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# Determinants of completion of advance directives: a cross-sectional comparison of 649 outpatients from private practices versus 2158 outpatients from a university clinic

Jochen Pfirstinger,[1,2] Bernhard Bleyer,[3,4] Christian Blum,[5] Michael Rechenmacher,[2] Christoph H Wiese,[6,7] Hans Gruber[5,8]

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For numbered affiliations see end of article.

**Correspondence to**
Dr Jochen Pfirstinger;
pfirstinger.jochen@klinikum-amberg.de

## ABSTRACT

**Objectives** To compare outpatients from private practices and outpatients from a university clinic regarding the determinants of completion of advance directives (AD) in order to generalise results of studies from one setting to the other. Five determinants of completion of AD were studied: familiarity with AD, source of information about AD, prior experiences with own life-threatening diseases or family members in need of care and motives in favour and against completion of AD.

**Design** Observational cross-sectional study.

**Setting** Private practices and a university clinic in Germany in 2012.

**Participants** 649 outpatients from private practices and 2158 outpatients from 10 departments of a university clinic.

**Outcome measures** Completion of AD, familiarity with AD, sources of information about AD (consultation), prior experiences (with own life-threatening disease and family members in need of care), motives in favour of or against completion of AD, sociodemographic data.

**Results** Determinants of completion of AD did not differ between outpatients from private practices versus university clinic outpatients. Prior experience with severe disease led to a significantly higher rate of completion of AD (33%/36% with vs 24%/24% without prior experience). Participants with completion of AD had more often received legal than medical consultation before completion, but participants without completion of AD are rather aiming for medical consultation. The motives in favour of or against completion of AD indicated inconsistent patterns.

**Conclusions** Determinants of completion of AD are comparable in outpatients from private practices and outpatients from a university clinic. Generalisations from university clinic samples towards a broader context thus seem to be legitimate. Only one-third of patients with prior experience with own life-threatening diseases or family members in need of care had completed an AD as expression of their autonomous volition. The participants' motives for or against completion of AD indicate that ADs are considered a kind of 'negative autonomy' as instruments to prevent particular forms of therapy. Interactive, repeated and situation-based AD discussions might reach a higher percentage of patients and concurrently enable personal volitions and thereby strengthen individual 'positive autonomy'.

## Strengths and limitations of this study

- Our study includes a very large number of completed questionnaires regarding determinants of completion of AD. Data on the response rate to the survey were not collected.
- The questionnaire had been developed from a previous study and had been refined in a preliminary interview study, but has not run through a structured validation process.
- The comparison between outpatients from private practices and university clinic outpatients indicates that generalisations from university clinic samples towards a broader context seem to be legitimate.
- However, our study was conducted in a medium-sized town with rural surroundings, so that our regional findings may be inapplicable in metropolitan areas with people from many different nationalities.

## INTRODUCTION

Life-threatening diseases and end-of-life decisions are an existential challenge for the relationship between patients and physicians. The physicians consider the indication of a medical intervention taking into account the principles of beneficence, best interests and futility. The relationship between patients and doctors has changed over the last decades from a paternalistic role model, where always the doctor decides what is best for a patient, to a patient-centred model, where autonomous patients are being informed by their doctors and then reach their own decisions. However, in end-of-life situations clinical experience has shown that the majority of patients use their autonomy

for the prevention of, for example, suffering or getting connected to machines representing a kind of 'negative autonomy'. The concept of patient autonomy and the necessity of an informed consent for all medical interventions have become the fundamental principles for every interaction between patients and medical professionals. In cases of impaired decision-making capacity, advance directives (ADs) can be used to express the patient's will. In Germany, ADs are regulated by the third act amending German guardianship legislation, effective from 1 September 2009. As in many other countries, ADs comprise the following legal instruments: living will and healthcare proxy. By completing a living will, a patient can record legally binding instructions for or against future medical interventions that would otherwise be medically indicated. Patient autonomy can also be exercised by assigning a healthcare proxy, who makes healthcare decisions on behalf of the patient, when he or she is incapable of making those decisions.

