

## CHAPTER III

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

### 1. The development of the debate on treatment directives

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

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<sup>1</sup> Schneiderman et al. 1985.

<sup>2</sup> Lynn 1991.

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

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

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<sup>3</sup> Emanuel and Emanuel 1989.

<sup>4</sup> The ‘substituted judgment’ standard for decision-making for an incompetent patient implies that the surrogate of the incompetent patient would take a decision in his behalf by answering the question: What would the patient want in these circumstances? The limits of such an approach are discussed by Beauchamp and Childress 1999: 170-173.

<sup>5</sup> *Cruzan v. Director, Missouri Dep’t of Health*, 110 S. Ct. 2841, 2858-59 (1990); *In re Claire C. Convoy*, 98 NJ 321 1985; *In re Nancy Ellen Jobes*, 108 NJ394 1987; *In re Mary Moe* 385 Mass. 555 1982. See generally Emanuel 1988.

<sup>6</sup> Greco et al. 1990; La Puma et al. 1990.

<sup>7</sup> Capron 1990.

<sup>8</sup> Greco et al. 1991.

<sup>9</sup> Some examples of these studies are Danis et al. 1991, and Schneiderman et al. 1992. More details concerning these studies will be given later in this chapter.

<sup>10</sup> SUPPORT Principal Investigators 1995.

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

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

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

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<sup>11</sup> Teno et al. 1997a and Teno et al. 1997b.

<sup>12</sup> Lynn and Teno 1993, Emanuel 1993, Pearlman 1994.

<sup>13</sup> Tonelli 1996, Dresser 1995.

<sup>14</sup> Pearlman et al. 1995, Teno and Lynn 1996, Martin et al. 2000.

<sup>15</sup> Molloy et al. 2000a, Ho et al. 2000, Tierney et al. 2001

<sup>16</sup> To date, only few studies have been published, and so far they have not added much to the debate, remaining sparse and unsystematic. Schiff et al. 2000, Van der Heide et al. 2003.

<sup>17</sup> Teno 2004.

<sup>18</sup> Degenholtz et al. 2004.

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

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

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

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

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

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<sup>19</sup> Fagerlin and Schneider 2004.

<sup>20</sup> Tonelli 1996, Dresser 1995, Fagerlin and Schneider 2004.

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

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

## 2. Demand for treatment directives

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

### 2.1. Demographic demand

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

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<sup>21</sup> Gavrilov and Heuveline 2003; Preston et al. 1989.

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

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

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

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

Source: United Nation, 2001

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

<sup>22</sup> UN 2002: 16. In the Netherlands, the population 65 years or over is expected to grows from 14% in 2005 to 22% in 2050.

<sup>23</sup> People 80 years or over are considered by United Nation as the 'oldest old' (UN 2001).

<sup>24</sup> Herbert et al. 2003. Although these estimates are controversial (see for example Grant 2004), the unquestioned fact remains that in the coming years, due to the aging of the population, there will be a substantial growth in the number of persons affected by Alzheimer's in particular, and dementia in general.

<sup>25</sup> Van den Berg et al. 2004: pp.146-147. Available also by [www.nationaalkompas.nl](http://www.nationaalkompas.nl), accessed 27.7.2005.

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

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

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

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

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

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

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

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

<sup>29</sup> Moller et al. 1998.

<sup>30</sup> Newman 2001.

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

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

## 2.2. *Social demand*

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

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

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

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

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

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



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

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

### *2.3. Frequency of treatment directives*

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

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<sup>35</sup> Information available on the site of the organization: <http://www.nvve.nl/>, accessed 9.2.2005.

<sup>36</sup> NVVE 2002, 2003.

<sup>37</sup> The internet site of the World Federation of Right To Die Societies (<http://www.worldrtd.net/>) gives an extended list of national right-to-die societies.

<sup>38</sup> Kerridge 1998.

<sup>39</sup> Schiff 2000.

<sup>40</sup> Fagerlin and Schneider 2004.

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

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

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

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

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

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

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

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<sup>41</sup> SUPPORT Principal Investigators 1995: 1592.

