follow a treatment directive that differs somewhat from medical judgment	10	64	23	3	70	7
Item 3. Would follow a treatment directive that is completely opposed to medical judgment	4	37	46	13	68	9

How is it possible to explain the general disinclination of nursing home doctors to accept the binding force of a treatment directive? A lack of knowledge of the legal rules might explain their erroneous interpretation of the role of treatment directives in the medical decision-making process. However, as we have seen, the majority of the doctors have been exposed to some information about treatment directives (previous paragraph 2.2.4). Their opinions may be the result of disagreement with the decisions of the legislator. This possibility is supported by a qualitative study, which found that doctors prefer to decide on the base of their medical assessment of the situation rather than on the previously expressed wishes of a currently incompetent patient.[17] If that is the case, it should be interesting to find out where the disagreement comes from. Is it the consequence of a paternalist attitude of Dutch nursing home doctors, or does it have some concrete basis in the intrinsic shortcoming of treatment directives?

As far as paternalistic attitudes are concerned, they do not seem to be characteristic of Dutch nursing home doctors. I put to my respondent a battery of opinion questions taken from the literature on medical paternalism,[18] and it seems that Dutch nursing home doctors recognize the right to autonomy as a general principle and disagree with paternalistic behavior toward patients. The results are presented in Table 33.

Table 33. Opinions of nursing home doctors about some statements concerning the doctor-patient relationship (row percentage)

Item	Agree	Disagree
A competent patient can refuse a medically proper treatment, even if this refusal has as a consequence his death.	95	5
Having being thoroughly informed by the doctor, the patient has the right to choose the treatment that accords most with own his values.	99	1
As a rule, the patient should be informed in such a way that encourages him to consent to the doctor's judgment about what should be done.	32	68
To be involved in decision-making about treatment is most often an additional burden for the patient.	47	53
Because the patient knows too little, his right of self-determination is a threat to his health in many situations.	19	81
In some situation the doctor should withhold information out of consideration for the patient.	38	62

From these results, we can exclude the idea that the reluctance to attach binding force to treatment directives derives from a pervasively paternalistic attitude of Dutch nursing home doctors. This does not necessarily mean that in practice Dutch doctors always exhibit behavior that fully respects the autonomy of their patients. However, it

[17] The et al. 2002 ; compare also the attitudes of intensive care doctors, Kleijer 2005.
[18] Falkum and Forde 2001.

does suggest that we should look for other factors that may affect a doctor's perception of the role of treatment directives in decision-making.

One possible explanation for their answers could lie in their actual experience with treatment directives, and especially the fact that the contents of treatment directives are often not clear enough to guide their course of action. We have already noted that clear specification of the treatments refused and the conditions of applicability are, in the literature, considered key to success of treatment directives in influencing a doctor's actions. Written refusal of treatment expressed in generic terms risks being ineffective because the doctor cannot use it as a secure guide to decision-making. This is the conclusion of several studies of treatment directives,[19] where the lack of clear specification is shown seriously to impede their translation into practical medical decisions about treatment.

To assess this possibility, it is possible to use the answers given to questions concerning the contents of treatment directives. In the questionnaire I asked doctors with some experience with treatment directives, how often these documents are expressed only in generic terms. I asked this question both for the conditions of applicability and for the treatment refused. The results are shown in Table 34.

It seems that the treatment directives of nursing home patients are often weak in both respects. Three quarters of the interviewed doctors said that the conditions of applicability are always, often or regularly expressed in generic terms, and more than 80% said the same for the treatment refused. If we take both the variables together, only 12% of the interviewed doctors said that both the conditions of applicability and the treatment refused are rarely or never expressed only in generic terms (Table 35). If conditions of applicability are specified, progressive dementia and coma are the situations most often mentioned. As far as the refused treatment is concerned, reanimation and artificial breathing support come first, but admission to a hospital and artificial feeding and hydration are also often mentioned (Table 36).

If this is the actual situation in the Dutch nursing home, part of the ineffectiveness of treatment directives could be attributed to their generality. Even a doctor who has the will to honor a patient's written instructions is thereby prevented from doing so.

Table 34. Percentage of generic expression of wishes in treatment directives (percentage)

	Conditions of applicability (n=56)	Refused treatment (n=53)
Always or often generic	57	62
Regularly generic	18	21
Rarely or never generic	25	17

[19] See Schneiderman et al. 1992, 1993.

Table 35. Generic expression of condition of applicability by refused treatment (table %, n=52)

CONDITIONS OF APPLICABILITY	REFUSED TREATMENT Always or often generic	Regularly Generic	Rarely or never Generic
Always or often generic	48	8	0
Regularly generic	2	12	6
Rarely or never generic	12	2	12

Table 36. Condition of applicability (n=47) and refused treatment (n=43) most often mentioned

CONDITION OF APPLICABILITY	Freq.	REFUSED TREATMENT	Freq.
Advanced dementia	28	Reanimation	29
Coma, Persistent Vegetative State	23	Breathing support	20
Need for breathing support	13	Admission to a hospital	15
Incurable disease, such as cancer	11	Artificial feeding and hydration	14
Other	7	Antibiotics	4
Admission to a hospital	6	Anders	2

3. Discussion

On the basis of the results concerning the social practice of treatment directives in Dutch nursing homes, I can give a preliminary answer to the main research questions. I will focus on two points:
a) the frequency of treatment directives among Dutch nursing home patients, and the extent to which the potential social demand for such documents is fulfilled;
b) the effectiveness[20] of treatment directives in nursing homes.

Frequency of treatment directives in nursing home practice
The frequency of advance directives among nursing home patients is about 5%. About half of these documents contains a treatment directive. Is it this a low or high frequency? Compared to other European countries, the frequency of treatment directives seems to be high, since the few measurements available, although not precisely comparable with my data because collected in other settings, show that even among dying patients the frequency of treatment directives is far below 5%.[21] If we consider that the Netherlands and Denmark are the only countries in Europe which

[20] For the concept of effectiveness of a treatment directive, see chapter 5 paragraph 6 (Implementation).
[21] Such conclusion can be drawn, for example, considering the data collected in Van der Heide et al. 2003, where all 6 European countries considered had far fewer than 5% of treatment directives among dying patients. Similarly, among hospitalized patients in one English study, no treatment directives were found (Schiff et al. 2001).

have had statutes dealing with treatment directives for some time,[22] we can infer that there seems to be some connection between the legal recognition of these documents and their use by patients.

On the other hand, if we compare my data with those coming from North America (see Chapter 3, paragraph 2), the percentage of nursing home patients with a treatment directive in the Netherlands seems very low. What might explain this difference? One could suppose that fewer people in the Netherlands are interested in treatment directives, but there is no substantial support for this idea. The Dutch show a high level of commitment to self-determination, as the public debate on euthanasia and the high membership of the voluntary euthanasia society (NVVE) illustrate. Other factors must explain the comparatively low frequency of treatment directives. The most plausible explanation is that Dutch nursing home patients are not adequately informed about the possibility of having a directive to guide medical decisions should they become incompetent. In the US, federal law (PSDA, 1991) obliges all care institutions funded with public money to inform their patients of their right to write a treatment directive. By contrast, none of the surveyed nursing homes has a standard procedure at admission to inform incoming patients about treatment directives. Almost no individual doctor takes the initiative to inform his patients about this possibility. Moreover, in general, the level of awareness of the possibility of drafting advance medical directives has increased in North America thanks to the attention the media have given some notorious cases. Comparing my results with the North American data, we can suppose that part of the potential demand for treatment directives is unmet due to a lack of information on the part of the patients.

Nonetheless, the number of treatment directives found among Dutch nursing home patients, although not high, does assure that nursing home doctors rather often encounter patients who have given written medical instructions in advance. Seventy percent of the interviewees have at least one patient with an advance directive, while more than a half had at least one patient who died in the previous year with such a document. That means that most nursing home doctors have faced a concrete situation of decision-making for a dying incompetent patient with a treatment directive. Direct experience with patients (especially patients who have died) with treatment directives means that most doctors have practical knowledge concerning these documents. If, in addition, we consider that 90% of the interviewed doctors said they had acquired some information about advance directives (from written sources, lectures or consultation with a colleague), we can conclude that the large majority of Dutch nursing home doctors are knowledgeable about the subject.

[22] Belgium and Spain, the other two European countries included in my survey that recognized treatment directives by statute, did so only recently, respectively in 2002 and 2003.

The expected effectiveness of treatment directives

Once a patient has a treatment directive, several factors can influence its effectiveness at the time of medical decision-making for an author who has become incompetent. First of all, the document must be in place at the relevant time; it must not give rise to doubts that the instructions contained represent the will of the author; it must contain instructions that are clear and specific enough to be applied in the decision-making process; the doctors to whom the document is addressed must accept that the will of the patient written in advance is binding.

From the data collected it seems that, if a nursing home patient has a treatment directive, the document will be in place at the time of decision-making. The nursing home managers stated that a written expression of medical preferences of a patient is always included in the medical dossier and, consequently, the treating doctor is informed about it; and the large majority of doctors advise their patients to inform other people, especially family members, of the existence of a treatment directive. In the case of transfer from a nursing home to a hospital, it is probable that a written directive will follow the patient, since it is a common practice to include it in the medical dossier sent to the receiving institution.

Nursing home doctors are seldom involved in the drafting of treatment directives. The lack of involvement of the doctors in the drafting procedure denies to patients the medical expertise that, in the words of the doctors themselves, is important to ensure an effective treatment directive. Keeping the instructions in a treatment directive up to date is also important. Nevertheless, less than half of the interviewees always advise their patients to do so. The passive attitude of the nursing home doctors surely has consequences for the medical quality of treatment directives and therefore presumably adversely affects the effectiveness of the document at the time of implementation.

One of the main reasons generally given to explain the lack of effectiveness of treatment directives is their lack of specificity, and this is strongly confirmed by my results: the contents of the treatment directives of nursing home patients are usually expresses only in generic terms. A possible solution to this problem could be an explicit mandate to a representative. But provision for a representative is rarely included in the treatment directives drafted by nursing home patients.