Despite the considerable role of patient autonomy in all medical and legal decisions, only a minority of patients complete an AD. A rate of <40% is found in patients with cancer[1–3] and in the elderly population.[4–7] An even lower rate is found in the general population.[8–12] Educational interventions to promote AD slightly increase the completion rate, which still remains below 50%.[13–15]

A prior investigation of our group published in 2014 revealed that in almost 400 patients with cancer a substantial percentage of patients who had not yet completed an AD were willing to receive AD consultations 'now' or 'in a few weeks', but longitudinal analyses showed that in fact none of these patients made an appointment. The same percentage of patients with cancer postponed AD consultations, because an AD 'is not relevant' now or they 'do not want to get involved in this issue'. Only a small proportion completely rejected the offer of AD consultations.[16] In summary, only a minority of all patients who visit a private practice or university outpatient clinic had in advance completed an AD. The majority either postpone completion of AD or even refuse to engage in discussion of AD issues. Two main determinants that impact completion of AD are age (older people are more likely to have completed an AD) and duration of a cancer diagnosis (longer duration is positively associated with completion of an AD).[16–18]

It is plausible that several other determinants play a role in patient decisions regarding the completion of ADs, including the source of information and prior experience with own life-threatening diseases or with family members in need of care. However, little is known from clinical studies about these determinants.[19–22] Whether patients have stable end-of-life preferences is still an open question.[23]

Healthcare research is usually performed either in centres such as university hospitals or in a very decentralised setting. Whether samples from university clinics legitimately can be compared with samples from private practices providing general primary care is an open question. Duration of diagnoses, severity of illnesses and the professional training of medical staff might contribute to differences of patient selection and thus also of completion of AD. However, a long-term trusting relationship to a family doctor may be a good basis for burdensome AD discussions leading to a higher completion rate. Therefore, studies using samples from university clinics are at risk of producing results that are not widely applicable in other settings. To our knowledge, determinants of completion of AD have not yet been investigated in a study that compares outpatients from a university clinic with outpatients from private practices.

We, therefore, conducted a study in a university clinic and in private practices in the same city. The objectives were to compare outpatients from private practices and outpatients from a university clinic regarding their familiarity with AD, their source of information about AD, their prior experience with own life-threatening disease or family members in need of care and their motives in favour and against completion of AD.

## PATIENTS AND METHODS

### Design

The study was conducted as an observational cross-sectional study. Two groups of participants were compared: outpatients from private practices and outpatients from a university clinic.

### Participants

Eligibility criteria for participation in the study included a minimum age of 18 years, the ability to provide informed consent and being an outpatient. Participants were either outpatients from a university clinic or outpatients from private practices. The university clinic group was a convenience sample of 2158 outpatients cared for at 10 outpatient departments located at a German university clinic. These included clinics for radiotherapy, haematology and oncology, gastroenterology, endocrinology, rheumatology, infectious diseases, surgery, trauma surgery, craniofacial surgery and maxillofacial surgery, neurosurgery, otorhinolaryngology, dermatology, ophthalmology, cardiology, nephrology and pulmonology. The private practices group was a convenience sample of 649 outpatients from 18 private practices in the same city as the university clinic. The overall sample size was 2807. Data on the response rate to the survey were not collected.

