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Determinants of Patient Attitudes toward Advance Directives: A Comparison of 649 Private Practice Outpatients versus 2158 University Clinic Outpatients

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Abstract

Objectives: To assess determinants of patient attitudes toward Advance Directives (AD), comparing participants from private practices and from university clinics with the assumptions, that both groups will not differ significantly and that prior experience with severe disease – own or in close relatives – as one of the strongest ways of gaining experience leads to an increase in completed living wills.

Setting: Group comparison of a) outpatients from private practices and from university clinics, b) participants with or without completed AD

Participants: 649 from private practices and 2158 from ten departments of a university hospital

Outcome measures: completed AD, AD information sources, consultation about AD, prior experiences with severe disease, motives for or against AD completion, socio-demographic data

Results: Attitudes towards AD did not differ between private practice vs. university hospital outpatients. Prior experience with severe disease lead to a significantly higher rate of completed living wills (33%/36% with vs. 24%/24% without experience with own disease/disease in close relatives). Participants with completed AD had more often received legal than medical consultation before completion, but participants without completed AD are rather aiming for medical consultation. The motives for or against completing an AD indicated inconsistent attitudes.

Conclusions: Attitudes towards AD are comparable in outpatients from private practices and from university hospitals. Only one third of patients with prior experience with severe disease had completed a living will (as expression of their autonomous volition). The participants' motifs for or against completing AD indicate that ADs are considered a kind of "negative autonomy" as instruments to prevent particular forms of therapy. Advance care planning as an interactive and situation based tool might reach a higher percentage of patients and concurrently enables personal volitions and thereby strengthens individual, "positive autonomy".

Trial registration: not applicable

Strengths and limitations of this study

Our study achieved a very high number of completed questionnaires comprising many different aspects that may influence patients' attitudes towards advance directives and advance care planning.

The questionnaire has been developed from a preliminary interview study with seven different interviewers who accomplished about ten patient interviews each, but has not run through a structured validation process.

The comparison between private practice patients and university hospital outpatients proofs that generalizations from university hospital findings can be made.

On the other hand 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.

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Introduction

The concept of patient autonomy and the necessity of an informed consent for all medical interventions are 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 September 1st, 2009. As in many other countries, ADs comprise the following legal instruments: living will and health care 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 health care 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 (living will and/or a health care proxy). A rate of below 40% is found in cancer patients [1-3] as well as 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 cancer patients 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 cancer patients postponed AD consultations, because an AD "is not relevant" now or they "do not want to get involved with 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 (living will and/or health care proxy). The majority either postpone AD completion or even refuse to engage in discussion of AD issues. Two main determinants that impact AD completion 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 factors play a role in patient attitudes and decisions regarding ADs, including the level and the source of information available as well as prior experiences with own serious illness or with relatives in need of care. However little is known from clinical studies about these determinants [19-22]. It is still an open question, whether patients have stable end-of-life preferences [23].

Many investigations about AD completion use convenience samples. It is an open question whether samples within university clinics can be compared to samples among private practice patients. Duration of diagnoses, severity of illnesses, and the professional training of medical staff might contribute to differences of patient selection and thus also of AD completion. 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 AD completion have not yet been investigated in a study that compares university clinic outpatients with private practice outpatients.

We therefore conducted a large study in several different outpatient specialty clinics of a university hospital compared to a number of private community family practices in the same city. Measured were the level and the source of information available, the utilisation of professional consultation, prior experiences, and the motivation for or against AD completion.

Method

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 or a health care proxy of an outpatient. Participants were recruited from two samples, namely patients at university hospital outpatient specialty clinics and patients from private community family practices. The first was a convenience sample of 2158 patients cared for at ten outpatient departments located at a German university hospital. These included clinics for: radiotherapy, haematology and oncology, gastroenterology, endocrinology, rheumatology, infectious diseases, surgery, trauma surgery, cranio- and maxillo-facial surgery, neurosurgery, otorhinolaryngology, dermatology, ophthalmology, cardiology, nephrology, and pulmonology. The second sample was comprised of 649 participants from 18 private practices in districts neighbouring the university hospital. The overall sample size was 2807. 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.