In the light of the forgoing findings, the effectiveness of the treatment directives of nursing home patients is doubtful. The same conclusion emerges from the opinions of doctors on the effects of treatment directives in hypothetical situations. The low capacity of treatment directives to influence the decision-making process could be a result of a negative attitude of nursing home doctors towards this legal tool. As a matter of fact, apart from a general acceptance of the principle of autonomy and its extension to incompetent patients, nursing home doctors are reluctant to accord

binding force to these documents, and if confronted with a situation where the instruction in a treatment directive conflicts with their medical judgment, they are inclined to give priority to the latter. This position might be based on a paternalistic attitude, but we have seen that the interviewees did not evidence any strong tendency to paternalistic attitudes in the doctor-patient relationship. Therefore it is more likely that the negative opinion doctors have concerning the effectiveness of the treatment directives stems from their experience with the generally low medical quality of the documents. We seem to be confronted with a vicious circle: the negative opinion of doctors have towards the binding force of treatment directives is reinforced by the low medical quality of the documents, which is produced in turn by the low involvement of doctors themselves in the drafting phase.

In summary, we can say that:

- patients in Dutch nursing homes sometimes but not regularly, have treatment directives, apparently more often than in other European countries where there is no legal recognition of treatment directives or such recognition is only recent;
- when a treatment directive is in place, nursing homes and their doctors make sure that the directive will be known at the time of need;
- however, doctors are otherwise not proactive in promoting the use of treatment directives or assisting those patients who want to draft such documents;
- the lack of initiative on the part of the doctors negatively influences the behavior of patients, both in that latent demand for treatment directives is not realized and that the treatment directives actually drafted are of low medical quality and consequently of low effectiveness;
- although generally in agreement with the principle of autonomy, nursing home doctors are not prepared to recognize the binding force of treatment directives;
- this attitude is possibly partly explained by the doctors' previous negative experience with treatment directives.

In short, in the nursing home context, a self-reinforcing combination of too few treatment directives of generally poor quality with a passive approach and negative attitude by nursing home doctors appears to be frustrating the legislative purpose in making such documents legally binding.

CHAPTER VIII

THE ROLE OF FAMILY DOCTORS IN THE SOCIAL PRACTICE OF TREATMENT DIRECTIVES

In this chapter, I present the findings of the third empirical study concerning the social practice of treatment directives in the Netherlands. In this case, I studied the social practice of treatment directives among family doctors.

1. Methods and instruments

1.1. Sample

The list of family doctors used for the study comes from Nivel,[1] which supplied me with a random sample of 300 doctors from the complete list of all family doctors in the Netherlands. The file with the names of the doctors contained the following variables: name; gender; address; province; telephone number; kind of practice (solo, duo or group practice); urbanization of the practice location (in 5 categories from 'very strongly urban' to 'not urban').

The first contact with the doctors was made with a letter containing a short description of the study and the aims of the research. Thereafter an interviewer made telephone contact with the selected doctors in order to secure their consent to participate in the study and, thereafter, to proceed with the collection of data.

[1] Nederlands instituut voor onderzoek van de gezondheidszorg (Dutch Institute for Heath-Care Research). Internet site: www.nivel.nl.

1.2. The instruments

Two instruments were used to collect the data on the practice of treatment directives among family doctors:

- a short written questionnaire;
- a structured questionnaire administered by telephone.

1.2.1. The written questionnaire

The short written questionnaire included quantitative questions concerning the doctor's patients. It was attached to the introductory letter mentioned above. The purpose of this questionnaire was to give the doctors the chance to think about and filling the quantitative answers in advance, possibly checking their records, and in this way to supply more reliable data.

The answers to the written questionnaire were collected during the telephone interview.[2] In this chapter, I will use them in a selective way, to complement the information from the telephone interviews.

The written questionnaire consisted of three blocks of questions. A first block focused on patients in the doctor's practice (number of current patients treated by the doctor; number of patients above 65; number of patients who died in the previous year). A second block of questions dealt with the number of advance directives among the current patients of the interviewed doctors; the doctors were asked to specify the contents of the directives, in terms of treatment directives, proxy directives, and advance requests for euthanasia, and to indicate how many of the advance directives were drafted using the NVVE form. The doctors were also asked to distinguish among the following four types of advance directives (AD), depending on the kind of specialized help the patient received to draft the directive:

a) AD drafted with the interviewed doctor as the primary source of specialized help;
b) AD drafted with another doctor as the primary source of specialized help;
c) AD drafted with a notary as the primary source of specialized help;
d) AD drafted by the patient himself without specialist support (possibly making use of a model such as that of the NVVE).

A third block of questions concerned patients who died in the preceding year and dealt only with treatment directives. The fact that the questions referred only to this specific

[2] This procedure differed from the one used in the study of nursing home doctors, which produced disappointing results (see chapter 7, note 5). For the family doctors I decided therefore to collect all the data at the time of the interview.

kind of directive was made clear to avoid any kind of misunderstanding. The doctors were asked to report the number of deceased patients with a written refusal of treatment, and to distinguish, as previously specified for current patients, among sources of specialized help in drafting the document.

1.2.2. The telephone questionnaire

The second instrument was a broad questionnaire administered by telephone which lasted approximately half an hour. The interviews were carried out in October 2003 - February 2004.

The questionnaire for family doctors concerned the practice of treatment directives, and followed the structure of the questionnaire for nursing home doctors, with a few additional questions about the experience of the doctors with advance directives containing a request for euthanasia (*euthanasieverklaringen)*. Although not central to my research, I decided to include these questions in order to gather at least some information about an issue that is quite often discussed in the Netherlands.[3]

The explanations given in the previous chapter (paragraph 7.1.2) concerning the choice of terminology in the questionnaire also hold here. However, thanks to the experience gained in the earlier study on nursing home doctors, I was able to refine the questions and to minimize the number of questions referring to advance directives in general.

Since I assumed that doctors with (almost) no experience with treatment directives would be unable to give soundly based answers to questions specifically related to such directives, I administered to them an abbreviated version of the questionnaire, excluding all questions whose answer required at least some experience with treatment directives. The assignment of a doctor to the experienced or inexperienced group was made by the interviewer during the interview. On the whole, the rule was: 'If a doctor has more than 5 treatment directives among current patients, he should be considered experienced and the whole questionnaire will be administered.' However, the application of the rule was not inflexible, and the interviewer had some discretion to decide to which category a doctor belonged. The results of the selection are shown in Table 37. Sixty-eight doctors were considered experienced enough to answer all the questions. Of these, 16 doctors had 5 treatment directives or less, but they had substantial experience with other sorts of directives. Three doctors with more than 5 treatment directives were classified as inexperienced, since they had only 6 treatment directives and stated at the beginning of the interview that they were not acquainted with the documents.

[3] The whole questionnaire is available from the author.

Table 37. Experience with treatment directive by decision to administer all or part of the questionnaire

Number of TD among current patients	Doctors received:	
	The whole questionnaire	Part of the questionnaire
0 to 5	**16**	58
More than 5	52	**3**
Total	68	61

1.3 Response rate and description of the sample

Of the 300 doctors in the sample, 21 were not accessible: either we could not make contact during the period of the interviews (leaves, illness) or they were not practicing anymore. These doctors were not considered in the computation of the response rate. Of the remaining 279 doctors, 129 agreed to answer the questionnaire and 150 refused.[4] The response rate is therefore 46%. Although this is rather low, it is comparable with the rates obtained in other studies in the same field. For example, a study carried out at about the same time by my colleague Donald van Tol, using a postal questionnaire administered to general practitioners, had a response rate of 40%.[5] The 1999 KNMG evaluation research on family doctors and the implementation of the WGBO had a similar response rate: 55%.[6]

In Table 38, the Chi-square test of independence between the variables available in the sample file and the result of the request for consent are shown. The only significant difference is in gender, with women doctors more often giving consent. As a consequence, women doctors are slightly overrepresented in the final group of doctors participating in the study. The doctors who agreed to participate do not otherwise differ significantly from those who refused, although there are some difference, for example the higher proportion of doctors practicing alone (solo practice) who refused to participate. Also doctors working in a very strongly urban environment also refused more often, but the effect could be explained by the overrepresentation in such an environment of solo-practices (48% of solo-practices in very strongly urban environment, against 32% in other environments).

[4] The most common reason for refusal was lack of time.
[5] See Van Tol 2005.
[6] Dute et al. 2000: 447-462

Table 38. Comparison between consent and refusal to participate in the study (significance and column percent)

Variable	Chi-square	d.f.*	p**	Categories	Consent N=129	Refusal N=150	Percentage of refusal
Sex	4.6	1	0.03				
				Man	63	75	58
				Woman	37	25	44
Zone[7]	2.5	3	0.47				
				North	11	9	48
				West	47	51	56
				East	18	12	44
				South	25	28	57
Kind of practice	4.7	2	0.09				
				Solo	28	40	62
				Duo	41	32	48
				Group	31	28	51
Environment of the practice	2.3	4	0.68				
				Very strongly urban	14	19	61
				Strongly urban	29	30	55
				Moderately urban	22	20	51
				Little urban	19	19	54
				Not urban	17	12	45

* d.f. = degrees of freedom ** p = probability

As far as the representativeness of the sample is concerned, we can compare my data with those coming from the KNMG evaluation of the WGBO in 1999 (Table 39). For the variables available, the two samples are not different, except for the overrepresentation of women and a higher standard deviation. A few variables can be compared with data from the Nivel national survey of registration data for family doctors. No relevant discrepancies are noticeable, although the overrepresentation of women is confirmed and doctors in solo-practice are slightly fewer in my sample than in the population. In short, the composition of my sample does not radically differ from the population of Dutch family doctors, and the results can therefore be cautiously generalized.

