

## CLINICAL ETHICS

# Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff

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**Objectives:** After years of public discussion too little is still known about willingness to accept the idea of writing an advance directive among various groups of people in EU countries. We investigated knowledge about and willingness to accept such a directive in cancer patients, healthy controls, physicians, and nursing staff in Germany.

**Methods:** Cancer patients, healthy controls, nursing staff, and physicians ( $n = 100$  in each group) were surveyed by means of a structured questionnaire.

**Results:** Only 18% and 19% of the patients and healthy controls respectively, and 10% of the medical staff had written an advance directive. However, 50–81% of those surveyed indicated that they wished to write one. This intention was associated with deteriorating health ( $p < 0.001$ ). Only 29% of the healthy controls and 43% of the patients knew about the possibility of appointing a health care proxy. A majority in all groups believed that advance directives may influence the course of treatment (79–85%), yet half of those surveyed in all groups fear that patients could be pressurised into writing an advance directive, and 38–65% thought that relatives could abuse such documents.

**Conclusions:** Only a minority of the participants had written an advance directive and knew about the possibility of authorising a health care proxy. Deteriorating health was associated with increasing willingness to make a directive. Despite a majority belief that advance directives may influence treatment at the end of life, other factors limit their employment, such as fear of abuse.

To uphold patients' autonomy, even when they are unable to make decisions, advance directives for medical care are being encouraged in many countries.<sup>1–6</sup> Yet, the binding nature of advance directives is a subject of controversy. Critics express the fear that patients' wishes could change in the course of a serious illness; wishes laid down in an advance directive when a patient was healthy—most particularly the limitation of life-preserving treatment—might then be no longer valid.<sup>7–8</sup> In Germany, a verdict of the Bundesgerichtshof (Federal Supreme Court) with regard to the obligation to honour advance directives has led to great uncertainty.<sup>9</sup> There are very few empirical data in Germany about attitudes among patients, healthy people, and medical staff towards the idea of advance directives. In representative surveys, only about 2.5% of those surveyed had actually written one.<sup>10</sup> A small number of studies have researched the acceptability of medical directives, all being carried out on small groups of patients.<sup>11</sup> There is a lack of research comparing the attitudes of patients, healthy people, and medical staff.

In Germany, a draft law has been presented by the second legislative chamber (Bundesrat).<sup>12</sup> This proposes that relatives should take a greater part in decision making for patients who are unable to decide for themselves, at least if they have not already ruled otherwise in an advance directive. This draft law is based on the assumption that there are only a few people who are prepared to concern themselves with questions pertaining to the end of their lives; it is assumed to be unlikely that a significant proportion of people will write an advance directive.

We investigated the prevalence of and attitudes towards advance directives among cancer patients, healthy controls, physicians, and nursing staff. In Germany there are at the moment three types of directive for health care. In an advance directive for medical care (Patientenverfügung)

patients' preferences concerning medical treatment at the end of their life can be laid down. In an authorisation of health care proxy (Vorsorgevollmacht) nominated persons can act as proxies if patients are no longer able to decide for themselves. The designation of guardian (Betreuungsvollmacht) allows for the naming of a person to act as a guardian if guardianship is enforced by law. In addition, we asked the following questions: To what extent, in the opinion of those asked, can an advance directive influence the choice of treatment? Are there fears that the existence of an advance directive could lead to abuse?

## METHOD

### Cohorts

Cancer patients who were being treated in the Oncology Clinic and in the Breast Cancer Centre of the German Clinic for Diagnosis between August and October 2003 were interviewed by means of a questionnaire developed by ourselves. Most patients were suffering from either newly diagnosed or advanced cancer.

Patients were asked by their doctors to take part in the survey, and permission obtained. They were informed that the study was not related to the course of their own disease and that data collection was strictly anonymous. The study was approved by the ethics committee of the Medical Council of the State of Hesse, Germany.

People who attended for routine medical checkups at the clinic during the same period were interviewed to obtain data from healthy controls. Nursing staff and physicians at the German Clinic for Diagnosis were also interviewed, as well as attendees at a conference for nursing staff and a doctors' symposium held during the annual congress of the German Society for Digestive and Metabolic Diseases in Nuremberg in 2003.