Insert Table 1 about here

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 (X^2 (1) = 61.31; $p = .001$; $\Phi = .148$). The university outpatient 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 (X^2 (4) = 260.23; $p = .001$; $V = .345$). These two variables did not confound any of the following results.

Procedure and instruments

We developed a structured questionnaire based on a previous investigation of ADs in patients with cancer [16]. In six sections, the questionnaire comprised dichotomous questions and multiple response questions: (1) Information about the purpose of the study and request for informed consent; (2) Socio-demographic questions (see Table 1); (3) Knowledge about and existence of living will and health care proxy; (4) Preferences regarding with whom the patient would like to consult and the convenient date for completion of an AD; (5) Prior experiences with serious diseases and with living wills or health care proxies; (6) Reasons for considering or rejecting advance care planning. The study was approved by the institutional ethics committee at Regensburg University Hospital.

During the survey period all patients of the above mentioned 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 appointments. At the end of their visits, they returned the filled questionnaires to the registration.

Statistical analysis

The analyses aimed at comparing the university clinic sample and the private practice sample. Data are presented in the form of proportions for categorical variables and means (and standard deviations) for continuous variables. X^2 tests, the Φ coefficient, Cramer's V and the Odds Ratio (OR) were used to detect statistically significant and clinically relevant group differences. All reported p values are two-sided, with $p < .05$ considered as significant. Data were analysed with SPSS software, version 21.

Results

Knowledge of and prior completion of AD

Among the sample, 2594 (92%) participants (university clinics: 1993; private practices: 601) were familiar with living wills and 1826 (65%) participants (university clinics: 1374; private practices: 452) were familiar with health care proxies. Of those who were familiar with the instruments of advance care planning, 781 (30%) participants (university clinics: 600; private practices: 181) had completed a living will, and 617 (34%) participants (university clinics: 467; private practices: 150) had completed a health care proxy. 1783 (64%) participants (university clinics: 1340; private practices: 443) were familiar with both instruments, of which 559 (31%) persons (university clinics: 418; private practices: 141) had completed both a living will and a health care proxy. Thus only about one third of the participants had previously completed a living will and/or a health care proxy. The data show that the sampled patients were more familiar with living wills than with health care proxies. There was no difference in prior completion of ADs between the two groups. This is remarkable as patients from the university clinic suffer from more serious diseases (see Table 1).

Table 2 shows for both groups the familiarity with and the presence of living wills and health care proxies.

Insert Table 2 about here

There was no substantial difference between the groups in familiarity with living wills (X^2 (1) = 1.36; *p* = .242). However, the groups significantly differed with regard to familiarity with health care proxies (X^2 (1) = 10.21; *p* = .001; Φ = .061, *OR* = 1.37). Due to the small effect size, however, this difference was considered negligible.

Consultation before completing an AD

Before completing a living will, 715 (92%) participants informed themselves. Five-hundred-nine (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 clinics: X^2 (2) = 395.04; *p* < .001; *V* = .433; private practices: X^2 (2) = 115.64; *p* < .001; *V* = .434). Whereas most participants talked at least once to another person about completing an 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.

The comparison of the samples of patients from the university clinic and from private practices revealed no significant differences regarding sources of information used before completing a living will (see Table 3).

Insert Table 3 about here

More participants from the university clinic group (143; 24%) were counselled by a physician than participants from the private practice group (30; 17%). However, this finding did not reach statistical significance (X^2 (1) = 3.37; p = .066; Φ = .07). When only participants without an AD were analysed, statistically significant differences between the two groups were noted. A larger percentage of participants in the private practice group, compared to the university clinic group, wanted to be informed about living wills by their family physician (X^2 (1) = 15.49; p = .001; Φ = .09, OR = 1.55). In contrast, participants from the university clinic group more often wanted to be informed about living wills by a clinician (X^2 (1) = 19.19; p = .001; Φ = .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.

Prior experiences

Prior familiarity with the instruments of advance care planning was associated with a higher rate of completed living wills and health care proxies (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 an AD (see Table 4). More participants who had cared for a relative until her/his death had completed an AD compared to participants lacking such an experience (X^2 (1) = 30.70; p = .001; Φ = .10, OR = 1.61). Similarly, participants who had suffered from a life-threatening disease had a higher rate of completion of ADs than participants without this experience (X^2 (1) = 40.89; p = .001; Φ = .13, OR = 1.77).