Some additional information on the professional background of the interviewed doctors is presented in Table 40. Family doctors have on average more than 2500 patients, and 17% of their patients is above 65. This means that, on average, family

[7] Zone is a recoding of the variable 'Province'. The four zones are defined as follows: *North*: Drenthe, Friesland, Groningen; *West*: Flevoland, Noord Holland, Utrecht, Zuid Holland; *East*: Gelderland, Overijssel; *South*: Limburg, Noord Brabant, Zeeland.

doctors have almost 500 elderly patients, a group that is of special interest for the study of the social practice of treatment directives. The proportion of their patients who die each year is less than 1%, but the death of a patient does occur on average more than once per month.

Table 39. Personal characteristics of the interviewed doctors compared with those in the KNMG evaluation study

		My sample N=129	KNMG study [a] N=87	Nivel registration survey [b] N=7270
Response rate (%)		46%	55%	
Sex				
	Man	63	78	77
	Women	37	22	23
Age				
	Mean	47	46	47 [c]
	s.d.	8	6	
Number of patients				
	Mean	2634	2734	
	s.d.	1025	849	
Years of experience as family doctor				
	Average	15	16	
	s.d.	9	7	
Kind of practice				
	Solo	28%		38%
	Duo	41%		33%
	Group	31%		29%

(a) Source: Dute et al. 2000.
(b) Source: "Cijfers uit de registratie van huisartsen. Peiling 2004" by Nivel The data reported here refer only to doctors with an independent practice. Doctors who work for another doctor are excluded. Data by 31 December 2000, except distribution per kind of practice by 31 December 2002.
(c) Computation by the author based on Table 3 of the above mentioned report.

Table 40. Characteristics of the interviewed doctors as far as their patients are concerned

	Mean	S.d.	N
Number of patients	2633	1029	129
Proportion of patients above 65	17	10	113
Patients who died in the previous year	16	12	120
Death rate (number of deaths / number of patients)	0.6%	0.4%	120

2. The social practice of treatment directives among Dutch family doctors

The following paragraphs report the empirical findings of the study of family doctors. The presentation is organized following the scheme of the questions in chapter 5. To avoid repetition of comments made in chapter 7 as much as possible, the comments on the data are here limited to the most essential matters.

2.1. The experience of family doctors with advance and treatment directives

One of the basic questions in this study is whether family doctors are acquainted with advance directives, and specifically with treatment directives. As I have already said, the doctors were asked before the telephone interview to fill in the written questionnaire covering the number of advance directives and treatment directives among their patients. This information can be used to estimate the experience doctors have with such documents. Some information concerning the use of documents containing an advance request for euthanasia (*euthanasieverklaringen*) was also collected.

The majority of family doctors have some experience with advance directives. Only 16 % have no patients with an advance directive, while almost 60% have more than 5 patients with such a document (Table 41, column A). The number of doctors with some experience with treatment directives is lower: almost a third have no current patients with a treatment directive and only 2/5 have more than 5 patients with a treatment directive (column B).

As far as patients who died in the previous year are concerned, the doctors were asked only about treatment directives. Almost half of them had seen at least one treatment directive in the case of a patient who died recently. However the large majority of these doctors had seen fewer than 6 treatment directives, and only 5% of the doctors had seen 6 or more (column C). This is understandable if we consider that the average number of patients who died in the previous year is 16.

Summing the treatment directives among current and dead patients, it seems that three quarters of the doctors have some experience with treatment directives, while one quarter has not (column D).

Table 41. Frequency of advance directives (AD) and treatment directives (TD) among current patients and patients who died in the previous year, percentage (N=129)

Number of patients	Current patients		Patients who died in the previous year	
	A With an AD	B With a TD	C With a TD	D (B+C) Total TD
0	16	29	52	23
1	5	9	23	7
2-5	20	20	20	25
6-10	19	19	4	15
11-20	15	11	1	16
21-50	16	8	0	6
More than 50	9	5	0	7

As noted, the questionnaire included a few questions about the doctors' experience with written requests for euthanasia. Such requests are not the subject of my research, but I was interested to know at least something about the occurrence of these documents in the practice of family doctors, especially given the extent of the confusion between treatment directives and written requests for euthanasia that we have encountered elsewhere in this research.

Thirteen percent of the doctors had performed euthanasia following a written request in advance, while 19% had agreed with at least one of their patients to do so. A much larger number of doctors had assisted patients to draft such a request (45%).

Table 42. Experience with advance written requests for euthanasia

Experience with *euthanasieverklaring (EV)*	percent
Performed euthanasia requested in an EV	13
Agreed to perform euthanasia requested in an EV	19
Drafted an EV	45

2.2. Frequency of advance directives

Quantitative questions concerning the number of advance directives among current patients and the number of treatment directives among the patients who died in the last year were asked in the written questionnaire sent to the doctors before the first telephone contact and the answers were collected during the telephone interview. As already noted, for current patients, the questions referred generally to advance directives (but including the request to specify which sorts of instructions they contained, in terms of treatment directives, proxy directives and advance requests for

euthanasia).[8] For the patients who died in the previous year, the questions referred only to treatment directives. The results are presented on Table 43 and Table 44.

Among the current patients of family doctors, 1759 advance directives were detected. Since the doctors interviewed had in total more than 300,000 patients, it seems that there is less than one advance directive for every 100 patients (precisely: 0.5); if we consider only advance directives containing a refusal of treatment the frequency is even lower (0.3). However, we must not forget that these figures refer to all patients, without regard to age. Since it is known that advance directives are usually drafted by elderly people, a more realistic indication of the frequency of treatment directives is given by the results concerning patients who died in the previous year. As is shown on Table 44, the frequency of treatment directives among patients who died in the last year is much higher than that among the general population of patients: almost 1 in 10 of such patients had a treatment directive.

Table 43. Number of advance directives among current patients

Number of doctors who gave valid answers	123
Total advance directives among current patients	1759
Containing a treatment directive	1106
Total number of current patients	322445
Frequency of advance directives per 100 current patients	**0.5**
Containing a treatment directive	**0.3**

Table 44. Number of treatment directives among patients who died in the previous year

Number of doctors who gave valid answers	117
Treatment directives among patients who died in the previous year	154
Total number of patients who died in the previous year	1790
Frequency of treatment directives per 100 patients who died in previous year	**8.6**

Among the advance directives of current patients, almost two thirds contained a refusal of treatment (Table 45, column A). An even larger proportion included an advance request for euthanasia, while only one third contained a proxy directive. The predominance of advance requests for euthanasia is not surprising, this kind of advance directive being the best known and most popular, despite its limited effectiveness.[9] As we have already noted, the predominance of advance requests for

[8] I also asked whether doctors had patients with positive treatment directives, but the frequency of these documents turned out to be negligible.
[9] Van Delden 2003, Wind et al. 2002.

euthanasia is reflected in the common use in the Netherlands of this label to indicate advance directives in general.

It is interesting to consider the directives in relation to the kind of specialized help the patients received in drafting them. The large majority of advance directives were drafted by patients alone (1350 of 1759 advance directives detected, that is 75%).[10] This confirms the low involvement of doctors (and also other experts) in drafting advance directives, a phenomenon already found in the study concerning nursing home doctors. Another observation concerns the importance of the form supplied by the NVVE, since more than two thirds of the advance directives detected were drafted using this form.

As far as the contents of directives is concerned, those drafted with the help of the interviewed doctor and those drafted by the patient alone (column B and E) more frequently contain a refusal of treatment. By contrast, only 1 of 10 advance directives drafted with the help of another doctor contains a refusal of treatment, while almost all of them have a request for euthanasia. Only 58 such advance directives were detected and we have no information about why there is such an apparently great difference between the two groups of doctors. It may be that the interviewed doctors do not look very carefully at advance directives written with the help of another doctor, and are only aware that they contain an advance request for euthanasia. Since these directives are almost always drafted using the NVVE form, which contains all three kinds of instructions, and all parts of the directives are usually completed by the authors who use them, this seems the most likely explanation.

Table 45. Frequency of advance directives and their contents among current patients

		With the assistance of:			
	A	B	C	D	E
	Total	The doctor himself	Another doctor	A notary	By the patient alone
Advance directives (of all kinds)	1759	318	58	33	1350
Containing a treatment directive	63%	68%	12%	52%	64%
Containing a proxy directive	37%	19%	7%	55%	42%
Containing an advance request for euthanasia	71%	71%	86%	61%	71%
Drafted using a NVVE form	70%	60%	93%	42%	72%

[10] This result also emerges from analysis of the data concerning the treatment directives of the patients who died in the previous year. Of 154 treatment directives detected, 105 were drafted by the patient alone (68%), 43 with the help of the interviewed doctor (28%), and the remaining 6 with the help of another doctor or a notary (4%).

2.3. Demand: reasons for drafting a treatment directive and patients most interested

I asked the doctors with some experience with treatment directives what the most common reasons are for drafting a treatment directive. These experienced doctors answered that a terminal disease is very often the main reason, followed by progressive dependency. Fear of dementia is less frequently the reason for drafting a treatment directive, although 12 doctors said that this occurs always or often and 24 regularly. Even less frequent is advanced age and a degenerative disease. The other conditions mentioned are hardly relevant as reasons to consider a treatment directive. The results of our study of nursing home doctors are confirmed: terminal illness is the most important reason for drafting a treatment directive.

This conclusion is further confirmed in the answers to the questions concerning those patients who most often ask for information about treatment directives. The most common answer refers to patients affected by a serious or terminal disease: almost two thirds of the doctors gave this answer (40 doctors). Elderly patients follow, but at a large distance (only 15 doctors mentioned them). A few doctors also mentioned patients who had some experience with end-of-life care in their family and were lead to think about treatment directives as a consequence of this (10). Finally, patients who want to keep control over their life sometimes ask for information on treatment directives (9).

Table 46. Frequency of various reasons for drafting a treatment directive in the experience of family doctors (percentage; N=67)

Reasons to draft a TD	Often or always	Regularly	Seldom or never
Terminal disease	41	20	6
Fear of progressive dependence	33	17	17
Fear of dementia	12	24	31
Old age	13	14	40
Degenerative disease	12	9	46
Admission to a nursing home	1	16	50
Chronic disease	0	5	62
Serious operation	0	4	63
Admission to a hospital	1	3	63
AIDS*	1	1	59

* N=61, 6 missing values.

