CLINICAL ETHICS

Importance of the advance directive and the beginning of the dying process from the point of view of German doctors and judges dealing with guardianship matters: results of an empirical survey

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Objectives: To analyse and compare the surveys on German doctors and judges on end of life decision making regarding their attitudes on the advance directive and on the dying process.
Design: The respondents were to indicate their agreement or disagreement to eight statements on the advance directive and to specify their personal view on the beginning of the dying process.
Participants: 727 doctors (anaesthetists or intensive-care physicians, internal specialists and general practitioners) in three federal states and 469 judges dealing with guardianship matters all over Germany.
Main measurements: Comparisons of means, analyses of variance, pivot tables (χ^2 test) and factor analyses (varimax with Kaiser normalisation).
Results: Three attitude groups on advance directive were disclosed by the analysis: the decision model, which emphasises the binding character of a situational advance directive; the deliberation model, which puts more emphasis on the communicative aspect; and the delegation model, which regards the advance directive as a legal instrument. The answers regarding the beginning of the dying process were broadly distributed, but no marked difference was observed between the responding professions. The dying process was assumed by most participants to begin with a life expectancy of only a few days.
Conclusions: A high degree of valuation for advance directive was seen in both German doctors and judges; most agreed to the binding character of the situational directive. Regarding the different individual concepts of the dying process, a cross-professional discourse on the contents of this term seems to be overdue.

The scope and binding character of the advance directive are at present the subject of fierce political controversies in Germany. In November 2004, the Federal Ministry of Justice[1] published a bill providing for the binding character of a concrete, situational advance directive without special formalities. The professed aim of the bill was to strengthen patient autonomy at the end of life. In a recent statement, the National Ethics Council[2] also came out in favour of the binding character of the advance directive by a majority. In September 2004, the Study Commission on Ethics and Law of Modern Medicine of the German Bundestag[3] demanded, in case of a legal regulation, the restriction of the scope and binding character of the advance directive to situations in which the patient's underlying disease has taken an irreversible and fatal course.

The advance directive has been discussed in Germany since the end of the 1970s. In 1978, the first form was published by a jurist.[4] Until the mid-1990s, the medical profession held a rather sceptical view on such documents. For example, in the preface to the guidelines for medical terminal care by the German Medical Association of 1993, it says, "In individual cases advance directive may present simple solutions from the legal point of view; however, from the ethical and medical points of view they are no appreciable relief."[5] This evaluation has undergone fundamental change during the past years. In the guidelines by the German Medical Association of 1998, an advance directive is regarded as an "important aid for the physician's acting", which is binding "if it applies to the concrete treatment situation and no circumstances are in evidence that the patient would not wish it to be valid anymore".[6] This evaluation is being acknowledged in the current principles of 2004.[7]

The main reason for this change of opinion was a trend-setting court decision of the Federal Court of Justice in 1994. The Federal Court of Justice determined that life-prolonging measures for a terminally ill and incompetent patient may be terminated if this was in accordance with the patient's presumed will. According to the court, important evidence for the presumed will are previous oral or written statements by the patient.[8] Thus, the importance of the advance directive lies in providing an indication of the patient's presumed will. In a court decision in 2003, the Federal Court of Justice[9] went one step further by describing the advance directive as an expression of the patient's continual right to self-determination and as such being binding for doctors and guardians. Therefore, the advance directive is an indication of the presumed will of the patient and also—when concrete and authentic—an expression of the patient's formerly expressed will.

ADVANCE DIRECTIVE IN PRACTICE

Empirical surveys in Germany show that, although many people can imagine drawing up an advance directive, only a few have already done so,[10] with the share of people in possession of an advance directive varying—depending on the group of respondents—between 3.5% (survey on the population[11]) and 16% (survey on patients with cancer[12]). Previous surveys on German doctors about this topic mainly focus on the frequency of occurrence and—mostly by case examples—on the relevance of the advance directive in clinical practice.[13–16]

In the framework of a joint project between jurists, doctors, ethicists and care givers, the first empirical survey on the attitudes of doctors and judges dealing with guardianship matters regarding medical measures and decisions at the end of life was conducted in 2003. The first results[17 18] showed considerable insecurity and diversity of opinion regarding the assignment of certain measures at the end of life to the various forms of euthanasia. Many doctors and judges do not understand the differentiation between (prohibited) active and (permitted) passive euthanasia in decisions of the high court. The surveys conducted on doctors and judges showed a great appreciation for the advance directive. However, both groups of respondents were sceptical about third-party statements on the patient's presumed will.