### Procedure and instruments

Based on items from a literature search and from a previous investigation about ADs in patients with cancer,[16] we developed a preliminary questionnaire, which was applied in an interview study with 70 patients. After deletion of redundant or inappropriate items, we established a final questionnaire, which in six sections comprised dichotomous questions and multiple response questions: (1) information about the purpose of the study and request for informed consent, (2) sociodemographic

Table 1 Characteristics of participants enrolled in the study, separately for outpatients of a university clinic and outpatients from private practices

| Characteristics | Outpatients from a university clinic ($N_1$=2158) | Outpatients from private practices ($N_2$=649) |
|---|---|---|
| Age ($n_1$=2122; $n_2$=622) | 52 (15) | 52 (17) |
| Women ($n_1$=2151; $n_2$=648) | 1027 (48) | 423 (65) |
| Type of disease ($n_1$=1746; $n_2$=444) | | |
| Tumour disease | 426 (24) | 30 (7) |
| Donor organ | 165 (10) | 5 (1) |
| Never been seriously ill | 438 (25) | 280 (63) |
| Other chronic illness | 580 (33) | 118 (27) |
| Proxy | 137 (8) | 11 (2) |
| Marital status ($n_1$=2153; $n_2$=643) | | |
| Never married | 377 (18) | 119 (19) |
| Married/cohabitation | 1508 (70) | 431 (67) |
| Divorced | 153 (7) | 45 (7) |
| Widowed | 115 (5) | 48 (7) |
| Education ($n_1$=2119; $n_2$=630) | | |
| Secondary education (nine grades) | 982 (46) | 266 (42) |
| Secondary education (10 grades) | 645 (31) | 226 (36) |
| A level (13 grades) | 423 (20) | 118 (19) |
| Elementary (grades 1–4) | 69 (3) | 20 (3) |
| Qualification ($n_1$=2081; $n_2$=619) | | |
| Non-academic professional | 1598 (77) | 482 (78) |
| Academic professional | 318 (15) | 92 (15) |
| No professional qualification | 165 (8) | 45 (7) |
| Location ($n_1$=2127; $n_2$=643) | | |
| Urban area | 588 (28) | 213 (33) |
| Rural area | 1539 (72) | 430 (67) |

Sample sizes ($n_1$, $n_2$) for particular variables differ from the total sample sizes ($N_1$, $N_2$) due to missing values. For age, the means (SD in brackets) in years are given. For all other variables, the numbers of participants (percentages in brackets) are given

questions (see table 1), (3) familiarity with and existence of AD, (4) questions about preferences regarding sources of information (eg, whom the patient would like to consult about completion of an AD), (5) questions about prior experiences with own life-threatening diseases or family members in need of care, and (6) questions about motives in favour of or against the completion of AD. The final version of the questionnaire listed 10 different motives in favour and 13 motives against the completion of AD with multiple answers allowed. The study was approved by the institutional ethics committee at the Regensburg University Hospital.

During March to June 2012, patients of the above-mentioned university clinics and private practices received the questionnaire from the clinic staff or the doctor's assistant as they signed up for their medical examination. The participants were requested to read the introduction and to complete the questionnaire while waiting for their appointment. At the end of their visits, they returned the filled questionnaires to the registration.

### Statistical analysis

The analyses aimed at comparing the university clinic group and the private practice group regarding the determinants of completion of AD (familiarity with AD, source of information about AD, prior experience with own life-threatening disease or family members in need of care and motives in favour of and against completion of AD). Data are presented in the form of proportions for categorical variables and means (and SD) for continuous variables. $\chi^2$ tests, the $\Phi$ coefficient, Cramer's $V$ and the OR were used to detect statistically significant and clinically relevant group differences. All reported P values are two-sided, with P<0.05 considered as significant. Data were analysed with SPSS software, V.21.

## RESULTS

The results are presented in the following order. After providing descriptive information on the two groups, outpatients from a university clinic and outpatients from

private practices, the results concerning the comparison of the two groups regarding determinants of completion of AD are displayed (familiarity with AD, source of information about AD, prior experience with own life-threatening diseases or family members in need of care, motives in favour of and against completion of AD).

### Descriptives

Table 1 shows the absolute and relative frequencies of age, gender, type of disease and sociodemographic characteristics (marital status, education, qualification, location) of the participants in each group.