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

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

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

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

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

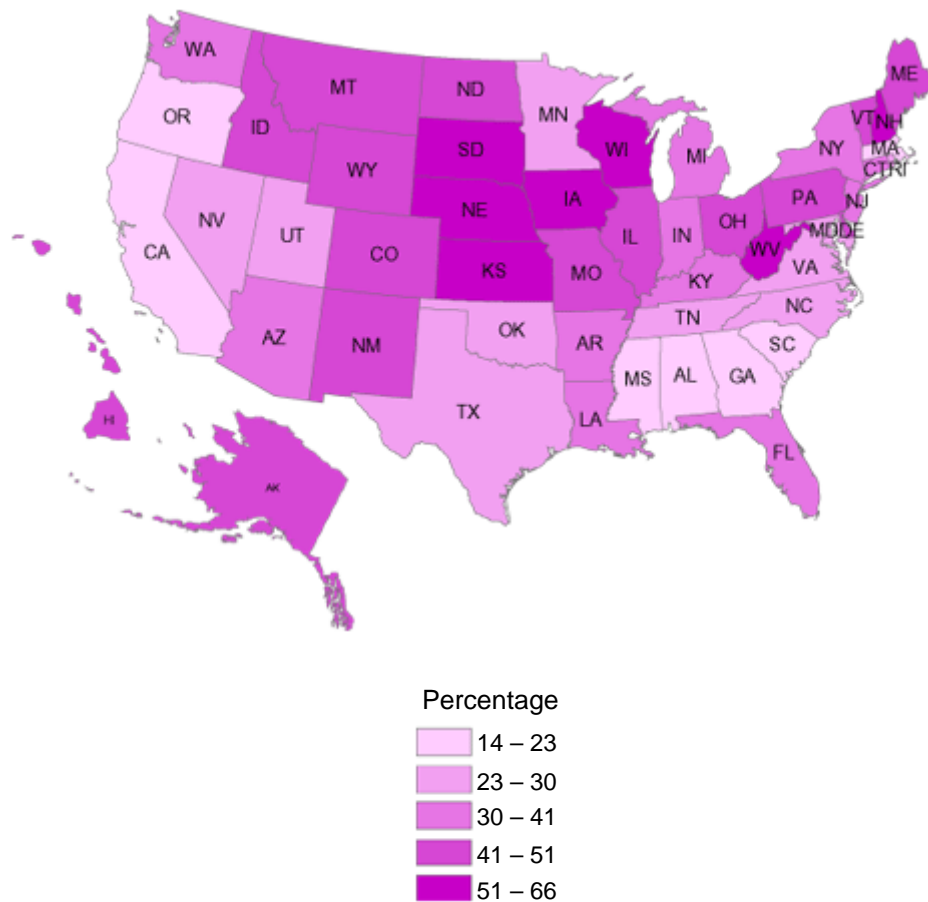
Source: [www.chcr.brown.edu/dying/factsondying.htm](http://www.chcr.brown.edu/dying/factsondying.htm), visited on November 1<sup>st</sup>, 2004.

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

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

<sup>44</sup> Minimum Data Set (MDS), see Hawes et al. 1995; Health Care Financing Administration, Medicare and Medicaid 1997.

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



**Source: Brown Medical School – Center for Gerontology & Health Care research**

([www.chcr.brown.edu/dying/factsondying.htm](http://www.chcr.brown.edu/dying/factsondying.htm), visited on November 1<sup>st</sup>, 2004)

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

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

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

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

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

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

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

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

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

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

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

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<sup>45</sup> Some caution is necessary because the two studies are not clear about the exact definition of the documents they were looking for.

<sup>46</sup> Reiserberg 2000.

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

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

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

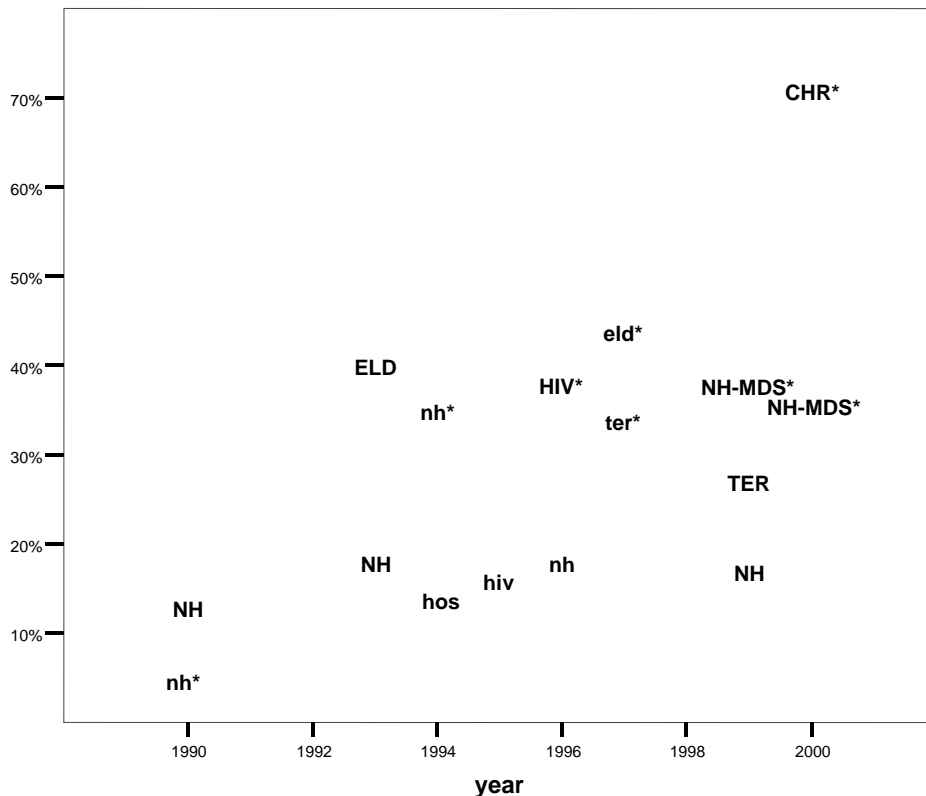
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<sup>47</sup> Fagerlin and Schneider 2004