Table 47. Patients who ask for information on treatment directives (N=68)

Groups of patients	Freq.*
Serious/terminal disease	40
Elderly people	15
Scared/something happened to loved ones	10
Wish for control over life and death	9
Other	11
No distinction	2
No answer	4

* More than one answer possible

The answers to the question 'Are there specific groups of patients in your practice who have a potential interest in drafting treatment directives?' are very similar to the answers to the previous question, pointing in exactly the same direction (Table 48). It is possible that the two questions are not independent, patients who ask for information being seen as the same as the group that is potentially interested.

Table 48. Groups of patients potentially interested in treatment directives (N=68)

Groups of patients	Freq.*
Serious/terminal disease	46
Older people	14
Dementia	4
Other	7
All people	2
No groups	5

* More than one answer possible

2.4. Doctors' knowledge concerning advance directives

As with the nursing home doctors, the family doctors were asked to describe the sources from which they have obtained information about advance directives. The questions concerned written materials, lectures, and consultation of a colleague. Moreover the doctors were asked whether they had read the text of the WGBO (the law on patient's rights) and used it to solve difficult situations concerning treatment of patients at the end of life. The questions on the sources of information referred to advance directives in general, because often the different sorts of advance instructions are treated together in articles and lectures.

A large majority of family doctors have been exposed to some information about advance directives (written material or lectures); only 14% have not read anything nor

been to a lecture about the subject (Table 49). Of these 18 'uninformed' doctors, 11 had filled the gap by consulting a colleague (Table 51).

As far as written material is concerned, the most popular is that supplied by the NVVE, closely followed by medical publications (Table 50). Eight doctors had used the services offered by the SCEN program of the Royal Dutch Medical Association.[11] Only a minority of the doctors had had direct access to legal or governmental publications on advance directives. The legal knowledge of most family doctors comes from sources that comment on practical situations where the legal rules are relevant, but the rules themselves are not explicitly presented. Exposure to written material, therefore, does not imply that family doctors know exactly what is in the legal rules surrounding the practice of advance directives. But when the family doctors were asked if they had read the WGBO itself and used it in difficult situations concerning patients at the end of life, it appeared that a substantial minority is acquainted with the text of the law: a little more than 40% of the interviewed doctors have read the WGBO, but only 9% have used it in difficult situations (Table 52).

Table 49. Source of information about ADs consulted by family doctors (N=129)

Sources of information	Frequency	Percent
Both written and lectures	48	37
Only written	56	43
Only lectures	7	5
None	18	14

Table 50. Kind of written sources consulted by family doctors

Kind of written souces	Freq.*
NVVE	65
Medical	64
Legal or governmental	14
SCEN	8
None	25

* More than one answer possible

Table 51. Written sources and consulatation (n=129)

	Consult colleagues	
Reading and/or lectures	Yes	No
Yes	50	61
No	11	7

[11] SCEN primarily offers advice and formal consultation in connection with euthanasia. See Jansen-Van der Weide et al. 2004.

Table 52. Have you read the WGBO and used it in difficult situations?

Consult of WGBO	Freq.	%
Read and used	11	9
Only read	42	33
Not read	76	59

2.5. Informing patients about treatment directives

Although only 11 doctors make it a standard practice to inform patients about treatment directives, more than half of the interviewed doctors (52%) said that they have informed patients on their own initiative about the possibility of drafting a treatment directive, while 40% have done so in the last year (Table 53). When a doctor gives information on his own initiative, the main reason is the health condition of the patient. This reason was mentioned 52 times, while other reasons were mentioned less than 10 times. Six doctors said that they give information on treatment directives as an alternative to euthanasia (Table 54). Patients apparently quite often ask for information about treatment directives. Half of the interviewed doctors (64) had received such a request in the previous year, and they always fulfilled it.

Table 53. Have you given information on your own initiative?

Information on own initiative	Frequency	Percent
No, never	62	48%
Yes, but not in the previous year	15	12%
Yes, once in the previous year	14	11%
Yes, more than once in the previous year	38	29%

Table 54. Reasons for informing a patient about treatment directives

Reasons	Freq.*
Health of the patient	52
Need to arrange things clearly and on time	8
Age of the patient	7
Suggest other options than euthanasia	6
Patient scared/insecure	5

* More than one answer possible

2.6. Drafting: assistance to patients

2.6.1. Treatment directives drafted with the interviewed doctor

Among the 68 doctors with some substantial experience with treatment directives, 29 have helped a patient to draft a treatment directive. Of these, 23 had done so in the

previous year. When drafting a treatment directive, almost all the doctors use a model, and a large majority takes advantage of the standard form supplied by the NVVE.

Table 55. Helping patients to draft treatment directives (N=68)

Helped patients to draft a treatment directive	Freq.	%
Yes, in the last year	23	34
Yes, but not in the previous year	6	9
No	39	57

Table 56. Models used when drafting treatment directives (N=29)

Models	Freq.
NVVE model	23
Other models	5
No model	1

A provision that can support the implementation of a treatment directive when the author has become incompetent is the appointment of a representative. Of the 29 doctors who helped patients to write a treatment directive, 15 always suggest including the appointment of a representative, while 5 do so regularly. In the majority of the cases where there is an appointment, the representative is also present during drafting of the treatment directive (12 always or often, 4 regularly). Often members of the family are also present (14 always or often, 5 regularly).

How intensive is the involvement of family doctors in the drafting of treatment directives? The large majority of the doctors who drafted a treatment directive with a patient met with him at least 3 times (the question referred to the last patient with whom they drafted a treatment directive).

Table 57. How many time did you meet the patient to complete a treatment directive? (N=29)

Number of meetings	Freq.
One	1
Two	4
Three	11
Four	6
More than four	7

2.6.2. Treatment directives not drafted with the assistance of the doctor

The doctors were asked whether they have ever received treatment directives drafted without their involvement. For example, a doctor could receive a treatment directive

from a patient completed either with the assistance of another expert (another doctor or notary) or by the patient alone.

Only a minority of the interviewed doctors have ever received directives already drafted without their involvement. Six doctors had received treatment directives drafted with the assistance of another doctor, and another 6 documents drafted by a notary. Two of these 12 doctors also received directives drafted with the assistance of a NVVE volunteer.

Much more common are treatment directives drafted by a patient alone. Sixty-five of 68 family doctors said they had received treatment directives drafted by patients, and 41 of them had received at least one such treatment directives in the previous year, for a total of 108 treatment directives. In a large majority of cases, the treatment directives drafted by patients alone follow the model of the NVVE (74 of 108 treatment directives).

Of the 65 family doctors who have received a treatment directive drafted by a patient alone, the large majority always discusses it with the patient (52 of 65 doctors); 10 do so often or regularly, only 3 do so seldom. However, such a discussion rarely produces changes in the treatment directive: for only one doctor does this often happen, for 4 regularly, while for 60 discussion seldom or never produces changes. If changes are made in the formulation of the treatment directive, these usually go in the direction of more specific formulation.

2.6.3. Checking the competence of the author

The law providing for treatment directives requires the author of such a document to be competent at the time of drafting it. Family doctors could play an important role in checking this requirement, either if they are directly involved in the drafting or when they simply receive an already drafted document. It is apparently very rare that a doctor has doubts about the competence of a patient to draft a treatment directive. Only four of the 29 interviewed doctors who have assisted a patient in drafting a treatment directive had ever doubted his competence. None of the 12 who had received treatment directives drafted with the help of another expert had had such doubts, but 6 of the 65 who had received treatment directives drafted by patients without any specialized help had had doubts (Table 58).

I asked the doctors what they would do if doubts about the competence of the author should arise. Although the small numbers reduce the significance of the data, they give an indication of the general approach of family doctors to the matter. The majority of the doctors interviewed said that they would not easily accept a treatment directive if they doubted the competence of the author. Often, they say they would consult a colleague or another expert to get a second opinion. In the specific case of a treatment

directive drafted by a patient whose competence is in doubt without the assistance of anyone else, the family doctor would discuss the matter further with the patient in order to understand if he is currently capable of competent decisions.

Table 58. Ever experienced doubts about the competence of the author of a treatment directive?

Source of specialized help	Yes	No
Doctor assisted in drafting	4	25
Other expert assisted in drafting	0	12
Patient drafted alone	6	59

2.7. Latency: informing other people and renewing treatment directives

The availability of a treatment directive at the time it is needed is essential to its effectiveness. To increase the chance that those to whom the treatment directive is addressed are informed of its existence, measures to increase its availability can be taken by doctors.

The first question in this regard is whether a family doctor will himself remember the existence of a treatment directive of one of his patients when necessary. I asked the doctors some questions about the way they manage and store the information about patients and, especially, their treatment directives. Among the 129 doctors, 126 have an electronic archive to store information about patients. In 92 cases, such an electronic archive has a field indicating the existence of a treatment directive. However, the doctors are not completely sure that all treatment directives are properly registered. Among the 92 doctors who have an electronic system to register treatment directives, 31 said that they are sure that some of these documents are not registered in their systems, while 9 said that they did not know if that was the case. And 45 of the 68 experienced doctors said that a treatment directive could be placed in the dossier of a patient by someone other than themselves and therefore not be registered in the system. In short, it can happen that a family doctor does not have the information concerning a treatment directive immediately available unless he consults the physical dossier of the patient concerned.

In general, if a family doctor is informed of the existence of a treatment directive of one of his patients, he takes steps to assure its availability, possibly also to other caregivers. First of all, a large majority of family doctors urge their patients to inform other people of the existence of a treatment directive, in particular other family members (Table 59). Moreover, at the time of admission to an institution (nursing home or hospital), two thirds of the interviewed doctors say they take the responsibility to inform the caregivers who will take over the care of the patient, either

in written form or orally (Table 60). If we connect these two pieces of information, we can safely assume that (leaving emergency situations aside), if a doctor is informed of the existence of a treatment directive, the document will usually be available at the time it is needed.