Insert Table 4 about here

Although there was no difference between the two sample groups in the presence of a living will, there were some differences regarding prior experiences with severe disease. 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 (X^2 (1) = 8.62; p = .003; Φ = .06, OR = 1.31). As expected, more participants from the university clinic group earlier had suffered from a severe disease than participants from the private practice group (X^2 (1) = 128.56; p = .001; Φ = .22, OR = 3.75).

Reported personal motives for completing a living will

The most frequent motive for the completion of a living will was to prevent unnecessary suffering (68%), followed by the avoidance of being a burden for others (55%) (see Table 5, multiple answers were possible).

Insert Table 5 about here

One third of the participants in each group reported wanting to make their own decisions. A similar proportion of each group reported fearing overtreatment by physicians who would otherwise be obligated to perform all possible life-preserving treatments. Further motives were: distrust that physicians (24%) or relatives (12%) would decide in the participant's best interest; experience with intense care for relatives (22%); and the completion of a living will in the course of receiving legal advice (18%). 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 reported as a motive more often by participants of the private practice group (X^2 (1) = 5.01; p = .025; Φ = .08, OR = 1.49). Due to the small effect size there is only limited practical significance. Among those 130 participants who completed a living will in the course of receiving legal advice, only 16 had consulted a physician in addition.

Motives against completing a living will

"I currently do not want to deal with the issue" was the most frequently reported motive (588; 35%) against completing a living will (see Table 6, multiple answers were possible), followed by "I am too young" (321; 19%).

Insert Table 6 about here

A substantial number of participants reported that they had not completed a living will because their "attitudes could possibly change during the progression of a disease" (279; 17%), because "medical treatment options could improve" (226; 14%), because they "delegate the decision to specialists in an emergency" (215; 13%), because they "feel confused by the legal regulation" (202; 12%), or because they "fear to give wrong instructions" (176; 11%). 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 completing a living will 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 a living will should be considered early, and 145 (26%) participants agreed with the statement that a living will 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 a living will ($N = 314$); 177 (56%) of them agreed that completing a living will should be done early, and 78 (25%) indicated that one should complete a living will independently of the presence of a disease.

Discussion

The issue of patient autonomy, despite its undisputable relevance, still poses many open questions. Many actors – 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 an AD. In the present study, three research questions were posed in order to get a better understanding of the issue. In order to increase the reliability of the answers to these research questions, a large sample size was used: more than 2800 participants were studied. First, it was investigated whether the reasons for (or against) completing a living will resemble each other in two different groups of patients: patients from several university clinics (many of whom suffer from serious diseases) and patients from private practices. Attitudes toward ADs have previously been reported in university hospital patients, but it is still an open question whether the results can easily be generalised to a broader population. The experience of suffering from a serious disease obviously influences the importance of making decisions related to patient autonomy [22]. Second, it was investigated to what degree professional consultation had been used before completing an AD, and from which professional groups such advice had been acquired. In addition, it was investigated whether those who had not completed an AD would like to receive professional advice – and, again, by whom – before making a decision in favour of completing a living will. Third, motives both for and against completion of a living will were investigated.

Concerning the first research question (comparability of samples from a university clinic and from private practices), few differences were found between the two groups indicating that the results likely are generalisable. The sample from private practices was slightly more familiar with health care 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 (living will and/or health care proxy) 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 experiences of serious 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 experiences (either personal or related to close relatives or friends) with life threatening diseases, intensive care treatment, nursing cases etc. only slightly increased the rate of completed ADs, and only to a level still clearly below 50 per cent.

Concerning the second research question (professional consultation, both before completion of an AD and desire in the future), our study was consistent with prior findings that more than one third of the patients with completed AD received legal advice [16, 24, 25]. In some patients, legal consultation about living wills may be related to receiving legal testament advice, as it has been shown, that patients were much more likely to complete a living will or a health care proxy when asked by legal staff compared to medical staff [26]. Among those who have not yet completed an AD, many state 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 close to 100 per cent can be found in interview data, which may reflect, what is socially desirable. In contrast none of the multiple interventions to promote ADs increased the rate of completed

ADs above 50 per cent, 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 family practice setting patients named the family doctor as the preferred person of trust for AD consultations. On the other hand 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 minutes. Providing an adequate financial compensation to family physicians for consultation around ADs could be a promising approach to promote completion of ADs.