Except for gender and type of disease, the groups did not significantly differ. In the private practice group, there was a higher proportion of female participants than in the university clinic group ($\chi^2$ (1)=61.31; P=0.001; $\Phi$=0.148). The university clinic group included more participants with a malignancy and more participants after organ transplantation. Most participants in the private practice group had never been seriously ill ($\chi^2$ (4)=260.23; P=0.001; $V$=0.345). These two variables did not confound any of the following results.

### Familiarity with AD, completion of AD

Among the sample, 2594 (92%) participants were familiar with living wills, and 1826 (65%) participants were familiar with healthcare proxies, the two forms of AD. Of those who were familiar with the instruments of ADs, 781 (30%) participants had completed a living will, and 617 (34%) participants had completed a healthcare proxy. A total of 1783 (64%) participants (university clinic: 1340; private practices: 443) were familiar with both instruments, of which 559 (20%) persons (university clinic: 418; private practices: 141) had completed both a living will and a healthcare proxy. Thus, only about one-third of the participants had previously completed a living will and/or a healthcare proxy. The data show that the sampled outpatients were more familiar with living wills than with healthcare proxies.

Table 2 shows the familiarity with AD and the presence of AD for both groups.

There was no substantial difference between the groups in completion of AD (living will: $\chi^2$ (1)=0.006; P=0.938; healthcare proxy: $\chi^2$ (1)=0.02; P=0.899), and in familiarity with living wills ($\chi^2$ (1)=1.36; P=0.242). However, the groups significantly differed with regard to familiarity with healthcare proxies ($\chi^2$ (1)=10.21; P=0.001; $\Phi$=0.061, OR=1.37).

### Source of information for completion of AD

Before the completion of AD, 715 (92%) participants informed themselves. A total of 509 (65%) participants stated that they had discussed their decision to complete an AD with a confidant several times. Another 204 (26%) participants discussed their decision only once, and 38 (5%) participants had no conversation at all with a confidant about their AD. In both samples, the correlation proved significant between having an AD and having had multiple discussions with a confidant (university clinic: $\chi^2$ (2)=395.04; P<0.001; $V$=0.433; private practices: $\chi^2$ (2)=115.64; P<0.001; $V$=0.434). Whereas most participants talked at least once to a confidant about completion of AD, only a minority asked for professional advice: 173 (22%) participants consulted a physician and 280 (36%) participants consulted a lawyer.

Participants who had not yet completed an AD (1998) reported different preferred sources of information. When asked by whom they want to be counselled, 1519 (76%) participants wished to be informed by a physician, whereas only 115 (6%) participants wished to be informed by a lawyer (see table 3).

The comparison of the samples of outpatients from a university clinic and outpatients from private practices revealed no significant differences regarding sources of information before completion of AD (all P values >0.05). When only participants without completion of AD were analysed, statistically significant differences between the two groups were noted. A larger percentage of participants in the private practice group, compared with the university clinic group, wanted to be informed about AD by their family physician ($\chi^2$ (1)=15.49; P=0.001; $\Phi$=0.09, OR=1.55). In contrast, participants from the university clinic group more often wanted to be informed about AD by a clinician ($\chi^2$ (1)=19.19; P=0.001; $\Phi$=0.10, OR=2.43). However, the effect sizes were only small. No difference between the two groups could be found as to their preference to be counselled by a lawyer.

**Table 2** Familiarity with and presence of advance directives (separate for living wills and for healthcare proxies), separately for outpatients from a university clinic and for outpatients from private practices

| | Outpatients from a university clinic ($N_1$=2158) | Outpatients from private practices ($N_2$=649) |
|---|---|---|
| Familiarity with living will ($n_1$=2146; $n_2$=638) | 1993 (93) | 601 (94) |
| Familiarity with healthcare proxy ($n_1$=2132; $n_2$=634) | 1374 (64) | 452 (71) |
| Presence of a living will ($n_1$=1990; $n_2$=597) | 600 (30) | 181 (30) |
| Presence of a healthcare proxy ($n_1$=1366; $n_2$=443) | 467 (34) | 150 (34) |

