

## CHAPTER VI

# THE ROLE OF NOTARIES IN THE SOCIAL PRACTICE OF TREATMENT DIRECTIVES

### 1. Introduction

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 However, the KNB has recently withdrawn the model as inadequate to fulfill the needs of clients and now encourages its members not to engage in a practice that demands a number of skills not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

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<sup>1</sup> See Chapter 4.

<sup>2</sup> Notaries are specialist in drafting legal documents such as wills, deeds, articles of incorporation, etc. In fact, in the Netherlands, the most popular source for legal advice concerning treatment directives is probably the NVVE.

<sup>3</sup> De Jong 1997.

<sup>4</sup> Hofman 2002.

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

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

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

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

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

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

## 2. The research questions

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

### *Frequency*

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

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

### *Opinions*

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

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

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

*Effectiveness: legal and medical quality*

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

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

### **3. Methods**

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

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

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<sup>7</sup> I used a proportionate stratified sample: that is for each geographical group the same proportion of offices was selected.

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

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

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

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

**4. Results**

*4.1. Experience with treatment directives*

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

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

the country, in urban areas, especially in the four biggest Dutch cities,<sup>9</sup> and in offices with only one notary.

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

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

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

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

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

Squared cells: all notaries in the office are involved

*4.2. Frequency*

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

<sup>9</sup> Amsterdam, The Hague, Rotterdam and Utrecht.

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

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

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

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

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

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

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

#### *4.3. Opinions*

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

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

<sup>11</sup> This idea is also suggested by De Jong 1997.



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

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

**Table 13 – Opinion of notaries**

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

#### 4.4. *The legal quality of treatment directives*

##### *Legal requirements*

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

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

<sup>12</sup> Van Veen 1998: page 44.

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

### *Technical quality*

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

- a) failure to distinguish between fundamentally different kinds of advance medical instructions;
  - b) use of imprecise terminology, not consistent with the law.
- a) Notaries scarcely distinguish between an advance refusal of treatment and a request for euthanasia. The fact that the KNB model is entitled a '*euthanasieverklaring*' ('request for euthanasia'), although it includes both kinds of instructions, reflects and probably adds to the confusion. Such confusion is a rather serious matter since a written refusal of treatment and an advance request for euthanasia are regulated by different laws and have a completely different legal status. The right to refuse treatment in advance is provided for in the law on patient's rights (WGBO), while an advance request for euthanasia is regulated in the new Dutch law on euthanasia. The legal force of a written refusal of treatment is unquestioned, whereas an advance request for euthanasia has a doubtful legal status and is certainly not binding.<sup>13</sup> Notaries appear to be unaware of these fundamental distinctions and, in the documents they draft, they combine rules taken from the different laws and apply them to both kinds of instructions. For example, a passage in the KNB model that applies to both treatment refusals and euthanasia requests says that if the attending doctor refuses to comply with the instructions, the author requests transfer to another doctor. However, while a doctor is entitled to refuse to perform euthanasia, this is not the case for a refusal of treatment.
- b) The time when the treatment directive comes into effect is described in the KNB model as follows: "this document takes effect when [...] the author is unable to express himself".<sup>14</sup> However, the relevant legal criterion in the WGBO is that the

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<sup>13</sup> See chapter 4, paragraph 2.2.

<sup>14</sup> The complete formulation in the KBN document is: "De comparant verklaarde dat deze wilsverklaring eerst aan de orde is, voor zover deze door hem op enig tijdstip niet bevestigd,

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

### *Availability*

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

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

### *Renewal*

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

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

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

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

<sup>17</sup> The office models we received always include a provision that the notary has permission to inform the client’s treating doctor about the existence of the document.

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

#### *Appointment of a representative*

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

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

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<sup>18</sup> See e.g. Tonelli 1996.

<sup>19</sup> The law provides that a doctor can decline to follow a treatment directive if he has “well-founded reasons” to do so. See Chapter 4.

<sup>20</sup> When the notaries who consider it important to renew a treatment directive were asked how often this should happen, 34 answered every 5 years, 9 said more frequently than 5 years and 2 said less frequently. Six of them did not answer the question.

<sup>21</sup> Van Veen 1998: 46-47.

<sup>22</sup> *Ibid.*: 48-49.

such a provision. We can therefore suspect that such a provision is often not included when a notary drafts a treatment directive.<sup>23</sup>

#### *4.5. The medical quality of treatment directives*

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

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

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

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

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<sup>23</sup> The same indication emerged from the qualitative pilot study conducted before our research. See Hofman 2002.

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

<sup>25</sup> Schneiderman et al. 1992.

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

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

\* 1 missing case

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

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

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

<sup>26</sup> The most frequently-mentioned condition of applicability being an incurable disease such as cancer or AIDS (3 notaries).

<sup>27</sup> The most frequently mentioned treatment specifically refused is artificial ventilation (3 notaries).

<sup>28</sup> Hofman 2002.

**Table 15 – Source of information about treatment directives**

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

\* more than one answer possible

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

## 5. Discussion

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

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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