Concerning the third research question (motives for or against completing a living will), the study revealed some inconsistent response patterns that need further analysis. Inconsistencies were revealed when cross tabulating the motives against completing a living will with the question of when it is appropriate to complete a living will. Possible explanations of these inconsistencies – although not deliberately investigated in the present study – could be identified in comments which some of the participants provided voluntarily in addition to the questionnaire answers. Among the 325 participants providing such comments, 172 (53%) stated that they just postponed completing a living will 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 among the 1998 participants, who had not completed an AD, 1643 (82%) were willing to discuss this subject. Although most people indicated being willing in principle to complete an AD, many did not initiate the completion on their own. Furthermore, among those who already had completed an AD, only 231 (31%) indicated that they “wanted to make his/her own decisions”. The majority of patients who had completed an AD had done so in reaction to distrust and fear around future treatments [28].

These findings might pose new questions concerning the motivations for completing an AD. It might be that the findings indicate a kind of “negative autonomy”: Living wills and health care proxies might be seen mainly as instruments to prevent particular forms of therapy, but not as instruments to design one’s own “positive autonomy”. Future studies could investigate under which conditions patients are most motivated to think proactively about future medical decisions. It is time for a paradigm shift in how the medical and legal professions approach ADs. In theory, ADs provide an opportunity for patients to exercise their autonomy and to actively engage in decisions about their future health care. 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. In order to increase the uptake of ADs amongst patients, it may be necessary to reframe ADs as a means of engaging proactively in future health care decisions rather than as a reactive tool used to prevent future unwanted experiences.

Up to this point, most attempts to increase uptake of ADs amongst patients have focussed 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 health care, may be more successful in increasing the number of patients with a completed 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.

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Beside the authors there are no further contributors to this work.

The corresponding author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Contributorship Statement

Jochen Pfirstinger initiated the study as a further development of a previous study [16], made major contributions to the questionnaire and to the data interpretation, contributed to the data analysis and wrote large parts of the manuscript.

Bernhard Bleyer made major contributions to the questionnaire and to the data interpretation in particular with respect to theological and ethical aspects, and helped writing and correcting the manuscript.

Christian Blum conducted a preliminary interview study (not published), the results of which have been integrated into the questionnaire. He performed large parts of the data acquisition and of the statistical data analysis, contributed to the data interpretation, and helped correcting the manuscript.

Michael Rechenmacher and Christoph Wiese made significant contributions to the questionnaire and to the data interpretation and helped correcting the manuscript.

Hans Gruber initiated und supervised the preliminary interview study (not published), the results of which have been integrated into the questionnaire. He supervised the statistical data analysis, made major contributions to the questionnaire and to the data interpretation in particular with respect to educational and learning aspects, and helped writing and correcting the manuscript.

Competing interests

All authors have completed the ICMJE uniform disclosure form and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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Data Sharing Statement

All authors agree to make the relevant anonymised patient level data available for all researchers on reasonable written request to the corresponding author.

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Table 1 | Characteristics of participants enrolled in the study, separately for the university clinic outpatient sample and the private practice outpatient sample. 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 (standard deviation in brackets) in years are given. For all other variables the numbers of patients (percentages in brackets) are given.

Characteristics	University Clinic Outpatients (N_1 = 2158)	Private Practice Outpatients (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 (9 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)

Table 2 | Familiarity with and presence of living wills and health care proxies, separately for the university clinic outpatient sample and the private practice outpatient sample. 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 patients (percentages in brackets) are given.

	University Clinic Outpatients (N_1 = 2158)	Private Practice Outpatients (N_2 = 649)
Familiarity with living will (n_1 = 2146; n_2 = 638)	1993 (93)	601 (94)
Familiarity with health care 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 health care proxy (n_1 = 1366; n_2 = 443)	467 (34)	150 (34)

Table 3 | Sources of information regarding living wills, separately for the university clinic outpatient sample and the private practice outpatient sample. 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 patients (percentages in brackets) are given.