**Table 1** Demographic characteristics and health status ( $n = 100$  except as shown)

Characteristic	Patients	Healthy controls	Nursing staff	Physicians	p value
Mean age: years (SD)	59.7 ( $\pm 11.6$ )	49.8 ( $\pm 13.1$ )	40.1 ( $\pm 8.3$ )	45.3 ( $\pm 9.3$ )	<0.0001
Men/women (%)	42/58	54/46	11/89	67/33	<0.001
Married (%)	78.0	71.0	52.0	82.0	<0.001
Health status: good/poor† (%)	35.0/65.0	87.0/13.0	87.0/13.0	97.0/3.0	<0.001
Religion: yes/no‡ (%)	72.5/27.5 ( $n = 98$ )	64.3/35.7 ( $n = 98$ )	55.0/45.0	74.5/25.5 ( $n = 98$ )	NS

SD, standard deviation; NS, not significant.

†, self-estimate of health status: very good + good/tolerable + poor; ‡, self-estimate of being religious or member of a church/religious community.

### Questionnaire

The first section contained questions pertaining to the existence of, their intention to write, and their knowledge about the different legal forms of advance directives in Germany.

Questions in other sections were about:

- How far people think the existence of such a directive can influence the course of an illness;
- Fears of possible abuse or wrong interpretation by physicians and relatives;
- Patients' own judgement of their health; the frequency of pain; demographic characteristics (age, marital status, children, living alone/with children/partner); educational qualifications; own judgement about religious beliefs—that is, devoutness or belonging to a religious organisation; and experience of serious illness, either in themselves or in a relative.

### Statistics

Comparisons of the frequencies of categorical variables in the groups and the association of categorical variables were calculated using the  $\chi^2$  test. Comparisons of the frequency of ordinal variables in the groups and their association with categorical variables were carried out using either the Wilcoxon or the Kruskal–Wallis test for non-parametric distributions.

## RESULTS

### Cohorts

A total of 400 cancer patients, healthy controls, nursing staff, and physicians (100 in each group) were interviewed. Table 1 summarises the distribution of important demographic characteristics and table 2 the educational qualifications of the patient and healthy control groups. Not unexpectedly, the groups differed according to their age and sex. Patients were older; nursing staff were younger, mostly female and usually unmarried, the latter reflecting the present social trend towards later or rejection of marriage. Patients showed a poorer state of health.

The patients suffered more frequent pain (data not shown,  $p < 0.001$ ); 55.5% of the patients felt very greatly, greatly, or moderately adversely affected by their illness. There was no difference between the groups regarding their own experience of a previous serious illness or that of relatives (data not shown).

### Frequency of existence of and knowledge about medical directives

Table 3 shows the frequencies of those surveyed who had written an advance directive, who knew about the legally possible forms of an advance directive, who possibly intended to write one, and who wished to know more about directives.

In all groups the proportion of those who had already written an advance directive is small. Significantly more patients expressed the intention to write an advance directive. Remarkably, less than half of those in the non-medical professional groups (patients and healthy controls) knew about the possibility of naming persons as health care proxies/guardians. We found an association between age/self-estimation of state of health/reported pain and the intention to write an advance directive. Older persons wanted to do this more often ( $p < 0.0001$ ). Only 54% of those surveyed who were in a very good state of health, but 80.5% of those in a tolerable and 95% of those in a bad state of health, said they wanted to write a medical directive ( $p < 0.001$  and  $p < 0.001$  respectively). Those who often suffered pain expressed the intention more often than those without pain (84% versus 60%,  $p < 0.01$ ). The intention was also associated with their own experience of a serious illness at some time in the past ( $p < 0.001$ ) but not with serious illness in relatives.

### Binding nature of advance directives and trust in proxies and guardians

Table 4 shows the interviewees' estimation of the influence of an advance directive on the type and quality of care they would receive if they were no longer able to decide for themselves, and also their trust in proxies/guardians. The majority in all groups believed that the existence of an advance directive could influence the quality of treatment received and expressed trust that guardians would act in the interest of patients if they could no longer decide for themselves. No associations with demographic data or current health status were found.