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

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



**Legenda**

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

\* = the study refers to advance directives in general

**Nota bene:**

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

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

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

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

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<sup>48</sup> Van der Heide et al 2003. The six countries considered are: Denmark, Sweden, Switzerland, Belgium, Italy and the Netherlands.

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

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

<sup>51</sup> Schiff et al. 2000.

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

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

\* All the studies refer to treatment directives

### 3. Factors influencing the completion of treatment directives

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

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

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

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

<sup>52</sup> Schiff et al. 2000.

<sup>53</sup> Teno et al 1997a.

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

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

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

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<sup>54</sup> This idea represents the basis for the literature promoting advance care planning (ACP), where discussion with the physician is generally recognized as an important factor improving end-of-life care generally and the effectiveness of treatment directives in particular.

<sup>55</sup> Larson and Tobin 2000.

<sup>56</sup> Song 2004 (literature survey).

<sup>57</sup> Negative factors connected with a lower chance of discussing end-of-life care with a physician were: being Latino or black, male, having being infected via injection drug use. Positive factors were: presence of children in the household, higher education, longer doctor-patient relation, more positive attitude toward coping with the disease.

<sup>58</sup> Teno 1997a.

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

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

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

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<sup>59</sup> Capron 1990.

<sup>60</sup> Molloy et al. 2000a.

<sup>61</sup> Molloy et al. 2000b.

<sup>62</sup> Ho et al. 2000.

<sup>63</sup> On the other hand, despite an increase in the rate of completion of treatment directives after the specific informational program, the legal quality of directives remained low: a quarter of them were invalid under Ontario law.

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

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

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

#### **4. Drafting a treatment directive**

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

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

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

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

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

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

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

<sup>66</sup> Teno et al. 1997b; Schneiderman et al. 1992; Tonelli 1996; Fagerlin and Schneider 2004.

<sup>67</sup> Wenger et al 2001; Teno and Lynn 1996.

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

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

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

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

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

## **5. Availability of treatment directives: the latency phase**

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

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

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

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<sup>70</sup> Riesenbergs 2000.

<sup>71</sup> Danis et al. 1991.

<sup>72</sup> Bradley et al. 1998, Teno et al. 1997a.



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

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

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

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

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

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

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<sup>73</sup> Vestergaard 2001.

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

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

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

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

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

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<sup>75</sup> See, for example, Jennet 2002.

<sup>76</sup> See previous note 74.

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

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

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

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<sup>77</sup> Schneiderman et al. 1993; Fagerlin and Schneider 2001.

<sup>78</sup> Schneiderman et al. 1992: the author interviewed patients who wrote a treatment directive on their real wishes concerning end-of-life treatment.

<sup>79</sup> Emanuel and Emanuel 1990, Cantor 1993.

<sup>80</sup> Teno et al. 1997a.

<sup>81</sup> The same limitations apply to the study of Morrison and Siu 2000, who found no effects connected to the presence of treatment directives in the treatment of elderly people hospitalized for pneumonia or hip fracture.

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

## 7. General social effects of the use of treatment directives

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

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

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

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<sup>82</sup> Dagenholtz et al. 2004. The probability of in-hospital death decreased from 65% to 52% for people living in the community, while for nursing home residents the probability decreased from 35% to 13%.

<sup>83</sup> Gross 2003.

<sup>84</sup> Loewy 1998.

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

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

## **8. Summary**

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

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

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<sup>85</sup> Emanuel and Emanuel 1994, Teno 1997c.

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

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

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

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

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

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<sup>86</sup> See Teno et al. 1997a.

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

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

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

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

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



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

**Demand**

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

**Factors influencing decision to complete a treatment directive**

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

**Preparation/drafting**

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

**Latency**

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

**Implementation**

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

**General social effects of the social practice**

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