	University Clinic Outpatients with Completed Living Will (N_1 = 600)	Private Practice Outpatients with Completed Living Will (N_2 = 181)
Participant self-informed before completing a living will (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)

Table 4 | Prior experience with disease and presence of a living will. For all variables the numbers of patients (percentages in brackets) are given.

	No Living Will	Completed Living Will
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.

Table 5 | Motives in favour of completion of a living will (multiple answers possible). For all variables the numbers of patients (percentages in brackets) are given.

Participant completed a living will because ...	Total (N = 736)*	University Clinic Outpatients (n_1 = 567)	Private Practice Outpatients (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.

Table 6 | Motives against completion of a living will (multiple answers possible). For all variables the numbers of patients (percentages in brackets) are given.

Participant did not yet complete a living will because ...	Total (N = 1665)*	University Clinic Outpatients (n_1 = 1285)	Private Practice Outpatients (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 *N* due to missing values.

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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

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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, source of information, prior experiences with own life-threatening diseases, 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 ten departments of a university clinic

Outcome measures: Completion of AD, familiarity, sources of information, prior experiences (with life-threatening disease), motives in favour of or against completion, socio-demographic data

Results: Determinants of completion of AD did not differ between outpatients from private practices vs. 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 life-threatening diseases had completed an AD as expression of their autonomous volition. The participants' motives for or against completion 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".

Trial registration: not applicable

Strengths and limitations of this study

Our study includes a very large number of completed questionnaires regarding determinants of completion of AD.

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.

On the other hand 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.

Determinants of Completion of Advance Directives: A Cross-Sectional Comparison of 649 Outpatients from Private Practices versus 2158 Outpatients from a University Clinic

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 e.g. 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 September 1st, 2009. As in many other countries, ADs comprise the following legal instruments: living will and health care 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 health care 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 less than 40% is found in cancer patients [1-3] as well as 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 cancer patients 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 cancer patients postponed AD consultations, because an AD “is not relevant” now or they “do not want to get involved with 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]. It is still an open question, whether patients have stable end-of-life preferences [23].

Healthcare research is usually performed either in centres like university hospitals or in a very decentralised setting. It is an open question whether samples from university clinics legitimately can be compared to samples from private practices providing general primary care. 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. On the other hand a longterm 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 for care, and their motives in favour and against completion of AD

Method

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 ten outpatient departments located at a German university clinic. These included clinics for: radiotherapy, haematology and oncology, gastroenterology, endocrinology, rheumatology, infectious diseases, surgery, trauma surgery, cranio- and maxillo-facial 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.

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 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) socio-demographic questions (see Table 1); (3) familiarity with and existence of AD; (4) questions about preferences regarding sources of information (e.g. 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 for care; (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, all 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 for 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 standard deviations) for continuous variables. X^2 tests, the Φ coefficient, Cramer's V and the Odds Ratio (OR) were used to detect statistically significant and clinically relevant group differences. All reported p

values are two-sided, with $p < .05$ considered as significant. Data were analysed with SPSS software, version 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 group 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 for 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 socio-demographic characteristics (marital status, education, qualification, location) of the participants in each group.

Insert Table 1 about here

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 (X^2 (1) = 61.31; p = .001; Φ = .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 (X^2 (4) = 260.23; p = .001; V = .345). These two variables did not confound any of the following results.

Familiarity with AD, completion of AD

Among the sample, 2594 (92%) participants (university clinic: 1993; private practices: 601) were familiar with living wills, 1826 (65%) participants (university clinic: 1374; private practices: 452) with health care proxies, the two forms of AD. Of those who were familiar with the instruments of advance directives, 781 (30%) participants (university clinic: 600; private practices: 181) had completed a living will, and 617 (34%) participants (university clinic: 467; private practices: 150) had completed a health care proxy. 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 health care proxy. Thus only about one third of the participants had previously completed a living will and/or a health care proxy. The data show that the sampled outpatients were more familiar with living wills than with health care proxies. There was no difference in completion of AD between the two groups. .

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

Insert Table 2 about here

There was no substantial difference between the groups in familiarity with living wills (X^2 (1) = 1.36; p = .242). However, the groups significantly differed with regard to familiarity with health care proxies (X^2 (1) = 10.21; p = .001; Φ = .061, OR = 1.37). Due to the small effect size, however, this difference was considered negligible.

