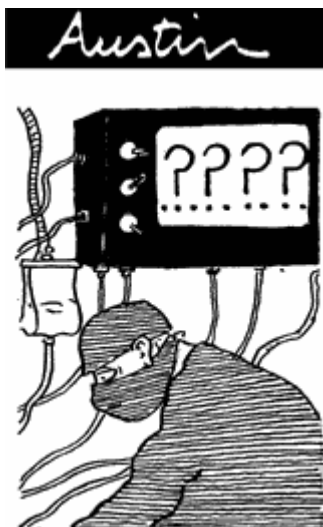


CHAPTER VII

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.

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 Arcare 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 (Jaarverslag 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 behandelweigerings*, 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 N=77	KNMG study 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 managers, 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)

Reading and/or lectures	Consult colleagues	
	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	→ Who?	Frequency*
Yes	48	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 informing other people	Advise renewing advance directives		
	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 effectiveness²⁰ 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 expressed 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 foregoing 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.