Sample sizes ($n_1$, $n_2$) for particular variables differ from the total sample sizes ($N_1$, $N_2$) due to missing values. For all variables, the numbers of participants (percentages in brackets) are given

Table 3 Sources of information about AD, separately for outpatients of a university clinic and outpatients from private practices

| | Outpatients of a university clinic with completion of AD ($N_1$=600) | Outpatients of private practices with completion of AD ($N_2$=181) |
|---|---|---|
| Participant self-informed before completion of AD ($n_1$=567; $n_2$=174) | 548 (97) | 167 (96) |
| Participant discussed her/his decision with a confidant ($n_1$=581; $n_2$=170) | | |
| Once | 154 (27) | 50 (29) |
| Several times | 398 (68) | 111 (65) |
| Participant was counselled ($n_1$=593; $n_2$=174) | | |
| By a physician | 143 (24) | 30 (17) |
| By a lawyer | 215 (36) | 65 (37) |
| | **University clinic outpatients ($N_1$=2158)** | **Private practice outpatients ($N_2$=649)** |
| Participant wants to be counselled ($n_1$=1483; $n_2$=428) (multiple answers possible) | | |
| By her/his family physician | 762 (51) | 266 (62) |
| By a medical specialist | 213 (14) | 35 (8) |
| By a clinician | 215 (15) | 28 (6) |
| By a lawyer | 87 (6) | 28 (6) |

Sample sizes ($n_1$, $n_2$) for particular variables differ from the total sample sizes ($N_1$, $N_2$) due to missing values. For all variables, the numbers of participants (percentages in brackets) are given
AD, advance directive.

### Prior experiences with own life-threatening disease or family members in need of care

Prior familiarity with the instruments of advance care planning was associated with a higher rate of completion of AD (see table 2). Also, having either suffered from a life-threatening disease or cared for a dying family member was positively associated with completion of AD (see table 4). More participants who had cared for a relative until her/his death had completed an AD compared with participants lacking such an experience ($\chi^2$ (1)=30.70; P=0.001; $\Phi$=0.10, OR=1.61). Similarly, participants who had suffered from an own life-threatening disease had a higher rate of completion of AD than participants without this experience ($\chi^2$ (1)=40.89; P=0.001; $\Phi$=0.13, OR=1.77).

Table 4 Prior experience with own life-threatening diseases or family members in need of care and presence of AD

| | No AD | Completion of AD |
|---|---|---|
| Cared for a family member until her/his death (N=2672)* | | |
| No | 1097 (76) | 341 (24) |
| Yes | 822 (67) | 412 (33) |
| Suffered from a life-threatening disease once before (N=2636)* | | |
| No | 1333 (76) | 419 (24) |
| Yes | 568 (64) | 316 (36) |

*N on this variable differs from the total N due to missing values. For all variables, the numbers of participants (percentages in brackets) are given
AD, advance directive.

Although there was no significant difference between the two sample groups in the presence of an AD, differences were found regarding prior experience with own life-threatening diseases. More participants in the private practice group had cared for a family member until her/his death than participants in the university clinic group. However, the effect size was small ($\chi^2$ (1)=8.62; P=0.003; $\Phi$=0.06, OR=1.31). As expected, more participants from the university clinic group earlier had suffered from a life-threatening disease than participants from the private practice group ($\chi^2$ (1)=128.56; P=0.001; $\Phi$=0.22, OR=3.75).

### Motives in favour of completion of AD

The most frequent motives in favour of completion of AD were to prevent unnecessary suffering (68%), followed by the avoidance of being a burden for others (55%). For additional but less frequently reported motives see table 5 (multiple answers were possible).