Source of information for completion of AD

Before completion of AD, 715 (92%) participants informed themselves. Five-hundred-nine (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: X^2 (2) = 395.04; p < .001; V = .433; private practices: X^2 (2) = 115.64; p < .001; V = .434). Whereas most participants talked at least once to another person 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.

The comparison of the samples of outpatients from a university clinic and outpatients from private practices revealed no significant differences regarding sources of information used before completion of AD (see Table 3).

Insert Table 3 about here

More participants from the university clinic group (143; 24%) were counselled by a physician than participants from the private practice group (30; 17%). However, this finding did not reach statistical significance (X^2 (1) = 3.37; p = .066; Φ = .07). 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 to the university clinic group, wanted to be informed about AD by their family physician (X^2 (1) = 15.49; p = .001; Φ = .09, OR = 1.55). In contrast, participants from the university clinic group more often wanted to be informed about AD by a clinician (X^2 (1) = 19.19; p = .001; Φ = .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.

Prior experiences with own life-threatening disease or family members in need for 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 to participants lacking such an experience (X^2 (1) = 30.70; $p = .001$; $\Phi = .10$, 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 (X^2 (1) = 40.89; $p = .001$; $\Phi = .13$, OR = 1.77).

Insert Table 4 about here

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 (X^2 (1) = 8.62; $p = .003$; $\Phi = .06$, 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 (X^2 (1) = 128.56; $p = .001$; $\Phi = .22$, OR = 3.75).

Motives in favour of completion of AD

The most frequent motive in favour of completion of AD was to prevent unnecessary suffering (68%), followed by the avoidance of being a burden for others (55%) (see Table 5, multiple answers were possible).

Insert Table 5 about here

One third of the participants in each group reported wanting to make their own decisions. A similar proportion of each group reported fearing overtreatment by physicians who would otherwise be obligated to perform all possible life-preserving treatments. Further motives were: distrust that physicians (24%) or relatives (12%) would decide in the participant's best interest; experience with intense care for relatives (22%); and the completion of a living will in the course of receiving legal advice (18%). 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 reported as a motive more often by participants of the private practice group (X^2 (1) = 5.01; p = .025; Φ = .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.

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 (see Table 6, multiple answers were possible), followed by "I am too young" (321; 19%).

Insert Table 6 about here

A substantial number of participants reported that they had not completed an AD because their "attitudes could possibly change during the progression of a disease" (279; 17%), because "medical treatment options could improve" (226; 14%), because they "delegate the decision to specialists in an emergency" (215; 13%), because they "feel confused by the legal regulation" (202; 12%), or because they "fear to give wrong instructions" (176; 11%). 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.

Discussion

The issue of patient autonomy, despite its undisputable relevance, still poses many open questions. Many actors – 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 the present 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 with in university clinic patients, but it is still an open question whether the results can legitimately be generalised towards a broader population, 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 was investigated, among them the sources of information about AD, i.e. to what degree professional consultation had been seeked before completion of AD, and from which professional groups such advice had been seeked. 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 health care 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 etc. only slightly increased the rate of completion of ADs, and only to a level still clearly below 50 per cent.

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 to 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 per cent 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 per cent, 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. On the other hand 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 minutes. 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 the present study – could be identified in comments which some of the participants provided voluntarily 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. For example, one participant quoted: “Because I procrastinated completing a living will up to now.” This finding was in line with the fact that among the 1998 participants without completion of AD, 1643 (82%) 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. Furthermore, among those who already had completed an AD, only 231 (31%) indicated that they “wanted to make his/her own decisions”. The majority of patients who had completed an AD had done so in reaction to distrust and fear around future treatments [28].

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 health care 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 health care proxies as something unpleasant, which must be done – somewhen 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, AD provide an opportunity for patients to exercise their autonomy and to actively engage in decisions about their future health care. 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. In order to increase the uptake of ADs amongst patients, it may be necessary to reframe ADs as a means of engaging proactively in future health care decisions rather than as a reactive tool used to prevent future unwanted experiences.

Up to this point, most attempts to increase uptake of ADs amongst patients have focussed 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 health care, 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.

