

## **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,<sup>1</sup> 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.

---

<sup>1</sup> Nederlands instituut voor onderzoek van de gezondheidszorg (Dutch Institute for Health-Care Research). Internet site: [www.nivel.nl](http://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.<sup>2</sup> 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

---

<sup>2</sup> 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.<sup>3</sup>

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.

---

<sup>3</sup> 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	<b>16</b>	58
More than 5	52	<b>3</b>
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.<sup>4</sup> 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%.<sup>5</sup> The 1999 KNMG evaluation research on family doctors and the implementation of the WGBO had a similar response rate: 55%.<sup>6</sup>

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).

<sup>4</sup> The most common reason for refusal was lack of time.

<sup>5</sup> See Van Tol 2005.

<sup>6</sup> 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 <sup>7</sup>	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

<sup>7</sup> 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 <sup>a</sup> N=87	Nivel registration survey <sup>b</sup> N=7270
Response rate (%)		46%	55%	
Sex				
	Man	63	78	77
	Women	37	22	23
Age				
	Mean	47	46	47 <sup>c</sup>
	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 <i>euthanasieverklaring</i> (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).<sup>8</sup> 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
<b>Frequency of advance directives per 100 current patients</b>	<b>0.5</b>
<b>Containing a treatment directive</b>	<b>0.3</b>

**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
<b>Frequency of treatment directives per 100 patients who died in previous year</b>	<b>8.6</b>

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.<sup>9</sup> As we have already noted, the predominance of advance requests for

<sup>8</sup> I also asked whether doctors had patients with positive treatment directives, but the frequency of these documents turned out to be negligible.  
<sup>9</sup> 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%).<sup>10</sup> 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**

	A Total	With the assistance of:			E By the patient alone
		B The doctor himself	C Another doctor	D A notary	
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%

<sup>10</sup> 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.<sup>11</sup> 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 sources	Freq.*
NVVE	65
Medical	64
Legal or governmental	14
SCEN	8
None	25

\* More than one answer possible

**Table 51. Written sources and consultation (n=129)**

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

<sup>11</sup> 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	→	Who?	Frequency*
YES	61		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.<sup>12</sup>

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:<sup>13,14</sup>

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.

<sup>12</sup> The figure refers to 2004 and was supplied on request by the CBS (Centraal Bureau voor de Statistiek).

<sup>13</sup> The statement "A carefully drafted written refusal of treatment has a major effect on the medical decisions concerning the end-of-life. (Een zorgvuldig opgestelde schriftelijke behandelweigerings 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.

<sup>14</sup> 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).<sup>15</sup>

**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.<sup>16</sup> 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

<sup>15</sup> 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.

<sup>16</sup> 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
<b>Item 1.</b> Treatment directives influence decision-making	37	40	19	4	120	9
<b>Item 2.</b> Would follow a treatment directive that differs somewhat from medical judgment	8	45	32	15	102	27
<b>Item 3.</b> 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.<sup>17</sup> 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.<sup>18</sup> 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,<sup>19</sup> casts doubts on the concrete effectiveness of treatment directives as an instrument to guide medical decision-making.

---

<sup>17</sup> See Schneidermann et al. 1992, Schneidermann et al. 1993.

<sup>18</sup> Teno 2004, Tonelli 1996, Fagerlin and Schneider 2004.

<sup>19</sup> 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,<sup>20</sup> 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.

---

<sup>20</sup> 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 than in the previous studies. For current patients, all the doctors supplied figures for advance directives in general, and for their specific contents in terms 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 than 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.