No significant differences were found between the university clinic group and the private practice group except for the avoidance of being a burden, which was

Table 5 Motives in favour of completion of AD (multiple answers possible)

| Participant completed an AD because… | Total (N=736)* | Outpatients of a university clinic ($n_1$=567) | Outpatients of private practices ($n_2$=169) |
|---|---|---|---|
| She/he does not want to suffer unnecessarily | 504 (68) | 385 (68) | 119 (70) |
| She/he does not want to be a burden to anyone | 402 (55) | 297 (52) | 105 (62) |
| Physicians are instructed to do everything possible to preserve one's life | 250 (34) | 186 (33) | 64 (38) |
| She/he wants to make her/his own decisions | 231 (31) | 183 (32) | 48 (28) |
| She/he distrusts physicians to decide in her/his best interest | 178 (24) | 131 (23) | 47 (28) |
| She/he has had experiences with intense care for relatives | 164 (22) | 127 (22) | 37 (22) |
| She/he completed it in the course of receiving legal advice | 130 (18) | 95 (17) | 35 (21) |
| She/he distrusts her/his relatives to decide in her/his best interest | 88 (12) | 68 (12) | 20 (11) |

*N on this variable differs from the total *N* due to missing values.
For all variables, the numbers of participants (percentages in brackets) are given.
AD, advance directive.

reported as a motive more often by participants of the private practice group ($\chi^2$ (1)=5.01; P=0.025; $\Phi$=0.08, OR=1.49). Due to the small effect size, there is only limited practical significance. Among those 130 participants who completed an AD in the course of receiving legal advice, only 16 had consulted a physician in addition. Furthermore, among those who already had completed an AD, only 231 (31%) indicated that they 'wanted to make his/her own decisions'.

### Motives against completion of AD

"I currently do not want to deal with the issue" was the most frequently reported motive (588; 35%) against completion of AD, followed by "I am too young" (321; 19%). For additional but less frequently reported motives see table 6 (multiple answers were possible).

The comparison of the patients from the university clinic group and the patients from the private practice group revealed no relevant differences.

Inconsistent response patterns were revealed by cross tabulating the motives against completion of AD with the question of when it is appropriate to complete one. Among those participants who stated that they were currently not willing to address this issue (n=555), 318 (57%) participants stated that the completion of AD should be considered early, and 145 (26%) participants agreed with the statement that an AD should be completed no matter whether one is suffering from a disease or not. A similar pattern was found among those who argued that they were too young to complete an AD (n=314); 177 (56%) of them agreed that completion of AD should be done early, and 78 (25%) indicated that one should complete an AD independently of the presence of a disease.

Some of the participants voluntarily provided comments in addition to the questionnaire answers. Among the 325 participants providing such comments, 172 (53%) stated that they just postponed completion of AD or were simply too idle. However among the 1998 participants without completion of AD, 1643 (82%) were willing to discuss this issue.

Table 6 Motives against completion of AD (multiple answers possible)

| Participant did not yet complete an AD because… | Total (N=1665)* | Outpatients of a university clinic ($n_1$=1285) | Outpatients of private practices ($n_2$=380) |
|---|---|---|---|
| She/he currently does not want to deal with this issue | 588 (35) | 468 (36) | 120 (32) |
| She/he is too young | 321 (19) | 246 (19) | 75 (19) |
| Her/his attitude could change during the progression of a disease | 279 (17) | 222 (17) | 57 (17) |
| Medical treatment options could improve | 226 (14) | 186 (15) | 40 (11) |
| She/he delegates the decision to a specialist in case of emergency | 215 (13) | 172 (13) | 43 (11) |
| She/he feels insecure with legal regulations | 202 (12) | 160 (12) | 42 (11) |
| She/he fears giving the wrong instructions | 176 (11) | 144 (11) | 32 (8) |
| She/he cannot appraise the listed medical treatments | 136 (8) | 113 (9) | 23 (6) |

*N on this variable differs from the total due to missing values.
For all variables, the numbers of participants (percentages in brackets) are given.
AD, advance directive.