I, Jochen Pfirstinger, the Corresponding Author of this article contained within the original manuscript which includes any diagrams submitted (the “Contribution”) has the right to grant on behalf of all authors and does grant on behalf of all authors, a licence to the BMJ Publishing Group Ltd and its licencees, to permit this Contribution (if accepted) to be published in the BMJ and any other BMJ Group products and to exploit all subsidiary rights, as set out in our licence set out at: http://www.bmj.com/about-bmj/resources-authors/forms-policies-and-checklists/copyright-open-access-and-permission-reuse.

Beside the authors there are no further contributors to this work.

The corresponding author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Contributorship Statement

Jochen Pfirstinger initiated the study as a further development of a previous study [16], made major contributions to the questionnaire and to the data interpretation, contributed to the data analysis and wrote large parts of the manuscript.

Bernhard Bleyer made major contributions to the questionnaire and to the data interpretation in particular with respect to theological and ethical aspects, and helped writing and correcting the manuscript.

Christian Blum conducted a preliminary interview study (not published), the results of which have been integrated into the questionnaire. He performed large parts of the data acquisition and of the statistical data analysis, contributed to the data interpretation, and helped correcting the manuscript.

Michael Rechenmacher and Christoph Wiese made significant contributions to the questionnaire and to the data interpretation and helped correcting the manuscript.

Hans Gruber initiated und supervised the preliminary interview study (not published), the results of which have been integrated into the questionnaire. He supervised the statistical data analysis, made major contributions to the questionnaire and to the data interpretation in particular with respect to educational and learning aspects, and helped writing and correcting the manuscript.

Competing interests

All authors have completed the ICMJE uniform disclosure form and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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Data Sharing Statement

All authors agree to make the relevant anonymised patient level data available for all researchers on reasonable written request to the corresponding author.

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Table 1 | Characteristics of participants enrolled in the study, separately for outpatients of a university clinic and outpatients from private practices. 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 (standard deviation in brackets) in years are given. For all other variables the numbers of participants (percentages in brackets) are given.

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 (9 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)

Table 2 | Familiarity with and presence of AD (separate for living wills and for health care proxies), separately for outpatients from a university clinic and for outpatients form private practices. 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.

	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 health care 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 health care proxy (n_1 = 1366; n_2 = 443)	467 (34)	150 (34)

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

	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)

Table 4 | Prior experience with own life-threatening diseases or family members in need for care and presence of AD. For all variables the numbers of participants (percentages in brackets) are given.

	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.

Table 5 | Motives in favour of completion of AD (multiple answers possible). For all variables the numbers of participants (percentages in brackets) are given.

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.

Table 6 | Motives against completion of AD (multiple answers possible). For all variables the numbers of participants (percentages in brackets) are given.

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 *N* due to missing values.

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
√ **Title and abstract**	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
√ Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
√ Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
√ Study design	4	Present key elements of study design early in the paper
√ Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
√ Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
√ Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
√ Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
√ Bias	9	Describe any efforts to address potential sources of bias
√ Study size	10	Explain how the study size was arrived at
√ Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
√ Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

Continued on next page

Results		
√ Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
√ Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
√ Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
√ Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
√ Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
√ Key results	18	Summarise key results with reference to study objectives
√ Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
√ Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
√ Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
√ Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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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

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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

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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 for 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 ten 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, socio-demographic data

Results: Determinants of completion of AD did not differ between outpatients from private practices vs. 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 for 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".

Trial registration: not applicable

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.

On the other hand 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.

Determinants of Completion of Advance Directives: A Cross-Sectional Comparison of 649 Outpatients from Private Practices versus 2158 Outpatients from a University Clinic

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 e.g. 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 September 1st, 2009. As in many other countries, ADs comprise the following legal instruments: living will and health care 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 health care 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 less than 40% is found in cancer patients [1-3] as well as 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 cancer patients 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 cancer patients postponed AD consultations, because an AD “is not relevant” now or they “do not want to get involved with 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 like university hospitals or in a very decentralised setting. Whether samples from university clinics legitimately can be compared to 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. On the other hand 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 for care, and their motives in favour and against completion of AD.