### Fears of possible abuse of an advance directive

Fears of abuse of an advance directive were pinpointed in three ways. Participants were asked to react positively or negatively to the following possibilities: (1) patients could be pressurised into writing an advance directive (coercion); (2) physicians could use a directive as the only basis for a decision without taking into account their own knowledge about prognosis and the type of illness (dictatory use); and (3) relatives could insist on cessation of therapy because a directive with such an instruction exists, although the

**Table 2** Educational level of patients and healthy controls

Group	%Unqualified school-leavers	%IGCSE "O" level	%IGCSE "A" level	%Training/apprenticeship	%College or university
Patients ( $n = 99$ )	24.2	25.3	7.1	25.3	18.2
Healthy controls ( $n = 99$ )	7.1	31.3	8.1	13.1	40.4

IGCSE, international general certificate of secondary education

**Table 3** Existence of, knowledge of, intention to write, and wish to know more about advance directives ( $n = 100$  except as shown)

	%Patients	%Healthy controls	%Nursing staff	%Physicians	p value
Already written an advance directive	18.0	19.0	10.0	10.0	NS
Intention to write an advance directive	81.0 ( $n = 97$ )	59.6 ( $n = 99$ )	68.6 ( $n = 99$ )	50.5 ( $n = 99$ )	<0.001
Knowledge of:					
Advance directive	74.0	89.0	91.0	98.0	<0.001
Authorisation of health care proxy	43.0	29.2 ( $n = 99$ )	37.0	69.0	<0.001
Designation of guardian	46.0	26.6	60.0	76.0	<0.001
Wanting to know more	83.0	89.9	89.0	69.0	<0.001

prognosis according to the physician is favourable (abuse by relatives). Table 5 summarises the results.

A surprisingly high proportion of those surveyed expressed the fear that advance directives could be abused in one way or another, with fewer patients fearing abuse by relatives compared with the other groups.

We found considerable and statistically significant differences only with regard to possible abuse by relatives: 62.2% and 52.3% respectively of those who felt very well/ well, but only 36.9% and 35.0% respectively of those who considered their state of health to be tolerable or poor, feared abuse by relatives ( $p < 0.005$ ). Those who believed that abuse by relatives was possible were younger than those who did not share this belief ( $p < 0.005$ ).

## DISCUSSION

In this study the frequency of existence of and willingness to write advance directives for medical care by cancer patients, healthy persons, nursing staff, and physicians were investigated for what would appear to be the first time in Germany. The results with regard to demographic parameters and health status indicated valid selection of the participants. However, in contrast, members of the healthy control group were educated beyond the average.

Remarkably, the groups did not differ in their essential attitudes towards advance directives. We found meaningful differences with respect to only three aspects: the cancer patients more often expressed their intention to write an advance directive; the possibility of appointing health care proxies was unknown by a majority of the people surveyed, with the exception of the physicians; and patients did not fear abuse by relatives as much as the other groups.

These differences seem easy to explain: to be diagnosed with a life-threatening disease increases the tendency to concern oneself with treatment at the end of life; physicians, as professionals, are better informed (although about 30% did not know about the possibility of designating health care proxies); and, the poorer their health condition and the older people are (which was the case in the patient group), the

more they tend to rely on their social network, in most cases their family.

These results may have an impact on advance directives in clinical practice. They suggest that doctors should broach the subject of treatment decisions at the end of life when life-threatening disease is diagnosed. It is at this time that people will be likely to be prepared to concern themselves with this matter.

If this holds true and, as only a minority in all groups had written a directive, one can assume inversely that advance directives are not likely to be to hand when life-threatening illness such as a stroke starts suddenly. In such cases it would be helpful to have named a health care proxy. However, less than half of the patients, healthy controls, and nursing staff knew about the legal possibilities of naming an authorised person. Here, education is necessary to inform people appropriately.

It is of overriding importance that the frequency of those who have written an advance directive was low in all groups (10–20%). This corresponds well with results obtained in the USA in different groups of patients and among nursing home residents.<sup>13–16</sup> There was no correlation between the existence of an advance directive and demographic characteristics, self-estimation of participants' state of health, or their religious beliefs.