### Limitations

Some limitations to the present research also warrant attention. First, the psychometrics of the used questionnaire are unknown. The questionnaire had been employed in previous research and had been revised in a preliminary interview study; nevertheless, a structured validation process is still lacking. Second, no information on the response rate to the survey was gathered. Thus, the representativeness of the study's sample is uncertain. In light of these caveats and despite the large sample size, the study results have to be interpreted cautiously.

## DISCUSSION

The issue of patient autonomy, despite its undisputable relevance, still poses many open questions. Many actors in Germany—both from policy and from medicine—are disappointed by the low percentage of people who have already completed an AD. It is not trivial to investigate the reasons preventing people from completion of AD. In this study, a number of attempts were undertaken in order to better understand the issue. First, a large sample size was used in order to increase the reliability and trustworthiness of the answers provided by the participants: more than 2800 participants were studied. Second, the major research question was to investigate whether the motives in favour of or against completion of AD resembled each other in two different groups of patients: outpatients from a university clinic (many of whom suffer from life-threatening diseases) and outpatients from private practices. Determinants of completion of AD previously mainly have been studied within university clinic patients. Whether the results can legitimately be generalised towards a broader population is still an open question, thus addressing the societal need to broadly discuss the issue of AD. A number of reasons were mentioned in prior research indicating that the experience of suffering from a life-threatening disease might influence the importance of making decisions related to patient autonomy.[22] The results show, however, that outpatients from a university clinic do not significantly differ from outpatients from private practices regarding most determinants of completion of AD. A broad number of such determinants were investigated, among them the sources of information about AD, that is, to what degree professional consultation had been requested before completion of AD, and from which professional groups such advice had been requested. In addition, it was investigated whether those without completion of AD would like to receive professional advice—and, again, by whom—before making a decision in favour of completion of AD. Motives both in favour of and against completion of AD were investigated.

Concerning the comparability of samples from a university clinic and from private practices, and thus of the generalisability of results, few differences were found between the two groups indicating that the results legitimately may be generalised. The group of outpatients from private practices was slightly more familiar with healthcare proxies, but the effect size was very small. In general, however, the groups did not differ significantly. These results, based on a large sample size, are a strong indicator that future studies might rely on results from either of those two samples. The percentage of those who had completed an AD was of the same size (about 30%) as in the general population. In both groups, the percentage was a bit higher (33% and 36%, respectively) among participants with prior experience of own life-threatening diseases. This matches findings from other studies,[22] but still leaves the question open why even those participants do not make much more use of the instruments of patient autonomy. Prior experience (either individual or related to one's family) with life-threatening diseases, intensive care treatment, nursing cases and so on only slightly increased the rate of completion of ADs, and only to a level still clearly below 50%.

Concerning the question of seeking professional consultation, both before completion of AD and the intention of completion in the future, our study was consistent with prior findings that more than one-third of the patients with completion of AD had received legal advice.[16 24 25] In some patients, legal consultation about AD may be related to receiving legal testament advice, as it has been shown that patients were much more likely to complete an AD when asked by legal staff compared with medical staff.[26] Among those who have not yet completed an AD, many stated their desire for professional advice, with a large majority preferring medical consultation to legal advice. The results match prior studies' finding that almost every patient considers ADs as something very important which should be completed early.[1] It should be noted that acceptance rates for completion of AD close to 100% can be found in interview data, which may reflect what is socially desirable. In contrast, none of the multiple interventions to promote completion of AD increased the rate above 50%, which may reflect that patient autonomy rests on a voluntary basis.[13] The deviation of the patients' intention to their acting can be explained as an example of the mind-behaviour-gap theory.[27]

In the group of outpatients from private practices, the family doctor frequently was named as the preferred person of trust for AD consultations. However, in the university clinic setting, the result was in favour of hospital physicians. Therefore, it can be concluded that patients are open to receive AD consultations, wherever they are treated.