On the other hand, the idea of advising patients to carry some kind of device to signal the presence of a possible treatment directive in an emergency situation seems not to be popular among family doctors: only 15 doctors do so, 8 suggesting carrying a card in the wallet, 5 wearing a brace or pendant, and 3 both.

Table 59. Do you advise informing other people of the existence of a treatment directive? (absolute values, N=68)

	Frequency				Frequency*
YES	61	→	Who?	Available family member	58
				Representative	0
				Other	9
NO	5				
No answer	2				

* More than one answer possible

Table 60. How to inform another institution in case of transfer to a hospital or a nursing home of a patient with a treatment directive

Way other institutions are informed	Freq.
Written	22
Oral	19
Let family do it	9
Let patient do it	9
No info	5
Total	64

Despite the importance of renewing a treatment directive, only slightly more than half of the interviewed doctors advise their patients to do so: 26 always advise renewal after a fixed period (6 advise once a year, the rest less often), and 8 only if they consider renewal necessary (table 12). Thirty-two of the interviewed doctors do not advise renewing treatment directives.

Table 61. Do you advise renewing an advance directive? (N=68)

Renewing treatment directives?	Freq.
No	32
Only if needed	8
Yes, always	26
No answer	2

2.8. Effects of treatment directives on decision-making

So far we have been concerned with the role of the family doctors in the drafting and latency phases of the social practice of treatment directives. But in the Netherlands, where 28% of all deaths take place at home, the family doctor's role is also extremely important in the implementation phase.[12]

As in the study of nursing home doctors, I did not directly ask about the effects of treatment directives on medical decision-making, but attempted to secure information indirectly by means of a set of questions concerning the interpretation of the legal rules at stake and the role of treatment directives in hypothetical situations.

2.8.1. The interpretation of the legal rules concerning treatment directive

The interpretation of the legal rules among family doctors was tested by asking them to assess a set of statements on the role of treatment directives in the decision-making process for incompetent patients. The interviewed doctors were asked to assess in terms of agreement (from complete agreement to complete disagreement) the following statements:[13,14]

S1. A doctor should consider a written refusal of treatment as supplementary information in the medical decision-making.
S2. A written refusal of treatment is as binding for the doctor as the oral refusal of a competent patient.
S3. If the written refusal of treatment and medical judgment are in conflict, the written refusal must prevail in the medical decision-making concerning the patient.
S4. A doctor must consider a written refusal of treatment as binding on the medical decision-making.

[12] The figure refers to 2004 and was supplied on request by the CBS (Centraal Bureau voor de Statistiek).
[13] The statement "A carefully drafted written refusal of treatment has a major effect on the medical decisions concerning he end-of-life. (Een zorgvuldig opgestelde schriftelijke behandelweigering heeft een grote invloed op medische beslissingen betreffende het levenseinde.)" was not used because it had already been used for nursing home doctors and gave as a result an almost complete agreement.
[14] For the Dutch version of the statements, see Chapter 7, notes 19-22.

The first statement presents a rather mild interpretation of the role of an treatment directive in the decision making, while the second to the fourth statements translate more precisely the legal rules contained in the WGBO. The results are presented in Table 62. As with the nursing home doctors, 90% of the family doctors completely or partly agreed with the statement that a treatment directive represents supplementary information in the medical decision-making (S1). But the situation changes as soon as the binding strength of advance directives is at issue.

Although almost two third of the doctors agree with the idea that a treatment directive is as binding as a current refusal of a competent patient (S2), only one third is ready to accept that a treatment directive should prevail in case of conflict between the instructions in the treatment directive and the medical judgment of the doctor (S3). Only one third of the doctors completely or partly agree that a treatment directive should be binding in the decision-making (S4).[15]

Table 62. Opinion of the interviewed doctors on the binding force of treatment directives (n=129).

Statement	Completely agree	Partly agree	Partly disagree	Completely disagree	Missing
S1. Treatment directive as supplementary information	63	28	8	2	1
S2. Treatment directive and current refusal same strength	20	42	21	17	2
S3. Treatment refusal prevails over medical judgment	8	27	33	33	6
S4. Treatment directive is binding	5	26	26	43	0

2.8.2. Hypothetical questions

Several questions dealt indirectly with the effects of a treatment directive at the time of decision-making for an incompetent patient.[16] The results for these hypothetical questions are shown on Table 63. In general, the doctors hold that a treatment directive would have some effect on their medical decision-making. However, it seems that the medical judgment of the doctor weighs more than a treatment directive in the decision-making for an incompetent patient. In the hypothetical situation where a treatment directive differs somewhat from their medical judgment, only 8% of the doctors say

[15] The results for nursing home doctors, presented in Chapter 7, paragraph 2.2.8, are similar, although nursing home doctors seem to be significantly more positive on the last two items (58% of nursing home doctors agrees on S3 versus 35% of family doctors, 44% vs. 31% on S4). For a comparison of the answers of family doctors and nursing home doctors, see chapter 9, paragraph 2.2.

[16] For the text of the questions and the answer categories, see chapter 7, paragraph 2.2.8.

they would definitely follow the instructions contained in the document, while 45% consider this probable. If the instructions in the treatment directive differ completely from their medical judgment of the situation, none of the interviewed doctors would surely follow the treatment directive; only 13% think there is some chance they would follow the treatment directive; but the large majority considers it probable (42%) or certain (45%) that they would not.

Table 63. Assessment of the degree of certainty for items related to the implementation of treatment directives (percentage)

Item	Surely yes	Probably yes	Probably no	Surely no	N	No answer
Item 1. Treatment directives influence decision-making	37	40	19	4	120	9
Item 2. Would follow a treatment directive that differs somewhat from medical judgment	8	45	32	15	102	27
Item 3. Would follow a treatment directive that is completely opposed to medical judgment	0	13	42	45	102	27

The doctors were further asked to assess the importance of a number of characteristics of a treatment directive that can influence its effectiveness. They were requested to say how important each of these characteristics is, using a five point scale, from absolutely not important to extremely important. The results are shown in Table 64, where the items are sorted in order of descending importance, from those that were more often judged important to those considered less important.

Table 64. Importance of the characteristics of a treatment directive on its effectiveness

Characteristics of treatment directive	Important	Neutral or Not important
Clear formulation of conditions of applicability	93	7
Clear formulation of refused treatment	90	10
Recent updating	63	37
Appointment of a representative	50	50
Involvement of the doctor in drafting phase	39	61

A clear formulation of the conditions of applicability and the refused treatment is in the opinion of family doctors crucial to the effectiveness of a treatment directive. This result finds strong support in the literature, where the shortcomings in the

implementation of treatment directives are often attributed to their poor formulation.[17] In the literature, the involvement of a doctor in the drafting phase is often seen as a way to avoid vague formulations of the instructions given. However, the interviewed doctors seem not to share this opinion, since 'involvement of the doctor in the drafting phase' is seen as the least important factor influencing the effectiveness of treatment directives.

More importance is attributed to a recent updating of the document: 63% of the interviewees consider this important. Interesting is that more than half of them consider the inclusion in a treatment directive of the appointment of a representative either neutral or not important for the effectiveness of the document. This is surprising since the appointment of a representative is in the literature often considered an important remedy for the lack of specificity of treatment directives.[18] The finding that so many family doctors do not consider an appointed representative important may be explained by considering that a representative can often be found among the available family members without the need of a written appointment, and the doctors may see this as sufficient. On the other hand, it may be the case that many doctors equate an appointed representative with a member of the family, and do not consider the opinion of either one very important. That family doctors do not regard the consent/views of the family as decisive for the medical decision-making is seen in the results of the next question concerning the ground on which the decision-making should be based (Table 65). The doctors were requested to order by importance three possible grounds for decision-making in the case of incompetent patients. The three grounds are: will of the patient, stated in writing; consent of the family; medical situation of the patient.

None of the interviewed doctors regard the consent of the family as the primary ground on which to base decision-making for an incompetent patient and 85% of the doctors regard the consent of the family as the least important of the three options offered. Fifty-four percent of the doctors hold that the most important ground for decision-making is the medical condition of the patients, 40 % put this in second position, and only 6% as third. The will of the patient is mentioned in 46% of the cases as the first ground, in 45% as second and in 9% as third. If we compare the choices for the medical condition versus will of the patient, we see that the first prevails (54% as first against 46%). This is interesting, since according to the WGBO, the patient's refusal of treatment considered appropriate by the doctor, even when this refusal is expressed in writing and the patient is incompetent, should prevail over the medical opinion of the doctor. This result, together with other research carried out in the Netherlands,[19] casts doubts on the concrete effectiveness of treatment directives as an instrument to guide medical decision-making.

[17] See Schneidermann et al. 1992, Schneidermann et al. 1993.
[18] Teno 2004, Tonelli 1996, Fagerlin and Schneider 2004.
[19] See The et al. 2003.

Table 65. Relative importance of various grounds for medical decision-making and their frequency (N=126)

Order					Percent
Medical situation	-	patient will	-	family consent	45
Medical situation	-	family consent	-	patient will	9
Patient will	-	medical situation	-	family consent	40
Patient will	-	family consent	-	medical situation	6

The doctors' opinions concerning the influence of various factors on the effectiveness of a treatment directive (see Table 66) seem to contradict the above-mentioned results, since agreement of the instructions with the doctor's judgment scores only forth in order of importance. However, if we read the results more carefully, the best interests of the patient and his terminal condition (respectively first and third factor in importance) depend very much on medical judgment. A doctor presumably considers that what he thinks is the proper treatment for an incompetent patient is also in the latter's best interest; and the terminal condition of the patients is generally based on the judgment of the doctor. The views of the representative and of the family are considered the least important factors influencing the effectiveness of a treatment directive, which seems to explain the low importance attached to the appointment of a representative. However, it should be noted that doctors do make a distinction between the two, attributing more weight to the representative than to the family in general.