In this paper, the surveys on doctors and judges are analysed, compared and discussed with regard to their attitudes on the advance directive and on the dying process. We focus on how the profession (medicine or law), the professional socialisation (work experience), sociodemographic factors (age, sex or religious affiliation) and possibly the work environment (size of the city of the workplace) influence attitudes.

MATERIALS AND METHODS

A multiprofessional group of doctors, care givers, ethicists and jurists developed the questionnaire for the cross-professional surveys from March to September 2003.

Eight statements were formulated to capture the attitudes to the advance directive. The respondents were to indicate their agreement or disagreement on a 4-point Likert scale (strongly agree, agree, disagree and strongly disagree). For the question on the beginning of the dying process from the respondent's personal point of view, four alternatives were given (life expectancy of a few months, a few weeks, a few days and a few hours). Furthermore, individual entries were possible. The self-attributed religiousness was captured by the religiousness scale established in social sciences (10-point Likert scale) and the sociodemography was taken from the Allgemeine Bevölkerungsumfrage der Sozialwissenschaften.[19]

After the pre-test, a national survey on judges dealing with guardianship matters was conducted between May and June 2003. As neither the number nor the names are officially registered, the judges were contacted—after consultation with the respective ministries of justice of the federal states—in an indirect way via the directors or presidents of all local courts in Germany. A letter was sent asking them to name the number of judges dealing with guardianship matters at their court. After their reply, the corresponding number of questionnaires was sent out. A total of 80% of local courts participated in the survey; 1254 questionnaires were sent out and 479 completed questionnaires were returned (rate of return 38%). Reminders were not sent.

The subsequent survey on doctors was conducted in three federal states (Bavaria, Westphalia-Lippe and Thuringia); the selection of federal states was intended to minimise regional effects. From the public lists of the representatives for continuing education, 1557 doctors, who, because of their specialisations would in all probability be confronted with dying people in their professional practice, were selected in a defined random process (419 anaesthetists or intensive-care physicians, 497 internal specialists and 641 general practitioners). The written survey, with the same questionnaire as for the survey on judges, was conducted between February and March 2004 in accordance with the respective medical associations; a reminder was sent out 6 weeks later. In all, 727 completed questionnaires were sent back (rate of return 47%).

Data were processed with SPSS V.11.5 for Windows. Significant differences were examined using pivot tables (χ^2 test) and comparisons of means and analyses of variance. For dimension reduction, a factor analysis was carried out (varimax with Kaiser normalisation). The level of significance was set at $p<0.005$. For the comparative analysis with regard to religiousness, three groups were established: 0 and 1, non-religious; 2–8, religious; 9 and 10, very religious.

RESULTS

Sociodemography of the respondents

In the surveys on both doctors and judges, noticeably more men than women answered the questionnaire. Most respondents were aged >50 years and had more than 20 years of work experience as doctors or judges dealing with guardianship matters (table 1). A total of 12.1% of the doctors and 18.1% of the judges characterised themselves as non-religious (scale values 0 and 1), 71.4% of the doctors and 75.2% of the judges characterised themselves as religious (scale values 2–8), and 12.7% of the doctors and 5.2% of the judges as very religious (scale values 9 and 10). As many as 74.4% of the doctors and 81.6% of the judges belonged to a church or religious community.

Beginning of the dying process

The question on the beginning of the dying process was answered by 469 judges (97.9%) and 705 doctors (97.0%; table 2); 10.8% of the doctors and 15.4% of the judges made individual entries. Above all, the doctors emphasised that the beginning of the dying process individually depends on the patient, his mental and physical state or his underlying disease.

Attitudes to the advance directive

The respondents were given eight typical statements on the advance directive (V1–V8) for assessment by a 4-point Likert scale. In the comparison of the answers by judges and doctors, the items "strongly agree" and "agree", and "disagree" and "strongly disagree" are merged (table 3).