A first step to initiate discussions about ADs often is made as a by-product of other issues, for example, the case in a legal advice setting, when a testament consultation is followed by a consultation about an AD. An important second step would be the trustful interaction with the family doctor. The results show that many participants felt confused by the legal regulation. In contrast to lawyers, however, family physicians do not receive a financial incentive when they involve themselves in consultations about ADs. It is reported that such consultation often takes a considerable amount of time, as it may easily exceed 30 min. Providing an adequate financial compensation to

family physicians for consultation around ADs could be a promising approach to promote completion of ADs.

Concerning the motives in favour of or against completion of AD, the study revealed some inconsistent response patterns that need further analysis or even a fresh theoretical perspective on the issue. Inconsistencies were revealed when cross tabulating the motives against completion of AD with the question of when it is appropriate to complete an AD. Possible explanations of these inconsistencies—although not deliberately investigated in this study—could be identified in comments, which 325 of the participants provided voluntarily in addition to the questionnaire answers. More than half of them stated that they just postponed completion of AD or were simply too idle. For example, one participant quoted: "Because I procrastinated completing a living will up to now." This finding was in line with the fact that more than 80% of the participants without completion of AD were willing to discuss this issue. Although most participants indicated being willing in principle to complete an AD, many did not initiate the completion on their own. The majority of patients who had completed an AD had done so in reaction to distrust and fear of future treatments.[28] Less than one-third of the participants who had completed an AD stated that they 'wanted to make his/her own decisions'.

These findings might pose new questions concerning the motives for completion of AD. It might be that the findings indicate a kind of 'negative autonomy': living wills and healthcare proxies might be seen mainly as instruments to prevent particular forms of therapy, but not as instruments to design one's own 'positive autonomy'. Our preceding interview study (not published) revealed that the majority of patients consider living wills and healthcare proxies as something unpleasant, which must be done—sometime in the future—but not as a chance to actively take control of their lives. The questionnaire items were developed as a result of the interviews and were formulated to elicit positive and negative motives concerning completion of AD. Our underlying intention was to find out whether patients' attitudes towards completion of AD could be influenced positively to achieve a higher completion rate. Future studies could investigate under which conditions patients are most motivated to think proactively about future medical decisions. This, however, would require a paradigm shift both in underlying research and in the practices how medical and legal professionals approach the issue of completion of AD. In theory, ADs provide an opportunity for patients to exercise their autonomy and to actively engage in decisions about their future healthcare. In practice, however, ADs are primarily used as a means to prevent certain unwanted treatments or in negative reaction to prior personal experiences. The use of ADs has been largely reactive instead of proactive. To increase the uptake of ADs among patients, it may be necessary to reframe ADs as a means of engaging proactively in future healthcare decisions rather than as a reactive tool used to prevent future unwanted experiences.

Up to this point, most attempts to increase uptake of ADs among patients have focused on educating medical or legal professionals[29 30] rather than focusing on methods to increase the patient's autonomy. The empirical evidence clearly demonstrates that most of these educational efforts have failed to successfully increase the usage of ADs by patients. Further studies are needed to investigate whether a different approach, with a focus on increasing patient autonomy and allowing patients to more proactively engage in decisions about their future healthcare, may be more successful in increasing the number of patients with a completion of AD. Further investigation is also warranted into whether patients might be more willing to engage in these decisions if the topic is presented by their trusted family physician as part of a discussion of future autonomy.

**Author affiliations**
[1]Department of Internal Medicine II, St. Marien Hospital Amberg, Amberg, Germany
[2]Department of Hematology, Regensburg University Hospital, Regensburg, Germany
[3]Institute of Sustainability, Ostbayerische Technische Hochschule Amberg-Weiden, Amberg, Germany
[4]Faculty of Catholic Theology, University of Regensburg, Regensburg, Germany
[5]Department of Educational Science, University of Regensburg, Regensburg, Germany
[6]Department of Anaesthesiology, Regensburg University Hospital, Regensburg, Germany
[7]Department of Anaesthesiology, Herzogin Elisabeth Hospital, Braunschweig, Germany
[8]Faculty of Education, University of Turku, Turku, Finland

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