Table 66. Assessment of the importance of the specific factors for the effectiveness of a treatment directive

Conditions influencing effectiveness of a treatment directive	Important	Neutral or not important
In best interest of patient	96	3
Know patient well	91	8
Terminal patient	90	10
Agreement with doctor's opinion	77	23
Representative agreement with the instructions in the treatment directive	73	27
Family agreement with the instructions in the treatment directive	50	50

Given the characteristics of treatment directives that are recognized by doctors as the most important for their effectiveness (clear specification of the conditions of

applicability and of the treatment refused), we can assume that one of the practical reasons why treatment directives appear to be of little effect is the generic way in which they are often expressed. When asked how often the documents are expressed only in generic terms,[20] half or more of the interviewed doctors said that both conditions of applicability and refused treatments are often or always expressed in generic terms. If we compare the treatment directives drafted with the assistance of the doctor or an expert with those drafted by the patients themselves, it seems that the latter are in the view of family doctors more often generic. This corresponds to our expectation, since consulting a doctor is supposed to increase the patient's ability to express his wishes in specific medical terms. The results are shown in Table 67. These findings confirm our earlier finding in the study of nursing home doctors.

Table 67. Percentage of generic expression of wishes in treatment directive (column percentages)

	Conditions of applicability		Refused treatment	
	With doctor or other expert	Patient self	With doctor or other expert	Patient self
	(N=35)	(N=58)	(N=34)	(N=58)
Always or often generic	49	57	50	53
Regularly generic	6	17	18	24
Rarely or never generic	45	26	32	22

It is interesting to know which specifications are most often contained in treatment directives that are clearly formulated. For each condition of applicability or refused treatment, the doctors were requested to say how often it appears in treatment directives, using a scale from always (score 5) to never (score 1). Summing the scores of the answers, and dividing by the number of valid answers, we obtain an average score for each condition or treatment and can then order them from the most frequent to the most infrequent (the higher the score, the higher the frequency). The results are presented in Table 68.

As far as conditions of applicability are concerned, the most frequent is: 'A terminal phase of an incurable disease', followed by 'Coma' and 'Advanced dementia'. For refused treatment, reanimation and artificial breathing are at the top of the list. Admission to an institution does not seem to be common in the specification of an advance directive, neither as a condition nor as something to refuse.

[20] The question was administered to all doctors who have either assisted a patient in drafting a TD or have received an already drafted TD from a patient. The numbers being small, I add together the answers concerning TDs drafted with the interviewed doctor and those concerning TDs drafted with another expert (another doctor or a notary).

Table 68. Conditions of applicability (n=47) and refused treatment (n=43) mentioned most often in a treatment directive

Condition of applicability	N	Average frequency	Refused treatment	N	Average frequency
Terminal phase of incurable disease	59	4.0	Reanimation	60	3.6
Coma	60	3.6	Artificial breathing	60	3.0
Advanced dementia	59	2.9	Artificial food and hydration	60	2.7
Extensive dependence for basic needs	58	2.7	Admission to a nursing home	60	2.0
Admission to a nursing home	59	2.1	Antibiotics	60	1.8
Admission to a hospital	60	1.5	Admission to a hospital	60	1.8

3. Discussion

The results of the study of family doctors confirm in general what we have already seen among nursing home doctors. However some supplementary comments are possible.

In first place, one of the advantages of the study of family doctors is that the focus on treatment directives could be much clearer that in the previous studies. For current patients, all the doctors supplied figures for advance directives in general, and for their specific contents in term of treatment directives, proxy directives and advance requests for euthanasia. For the patients who had died the previous year, the data were collected only for treatment directives. As a result, the quantitative data on the frequency of treatment directives are more reliable that in the nursing home study.

Among family doctors' patients, the frequency of treatment directive is rather low, but if we consider patients who are close to death (patients who died in the previous year), the frequency of such documents is considerably higher, reaching the level of 1 in 10. This frequency comes close to the figures found in the North American empirical literature.

A second added value of the study of family doctors is that quantitative data on the origins of the documents were collected. The doctors were asked to distinguish between the directives depending on the source of specialized help the patients received in drafting them. Although I indicated four different possibilities for specialized help (the interviewed doctor, another doctor, a notary, the patient alone), only the first and the fourth groups were substantial. The majority of advance directives are drafted by the patient alone, and this is also the case for treatment directives. This result confirms earlier tentative conclusions that the involvement of

doctors (and other experts) in the drafting procedure is not common. But the involvement of family doctors is much higher than what we have seen for nursing home doctors in chapter 7. Almost a quarter (29 of 129) has helped patients to draft treatment directives, an activity that took in most of the cases required up to 3 meetings per patient. Family doctors also seem rather more proactive than nursing home doctors. More than a half of them give information on treatment directives on their own initiative, mostly being triggered by the health condition of the patient.

Considering directives drafted with the involvement of a family doctor and those drafted by the patient alone, we can also note that in both groups treatment directives are less frequent than requests for euthanasia. One might have expected family doctors to have a preference for treatment directives, firstly because their legal status is far more secure, and secondly because euthanasia is ethically, legally and emotionally more problematic than refusal of treatment. If a doctor helps a patient to draft a directive, one might therefore expect him to suggest including a treatment directive, even if the patient was primarily interested in euthanasia. Consequently, one would predict that advance directives drafted with the help of family doctor would more often include a treatment directive than when such a doctor is not involved; they ought to include treatment directives at least as often as requests for euthanasia. A similar argument can be made as far as the inclusion in a directive of the appointment of a representative is concerned. In fact, however, advance directives drafted with the help of the interviewed doctors contain a proxy directive less often than directives written by the patient alone.

Similar unexpected conclusions can be drawn if we focus on treatment directives and consider the way the conditions of applicability and treatments refused are expressed. The proportion of directives written in generic terms does not decrease significantly when a doctor intervenes in the drafting phase. This result is dissonant with the opinion of the doctors themselves that the main factor of importance for the effectiveness of a treatment directive lies in a clear specification of the conditions of applicability and the treatment refused. Family doctors do not in fact seem to effect much improvement on these aspects.

Despite the relatively high involvement of family doctors in the social practice of treatment directives, their attitude toward the role and effectiveness of these documents is rather negative, and the picture here does not differ from that among nursing home doctors. Only a minority of family doctors recognize the binding force of treatment directives and, if confronted with a hypothetical situation where the instructions in a directive strongly conflict with their medical judgment, the large majority of doctors say that they probably would not follow the directive.

Summing up the previous points, we obtain an ambiguous picture. It seems that family doctors do not want to retreat from the practice of treatment directives, they are not opposed to them in principle and they regularly help patients who express the will to have one. But they do not do those things that would actually promote the effectiveness of treatment directives. And in the end, they are not ready to accord binding force to treatment directives. Asked to list grounds for medical decision-making for incompetent patients in order of importance, family doctors consider their medical judgment concerning the situation of the patient more important than the will of the patient expressed in advance.

A final remark concerns the meaning of treatment directives for patients, according to their family doctors. At several points in the interviews, it appears that the persons considered most interested in considering drafting a treatment directive are those affected by a terminal disease. Similarly, the main reason for those who do draft a treatment directive is a terminal condition. It seems that a treatment directive is generally conceived as a tool to maintain control over events that will soon unfold rather than to govern a distant and unforeseeable future.

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

	Nursing home doctors		Family doctors	
Would you follow a treatment directive if:	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.

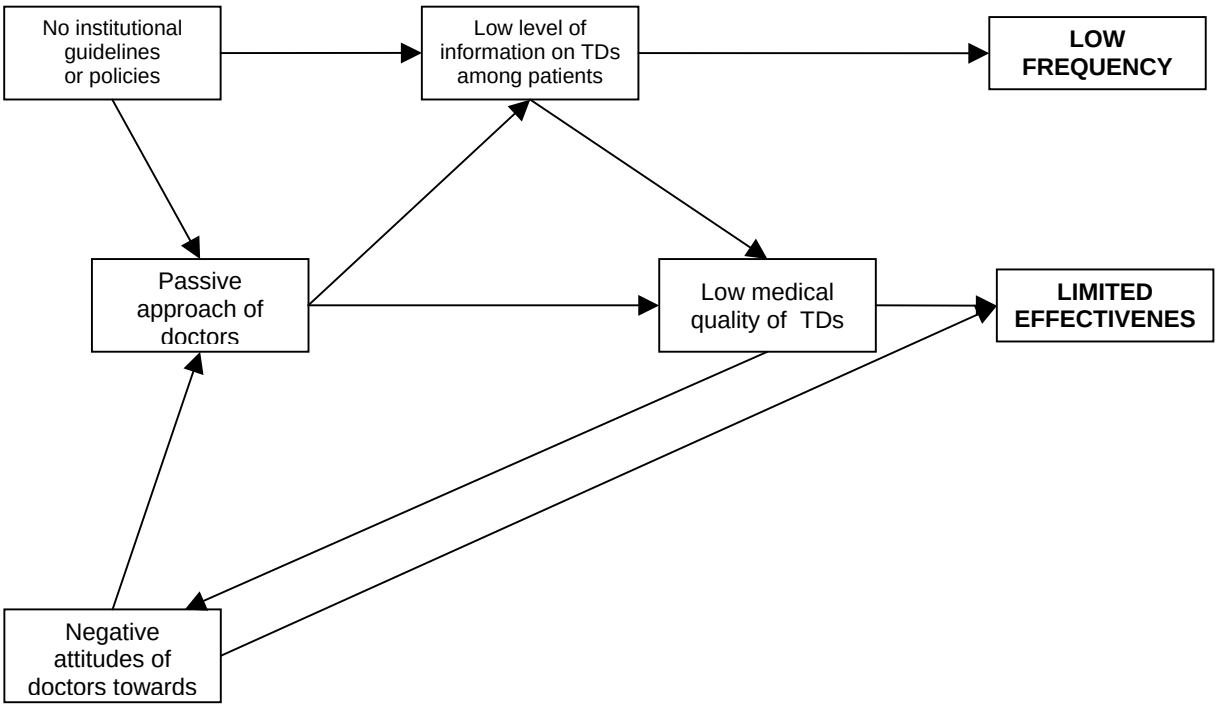
Table 73. Attitudes of nursing home and family doctors concerning the role of treatment directives in medical decision-making (row percentages)

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.