Attitudes to the advance directive: decision model, deliberation model and delegation model

With a factor analysis, the eight variables were reduced to three statistically separated types of attitudes (Kaiser–Meyer–Olkin criterion 0.749; explained variance 60.4%). The largest group of respondents were of the opinion that the advance directive as a valid expression of will disburdens the doctor

Table 1 Sociodemographic characteristics of the respondent doctors and judges

	Doctors	Judges
Sex		
Male	78.6	72.0
Female	21.4	28.0
Age (years)		
<50	31.2	28.0
51–60	38.8	30.1
>60	20.5	7.1
Work experience (years)*		
<5	0.3	27.6
5–10	3.7	24.0
11–20	24.1	25.3†
>20	69.6	
Size of the city of the workplace‡		
<20 000	31.6	68.5
20 000–100 000	39.2	20.0
>100 000	18.7	10.2

Values in valid percentages.
Difference at 100% because of the category "not applicable".
*Judges: work experience in dealing with guardianship matters.
†Including the category >20 years.
‡Number of inhabitants.

Table 2 Thinking about a critically ill person: when does the dying process begin according to your personal opinion?

When the medically assessed life expectancy amounts to …	Doctors	Judges
A few months	7.4	7.5
A few weeks	23.7	24.4
A few days	48.8	45.5
A few hours	6.6	10.9

Values in valid percentages.
Difference at 100% because of the category ''not applicable''.

and relatives in their decisions (decision model; V1, V2 and V4; explained variance 25.6%). A second group emphasised the importance of the advance directive for the communication between patients, doctors and relatives, and at the same time emphasised the necessity of the topicality of the advance directive (deliberation model; V8 and V5; explained variance 18.8%). The third attitude group opened the triad of doctor–patient–relatives in decision-making situations to a representative of the legal system, with the possibility of delegating decisions: the advance directive has to be certified by a notary and makes the doctor–patient relationship even more complex legally (delegation model; V6 and V7; explained variance 15.9%).

Regarding the first attitude group ''the advance directive facilitates decision making'' (decision model), the univariate analysis of variance showed no marked differences with regard to the two professions, the sex, age and work experience, as well as religious affiliation. The second attitude group ''the advance directive as a communication aid'' (deliberation model) was found noticeably more often in older respondents. Profession, sex and religious affiliation were not significant. The third attitude group ''the advance directive is a legal instrument'' (delegation model) was found noticeably more often in judges than in doctors. Marked differences were found with regard to the respondents' sex. The highest degree of agreement was found in (male) judges and the highest degree of disagreement in (male) doctors. Female doctors agreed with the item more often than female judges, noticeably more rarely than male judges. Age, work experience, size of the city of the workplace or religious affiliation did not show any significance ($p = 0.109$; $p = 0.353$; $p = 0.289$; $p = 0.745$).

DISCUSSION

Representativenes

The survey on doctors was conducted on a representative sample. In the survey on judges, 80% of all German local courts participated. The rate of return (47%) for the survey on doctors was average in comparison with similar surveys. In a large-scale European survey on end of life decision making, the rate of return varied between 44% and 75%, depending on the country.[20] In the comparable survey on German senior neurologists, the rate of return of 37% was noticeably lower.[21] The rate of return for the survey on judges was 38%, which among others is a result of the fact that reminders could not be sent because of methodological reasons. As judges were not previously surveyed on this topic, comparative statements about the rate of return are not possible. However, systematic distortions cannot be ruled out, for example, because mainly doctors and judges interested in the topic participated in the survey. Thus, generalisations are not possible.

Dying process

A broad distribution on the beginning of the dying process exists, but with a high degree of agreement between the responding professions on the whole. Most participants assumed that the beginning of the dying process starts with a life expectancy of only a few days. However, if the difficulties in the assessment of life expectancy and the broad distribution of answers are taken into account, misunderstandings and communication problems both in the professional groups and in the discussion between judges and doctors are unavoidable. This is problematic, because the beginning of the dying process has an important normative relevance in medical guidelines[6 7] and in high court decisions,[8 9] as it marks the point in time from which foregoing or terminating life-prolonging measures is possibly independent of the patient's will, because those measures would only prolong the patient's dying and as such are not medically indicated anymore. Thus, a cross-professional discourse on the term ''dying process'' seems to be overdue, also taking into account the difficulties of a definition of the individually assessed remaining lifetime.