It is doubtful whether the proportion of the population who will write an advance directive can be raised to such a degree that this instrument will contribute to the solution of most associated ethical problems. We can assume that nursing staff and physicians have an above-average sensitivity towards this subject. The same applies to the group of healthy controls; they took part in this survey, which presumably meant that they had a positive attitude towards advance directives. We also assume there was an educational effect in the process of completing the questionnaire. However, only 50–70% of the healthy controls, nursing staff, and physicians expressed an intention of concerning themselves in the near future with the subject of advance directives. In addition, it cannot be assumed that those

**Table 4** Opinions on influence of medical directives on course of disease and trust in health care proxies

Question	%Patients	%Healthy controls	%Nursing staff	%Physicians	p value
Could you imagine influence being exerted by a medical directive on:					
Type of treatment? (yes/no)	81.7/18.2 ( $n = 93$ )	85.3/14.7 ( $n = 95$ )	78.8/21.2 ( $n = 99$ )	82.0/18.0 ( $n = 100$ )	NS
Pain? (yes/no)	78.3/21.7 ( $n = 92$ )	85.0/15.0 ( $n = 93$ )	75.8/24.2 ( $n = 99$ )	71.0/29.0 ( $n = 100$ )	NS
Duration of suffering? (yes/no)	75.8/24.2 ( $n = 95$ )	90.9/9.1 ( $n = 99$ )	84.8/15.2 ( $n = 99$ )	83.0/17.0 ( $n = 100$ )	<0.05
Do you think that a health care proxy authorised by yourself would act according to your intentions? (yes)	88.0 ( $n = 100$ )	92.0 ( $n = 100$ )	90.0 ( $n = 100$ )	82.0 ( $n = 100$ )	NS

NS, not significant.

**Table 5** Fears of abuse of medical directives

Fear	%Patients	%Healthy controls	%Nursing staff	%Physicians	p value
Coercion (yes/no)	55.1/44.9 (n = 98)	56.57/43.4 (n = 99)	61.0/39.0 (n = 100)	75.7/24.2 (n = 99)	NS
Dictatory use (yes/no)	26.5/73.5 (n = 98)	30.6/69.4 (n = 98)	31.0/69.0 (n = 100)	33.0/67.0 (n = 100)	NS
Abuse by relatives (yes/no)	38.4/61.6 (n = 99)	52.0/47.9 (n = 98)	53.0/47.0 (n = 100)	64.6/35.3 (n = 99)	<0.005

NS, not significant.

who announce this intention will later really write one. The assumption that is the basis for the draft law being discussed at the moment in Germany, that the majority of the population does not have the intention to stipulate in advance their wishes about medical treatment at the end of their lives, seems, therefore, to be realistic. It thus appears to be a useful and justifiable step to strengthen the right of relatives to make decisions if nothing else is stipulated in an advance directive, as has been proposed in that bill.<sup>17</sup> Such a ruling would also take into consideration our finding that patients tend to rely more on relatives, as others do.

Experience after the introduction of the Patient Self-determination Act in the USA confirms this conclusion. The number of advance directives rose less steeply than expected, although Emanuel *et al* had already foreseen in 1991 a similarly high level of willingness among outpatients and healthy controls to write an advance directive, as we have in our study.<sup>5</sup> The SUPPORT investigators found that many patients did not want to talk to their physicians about life-sustaining treatments.<sup>18</sup>

Most US federal states have implemented laws that enforce adherence to advance directives, but now, after years of experience, some bioethicists believe that living wills have failed entirely.<sup>19</sup> Nevertheless, the British and German parliaments have embarked on legislative processes to strengthen the binding nature of such documents,<sup>20, 21</sup> but our results pinpoint limitations of advance directives of which those surveyed seemed to be aware.

Many of those surveyed feared that advance directives could be misused. More than half of the interviewees in all groups believed that patients could be pressurised into writing such a document. One quarter of the patients and one third of the other groups, including the physicians, feared a dictatory use of directives, even if they are no longer appropriate to the medical situation. The majority in the healthy groups (healthy controls, nursing staff, and physicians) believed that advance directives could be abused by relatives to the disadvantage of patients.

The extent of mistrust in advance directives expressed by these results has not so far been sufficiently emphasised in the bioethical literature. We see in this a barrier, hitherto too little recognised, to the spread of advance directive use.

Efforts to strengthen this instrument should be welcomed. In this context, people should be informed about the possibility of authorising a proxy. The results of this study have shed light on some aspects that have been neglected so far in the debate about the role of advance directives in decision making at the end of life.

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