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SAMENVATTING

Het onderwerp van dit proefschrift is de juridische status en de sociale praktijk van schriftelijke wilsverklaringen in Nederland.

De term schriftelijke wilsverklaring verwijst naar een geschreven document waarin de auteur instructies geeft betreffende de behandeling die hij wel of niet wenst te ondergaan onder gespecificeerde omstandigheden. Een dergelijk document wordt opgesteld wanneer de auteur nog steeds wilsbekwaam is en wordt van kracht op het moment dat deze zijn wilsbekwaamheid verliest. Een schriftelijke wilsverklaring kan direct tot de verantwoordelijke dokter gericht worden, of indirect via een vertegenwoordiger, of allebei. De term correspondeert met de uitdrukking 'living will', die veelal in Noord-Amerika gebruikt wordt.

Een schriftelijke wilsverklaring kan positief of negatief zijn. Een voorbeeld van een negatieve schriftelijke wilsverklaring is de weigering van beademingsapparatuur onder gespecificeerde omstandigheden, zoals een persistente vegetatieve staat. In een positieve schriftelijke wilsverklaring verzoekt de auteur specifieke levensverlengende behandeling (zoals reanimatie). Het is van belang te benadrukken dat het proefschrift zich enkel bezighoudt met de negatieve schriftelijke wilsverklaringen, daarmee de positieve schriftelijke wilsverklaringen en, in het bijzonder, de euthanasieverklaringen uitsluitend.

Interessen op verschillende niveaus motiveerden de keuze voor dit onderwerp. Op het theoretische vlak was ik geïnteresseerd om de effecten van rechtsregels op menselijk gedrag te bestuderen. Het theoretische fundament van deze vraag is het paradigma van de 'sociale werking' van recht, een paradigma dat handelt over de directe effecten van wetgeving op menselijk gedrag. De regulering van schriftelijke wilsverklaringen biedt

een interessant veld waarop het paradigma kan worden toegepast. De centrale vraag van het onderzoek is:

- Volgen mensen de regels betreffende schriftelijke wilsverklaringen?
- En waarom – onder welke voorwaarden – doen zij dit?

Op het beleidsinhoudelijke niveau was ik geïnteresseerd in de vraag of het volgen van de vastgelegde rechtsregels, in zo ver dit plaatsvindt, de sociale effecten heeft die de wetgever verwachtte. Deze vraag ligt buiten de reikwijdte van het paradigma van de sociale werking van recht, maar is relevant voor het onderzoek en dit heb ik dan ook voortdurend als een referentiepunt gehanteerd.

Ten slotte lijkt de tijd die besteed is aan dit onderzoek gerechtvaardigd vanwege het feit dat empirisch onderzoek naar schriftelijke wilsverklaringen in Nederland schaars en onsystematisch is. Voorzover mij bekend, bestond er geen kwantitatieve studie die expliciet aan dit onderwerp gewijd is vóór dit onderzoek. Het verzamelen van empirische gegevens over de sociale praktijk van schriftelijke wilsverklaringen was daardoor een unieke onderneming, die het vooruitzicht bood verdere discussie te stimuleren.

Als voorbereiding van het empirisch onderzoek heb ik een aantal voorstudies uitgevoerd. De eerste betrof een vergelijkend onderzoek naar de juridische status van schriftelijke wilsverklaringen in verscheidene, voornamelijk westerse landen. Dit onderzoek resulteerde in een typologie die de landen in drie groepen verdeelden al naar gelang van de sterkte van de juridische status die schriftelijke wilsverklaringen hebben. Op grond van deze analyse kan Nederland worden geplaatst bij de kleine groep landen, waar de juridische status van schriftelijke wilsverklaringen bijzonder sterk is, wat wil zeggen dat de instructies in de wilsverklaring bindend zijn voor de arts die verantwoordelijk is voor de behandeling van een wilsonbekwaam geworden patiënt. Een ander inzicht, dat uit de vergelijkende studie naar voren kwam, is dat landen die een grote toewijding aan de doctrine van ‘informed consent’ tonen, vroeger of later gedwongen lijken om de bindende kracht van schriftelijke wilsverklaringen juridisch te erkennen: het ontzeggen van een dergelijke mogelijkheid tot het handhaven van een zekere mate van autonomie aan wilsonbekwame personen lijkt een onhoudbare positie.

Een tweede voorbereidende stap was een onderzoek van de beschikbare internationale empirische literatuur betreffende schriftelijke wilsverklaringen. Een algemeen gemaakte opmerking is dat veel van het tot dusver uitgevoerde onderzoek gebaseerd is op niet-representatieve steekproeven en dat de resultaten vaak tegenstrijdig zijn. Bovendien zijn vrijwel alle studies afkomstig uit Noord Amerika en de generaliseerbaarheid van de bevindingen voor andere westerse landen is onzeker. Ondanks deze beperkingen was de analyse van de betreffende literatuur nuttig als basis

voor het uitwerken van een systematisch schema van de sociale praktijk van wisverklaringen. Dit schema, dat alle factoren bevat die bij de sociale praktijk betrokken zijn, werd gehanteerd bij het maken van de telefonische vragenlijsten, die zijn gebruikt in het empirische deel van de studie.

De derde voorbereidende stap bestond uit een gedetailleerde analyse van de Nederlandse wetgeving over schriftelijke wilsverklaringen en een onderzoek van het schaarse empirische materiaal beschikbaar over Nederland. Het recht aangaande schriftelijke wilsverklaringen is vastgelegd in de Wet op de Geneeskundige Behandelovereenkomst (WGBO), welke slechts negatieve wilsverklaringen betreft: schriftelijke wilsverklaringen die een behandelweigering bevatten. De juridische status van een schriftelijke behandelweigering in Nederland is sterk. Maar de wet is op bepaalde punten nogal vaag en bevat geen bepalingen betreffende de implementatie van het erkende recht, noch zijn er gouvernementele of institutionele richtlijnen verstrekt aan de actoren die bij het proces betrokken zijn (voornamelijk artsen, patiënten, familieleden en vertegenwoordigers). Empirisch materiaal betreffende schriftelijke wilsverklaringen is zeldzaam en vaak slechts impressionistisch. De enige indicaties, die uit het bestaande onderzoek kunnen worden afgeleid, zijn dat schriftelijke wilsverklaringen vaker voorkomen in Nederland dan in andere landen in Europa en dat Nederlandse artsen er de voorkeur aan geven de besluitvorming over wilsonbekwame patiënten te baseren op hun eigen medisch oordeel in plaats van de wensen, die patiënten voorheen in hun schriftelijke wilsverklaring tot uitdrukking hebben gebracht.

Voor het empirische onderzoek heb ik ervoor gekozen mij te richten op artsen, in het bijzonder verpleeghuisartsen en huisartsen. Desalniettemin is een kleine survey gewijd aan de rol van notarissen in de sociale praktijk van schriftelijke wilsverklaringen, aangezien notarissen de juridische experts zijn die het meest geconsulteerd worden door de Nederlandse burger bij het opstellen van een schriftelijke wilsverklaring.

Voor alle drie de studies heb ik gekozen voor een kwantitatieve methodologie en de data is verzameld met behulp van een gestructureerde vragenlijst die telefonisch werd afgenomen en welke gebaseerd was op het schema van de sociale praktijk afgeleid uit de analyse van de empirische literatuur. Helaas was het proces van dataverzameling onderhevig aan een vrij hoog niveau van non-repons, welke de representativiteit van de steekproeven mogelijkerwijs gereduceerd heeft. Hoe dan ook, gezien het hoge niveau van homogeniteit in gedrag van de onderzochte beroepsgroepen, kunnen de belangrijkste resultaten met gepaste voorzichtigheid gegeneraliseerd worden tot de populatie in zijn geheel.

Twee belangrijke resultaten komen uit het onderzoek naar voren:

a. de frequentie van schriftelijke wilsverklaringen in Nederland is gering;

b. de schriftelijke wilsverklaringen die er zijn, hebben waarschijnlijk weinig effect op medische besluitvorming.