Attitudes to the advance directive

When analysing the statements of the judges, the three attitude groups from the survey on doctors (decision model, deliberation model and delegation model) are reflected again.

Table 3 Attitudes to the advance directive

	Agreement		Disagreement	
	Doctors	Judges	Doctors	Judges
(V2) The advance directive may be a relief for relatives in certain situations	97.6	96.6	2.4	3.3
(V1) The advance directive is important, because it may facilitate the doctor's decision in the concrete case	97.3	95.6	2.6	4.4
(V4) Basically, the will expressed in an advance directive is valid if there are no concrete indications for a change of will	93.1	93.7	6.9	6.4
(V8) The advance directive is rather an instrument to further the conversation between a patient, relatives and a doctor than to give directives for action in the concrete decision-making situation	52.5*	28.5*	48.1*	71.5*
(V7) The advance directive contributes to making the doctor–patient relationship even more legally complex	30.5*	49.1*	69.5*	51.0*
(V5) The advance directive that was composed or updated more than 1 year ago is not binding anymore	25.7*	16.0*	74.3*	84.0*
(V3) The advance directive in practice is mostly not helpful because it was composed in healthy days and people often change their opinion when they are ill	21.8	18.8	78.2	81.1
(V6) The advance directive has to be notarially certified	16.2	16.1	83.8	84.0

Agreement in valid percentages.
Difference at 100% because of the categories ''I don't know'' and ''not applicable'', arranged according to frequency of doctors' agreement (descending).
*Difference in attitude between the professions is significant $p = 0.000$.

The highest agreement among all respondents was for the decision model (26% explained variance), which emphasises the binding character of the situational advance directive. Representatives of this model regard the advance directive as an important decision-making aid for the doctor (as the person ultimately bearing the responsibility) and as a relief for relatives. This model also corresponds with the increasing importance of the tool advance directive in court decisions, medical guidelines and the public discourse.

Second, with regard to agreement is the deliberation model (explained variance 19%), which puts more emphasis on the communicative aspect of the advance directive. The fact that this model is more often favoured by older respondents may be a result of the growing realisation that comes with increasing professional experience that the diversity of possible situations often does not allow for clear instructions to the doctors who are treating the patients. This is not necessarily a reason against the binding character of the advance directive, but probably reflects the experience of the advance directive in practice often not being so unequivocal and concrete to suffice as the only decision-making criterion. A further problem in connection with the binding character of the advance directive seems to be founded on the experience that how a patient wishes to receive treatment may change during the course of an illness. This is why the representatives of the deliberation model emphasise the topicality of the advance directive.

The delegation model, which regards the advance directive along the lines of a (legally binding) contract, met with the least agreement (explained variance 16%). The fact that this model was highly approved of by the male judges, whereas it was strongly disapproved of by the male doctors, may be the expression of a latent professional competitive dimension that is relevant neither for the respondent female judges nor for the female doctors. The advance directive is the responsibility of the judges, whereas doctors do not want to have the last decision taken out of their hands by either the advance directive or by the judges. Future surveys can examine how far this is just an expression of professional action related to the individual case and the topical situation or evidence of a critical distance to the advance directive in principle.

SUMMARY AND PROSPECTS

The results of the surveys on doctors and judges show a high degree of valuation for the advance directive. Most respondents agree to the binding character of the situational advance directive, as emphasised in the bill by the Federal Ministry of Justice and in the statement by the National Ethics Council. At the same time, however, it becomes obvious that a legal clarification of the binding character of the advance directive will solve only (a small) part of the problems in dealing with the advance directive in practice. Because of a lack in predictability of the advance directive in topical treatment situations that are often not concrete and unequivocal enough when being written, doctors will be bound to discuss the contents of the advance directive with relatives and proxies of patients, as well as with judges dealing with guardianship matters. For such a process of shared decision making, it is necessary to legally clarify the roles of the parties concerned as proposed in various suggestions for regulations and also to enhance the ethical and communicative skills of doctors and judges by further education and institutional support (eg, in the form of clinical ethics committees or ethics councils).

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