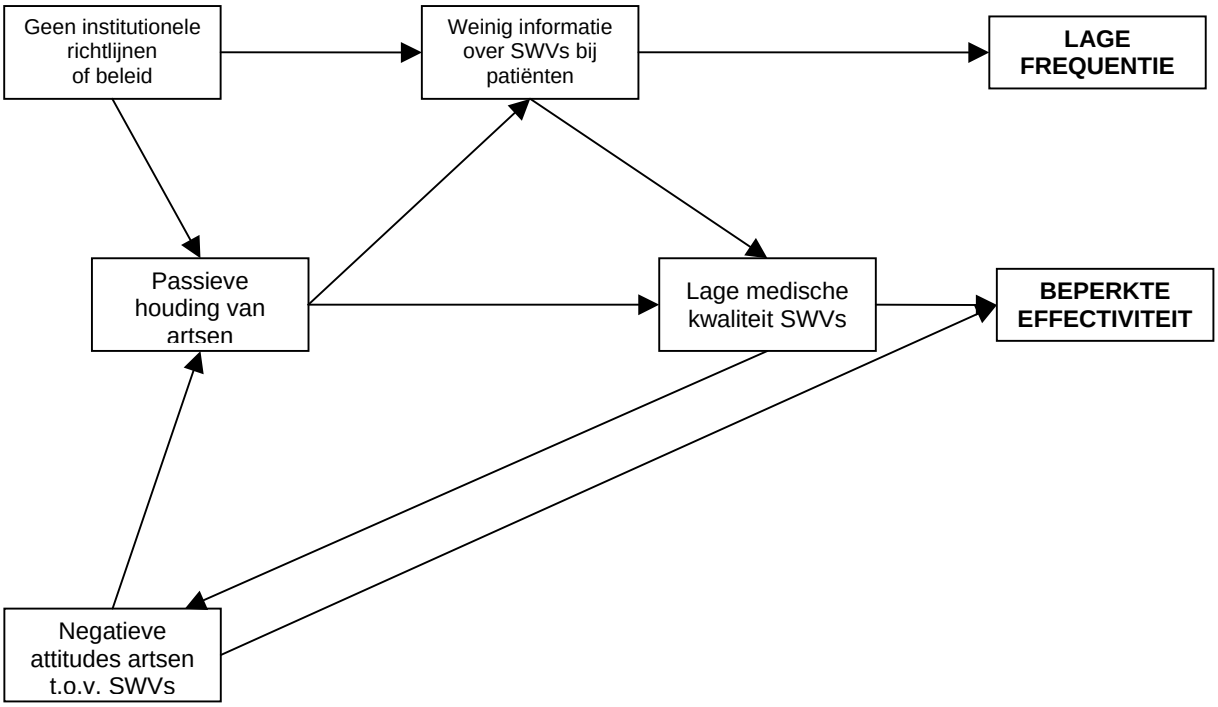
Alhoewel de frequentie van schriftelijke wilsverklaringen in Nederland hoog lijkt in vergelijking met alle andere Europese landen (5 tot 10% in de populaties die onderzocht zijn), is het laag indien vergeleken met gegevens die afkomstig zijn uit de Verenigde Staten, waar officiële cijfers laten zien dat onder verpleeghuisbewoners ongeveer een op de drie inwoners over een schriftelijke wilsverklaring beschikt. Een belangrijke factor in het verklaren van deze verschillen lijkt het verschil in de relevante wetgeving tussen de twee landen te zijn. De Amerikaanse federale wetgeving voor dit onderwerp (the Patient Self Determination Act 1991) vereist dat gezondheidszorginstellingen die gefinancierd worden door de Federal Medicare en Medicaid programma's, alle inkomende patiënten informeren over hun recht een schriftelijke wilsverklaring op te stellen. In Nederland vereisen noch de wet, noch een actief ondersteunend regeringsbeleid een dergelijke notificatie noch voorzien zij in een publieke voorlichtingscampagne of in specialistische ondersteuning bij het opstellen van schriftelijke wilsverklaringen. De overheid bemoedigt instellingen zoals ziekenhuizen of verpleeghuizen niet om het gebruik van schriftelijke wilsverklaringen te bevorderen en protocollen en richtlijnen op te stellen die gevolgd moeten worden bij besluitvorming ten behoeve van een wilsonbekwame patiënt met een schriftelijke wilsverklaring. De houding van deze instellingen is dientengevolge passief gebleven en heeft mogelijkerwijs de aanpak van individuele artsen beïnvloed, die geen enkele institutionele druk voelen om een meer vitale sociale praktijk betreffende schriftelijke wilsverklaringen te ondersteunen.

Bovendien, de schriftelijke wilsverklaringen die er wel zijn lijken niet erg effectief te zijn, dat wil zeggen, hun bestaan oefent kennelijk amper invloed uit op het besluitvormingsproces betreffende wilsonbekwame patiënten. Uit de gegevens die in dit onderzoek verzameld zijn komt naar voren dat indien een schriftelijke wilsverklaring afwijkt van of tegengesteld is aan het medisch oordeel van de arts tot wie de verklaring is gericht, de arts sterk geneigd zal zijn de instructies in het document te negeren. De geringe effectiviteit van schriftelijke wilsverklaringen kan verklaard worden door de attitudes van artsen ten opzichte van deze documenten. Alhoewel artsen in beginsel het principe van respect voor zelfbeschikking ondersteunen en bereid zijn schriftelijke wilsverklaringen als ondersteunende informatie te gebruiken in de besluitvorming, zijn zij gewoonweg niet bereid hun medisch oordeel te onderwerpen aan een tevoren opgestelde behandelweigering. Dergelijke negatieve houdingen ten aanzien van de bindende kracht van schriftelijke wilsverklaringen lijken niet alleen een directe invloed te hebben op de effectiviteit van de documenten op het moment van implementatie, maar veroorzaken ook een passieve benadering in de voorgaande fasen van de sociale praktijk van schriftelijke wilsverklaringen (geen informatieverstrekking aan de patiënt over de mogelijkheid tot

het opstellen van een schriftelijke wilsverklaring; weinig betrokkenheid bij het opstellen van schriftelijke wilsverklaringen). Deze passieve houding in de fase van het opstellen van een schriftelijke wilsverklaring draagt bij aan de door artsen gerapporteerde lage kwaliteit van schriftelijke wilsverklaringen; en de ervaring dat schriftelijke wilsverklaringen meestal te vaag en algemeen zijn om houvast te bieden in de medische besluitvorming heeft als feedback-effect een bevestiging van de passieve houding van artsen.

Dit is in het kort het beeld dat uit de empirische analyse van de sociale praktijk van schriftelijke wilsverklaringen in Nederland naar voren komt: enerzijds houdt de geringe informatie over schriftelijke wilsverklaringen de frequentie van deze documenten onder de Nederlandse bevolking laag. Dit lage informatieniveau wordt niet gecorrigeerd door een pro-actieve benadering van instellingen en individuele artsen. Anderzijds verhindert de negatieve attitudes van artsen ten opzichte van de bindende kracht van schriftelijke wilsverklaringen en de doorgaans lage kwaliteit van de verklaringen, gevoed onder meer door de passieve houding van de artsen en de geringe kennis onder patiënten, dat schriftelijke wilsverklaringen effectief zijn in het besluitvormingsproces aangaande wilsonbekwame patiënten. Het schema beneden synthetiseert de bevindingen.

Synthetisch schema van de bevindingen



Met deze resultaten verkeer ik in de positie de hoofdvragen van mijn onderzoek te beantwoorden.

Beïnvloeden rechtsregels inzake schriftelijke wilsverklaringen het gedrag van artsen en patiënten?
Als de kern van wetgeving over schriftelijke wilsverklaringen bestaat uit de bindende kracht die deze zouden moeten hebben in de medische besluitvorming voor wilsonbekwame patiënten, dan moet de vraag negatief worden beantwoord.

- Artsen volgen eerder hun medisch inzicht dan de wil van de patiënt zoals schriftelijk vastgelegd alvorens zij wilsonbekwaam werden. Artsen beschouwen de instructies in een schriftelijke wilsverklaring slechts als aanvullende informatie. Indien de geschreven instructies en het medisch inzicht niet overeenstemmen, zal de laatste prevaleren. De invloed van wetgeving op het gedrag van artsen is wellicht niet volledig afwezig, maar toch vrij marginaal.
- Wegens de afwezigheid van publieke informatieverstrekking en specialistische ondersteuning stellen de meeste potentiële gebruikers geen schriftelijke wilsverklaringen op en zijn de meeste schriftelijke wilsverklaringen van lage kwaliteit. Het gebruik van vage en algemene formuleringen in de meeste wilsverklaringen geeft artsen een vrijbrief om naar hun eigen opvattingen te handelen.
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Draagt de wet aangaande schriftelijke wilsbeschikking bij aan het realiseren van de patiëntenautonomie?
Gegeven de bovenstaande conclusie over de directe effecten van wetgeving op het gedrag van diegenen tot wie de wet zich richt, is het moeilijk in te zien hoe de wet zou kunnen worden beschouwd als een belangrijke bijgedrage aan de meer ambitieuze indirecte doelstelling, het realiseren van een grotere autonomie voor de patiënt.

Deze resultaten geven aanleiding tot een meer algemene reflectie. Om een sociale praktijk effectief te doen zijn zal het louter invoeren van een nieuw subjectief recht meestal niet voldoende zijn. Het nieuwe recht zal verscheidene vormen van ondersteuning vereisen, als verwacht mag worden dat mensen er gebruik van zullen maken. Dit is in het bijzonder het geval bij het invoeren van een nieuwe faciliteit (in dit geval het recht om een schriftelijke wilsverklaring op te stellen), waar het succes van de wetgeving grotendeels overeenkomt met het gebruik dat potentieel geïnteresseerde mensen hiervan maken.

In het licht van deze overweging is het mogelijk een aantal mogelijkheden voor te stellen die de situatie zouden kunnen corrigeren. Ten eerste zouden maatregelen, bedoeld om de kans te vergroten dat potentiële gebruikers geïnformeerd zijn over hun rechten, kunnen resulteren in een groter gebruik en betere kwaliteit van de documenten. Een andere mogelijk effectieve maatregel zou zijn het bevorderen van

een meer actieve betrokkenheid van doktoren in het adviseren van patiënten die een schriftelijke wilsverklaring willen opstellen. Meer actieve betrokkenheid van artsen in de eerste fasen van de sociale praktijk van schriftelijke wilsverklaringen zou ook een positieve invloed kunnen hebben op hun attitudes ten opzichte van het nut en het belang van deze documenten. Uiteindelijk zou dit de effectiviteit van schriftelijke wilsverklaringen ten tijde van hun implementatie kunnen vergroten. Ten slotte zou het wellicht helpen indien een sterkere band tussen schriftelijke wilsverklaringen en benoemingen van vertegenwoordigers zou worden gerealiseerd, bijvoorbeeld door te bevorderen dat elke schriftelijke wilsverklaring tevens een persoon aanwijst die participeert in de interpretatie van de wilsverklaring en toeziet op de implementatie ervan.

Enkele beperkingen in mijn onderzoek zijn evident. In het bijzonder het synthetische schema dat de waargenomen empirische bevindingen verklaart, suggereert het bestaan van specifieke relaties tussen verscheidene variabelen (bijvoorbeeld de attitudes van artsen en de effectiviteit van schriftelijke wilsverklaringen), een onderwerp waarover ik slechts kan speculeren. Nader onderzoek zal nodig zijn als wij een beter inzicht willen krijgen in de sociale praktijk van schriftelijke wilsverklaringen. In het bijzonder kwalitatieve studies, gericht op het ontdekken van de causale mechanismen die ten grondslag liggen aan de waargenomen relaties, kunnen een belangrijke bijdrage leveren, evenals onderzoek naar de populatie van potentiële gebruikers. Mijn resultaten zijn slechts een eerste stap in de richting van het inzicht dat nodig is voor een meer effectieve sociale praktijk en voor een beter theoretisch begrip van de sociale werking van dergelijke wetgeving.