Method

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 ten outpatient departments located at a German university clinic. These included clinics for: radiotherapy, haematology and oncology, gastroenterology, endocrinology, rheumatology, infectious diseases, surgery, trauma surgery, cranio- and maxillo-facial 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) socio-demographic questions (see Table 1); (3) familiarity with and existence of AD; (4) questions about preferences regarding sources of information (e.g. 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 for care; (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 for 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 standard deviations) for continuous variables. X^2 tests, the Φ coefficient, Cramer's V and the Odds Ratio (OR) were used to detect statistically significant and clinically relevant group differences. All reported *p* values are two-sided, with $p < .05$ considered as significant. Data were analysed with SPSS software, version 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 group 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 for 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 socio-demographic characteristics (marital status, education, qualification, location) of the participants in each group.

Insert Table 1 about here

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 (X^2 (1) = 61.31; $p = .001$; $\Phi = .148$). 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 (X^2 (4) = 260.23; $p = .001$; $V = .345$). 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 health care proxies, the two forms of AD. Of those who were familiar with the instruments of advance directives, 781 (30%) participants had completed a living will, and 617 (34%) participants had completed a health care proxy. 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 health care proxy. Thus only about one third of the participants had previously completed a living will and/or a health care proxy. The data show that the sampled outpatients were more familiar with living wills than with health care proxies.

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

Insert Table 2 about here

There was no substantial difference between the groups in completion of AD (living will: X^2 (1) = 0.006; p = .938; health care proxy: X^2 (1) = 0.02; p = .899), and in familiarity with living wills (X^2 (1) = 1.36; p = .242). However, the groups significantly differed with regard to familiarity with health care proxies (X^2 (1) = 10.21; p = .001; Φ = .061, *OR* = 1.37).

Source of information for completion of AD

Before completion of AD, 715 (92%) participants informed themselves. Five-hundred-nine (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: X^2 (2) = 395.04; p < .001; V = .433; private practices: X^2 (2) = 115.64; p < .001; V = .434). Whereas most participants talked at least once to a confidantabout 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).

Insert Table 3 about here

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 > .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 to the university clinic group, wanted to be informed about AD by their family physician (X^2 (1) = 15.49; p = .001; Φ = .09, OR = 1.55). In contrast, participants from the university clinic group more often wanted to be informed about AD by a clinician (X^2 (1) = 19.19; p = .001; Φ = .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.

Prior experiences with own life-threatening disease or family members in need for 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 to participants lacking such an experience (X^2 (1) = 30.70; p = .001; Φ = .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 (X^2 (1) = 40.89; p = .001; Φ = .13, OR = 1.77).

Insert Table 4 about here

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 (X^2 (1) = 8.62; p = .003; Φ = .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 (X^2 (1) = 128.56; p = .001; Φ = .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).

Insert Table 5 about here

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 reported as a motive more often by participants of the private practice group (X^2 (1) = 5.01; p = .025; Φ = .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).

Insert Table 6 about here

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. On the other hand among the 1998 participants without completion of AD, 1643 (82%) were willing to discuss this issue.

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 the present 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 was investigated, among them the sources of information about AD, i.e. 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 generalizability 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 health care 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 etc. only slightly increased the rate of completion of ADs, and only to a level still clearly below 50 per cent.

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 to 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 per cent 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 per cent, 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. On the other hand 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 minutes. 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 the present 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 health care 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 health care 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, AD provide an opportunity for patients to exercise their autonomy and to actively engage in decisions about their future health care. 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. In order to increase the uptake of ADs amongst patients, it may be necessary to reframe ADs as a means of engaging proactively in future health care decisions rather than as a reactive tool used to prevent future unwanted experiences.

Up to this point, most attempts to increase uptake of ADs amongst patients have focussed 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 health care, 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.

Limitations: Some few 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.

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Beside the authors there are no further contributors to this work.

The corresponding author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Contributorship Statement

Jochen Pfirstinger initiated the study as a further development of a previous study [16], made major contributions to the questionnaire and to the data interpretation, contributed to the data analysis and wrote large parts of the manuscript.

Bernhard Bleyer made major contributions to the questionnaire and to the data interpretation in particular with respect to theological and ethical aspects, and helped writing and correcting the manuscript.

Christian Blum conducted a preliminary interview study (not published), the results of which have been integrated into the questionnaire. He performed large parts of the data acquisition and of the statistical data analysis, contributed to the data interpretation, and helped writing and correcting the manuscript.

Michael Rechenmacher and Christoph Wiese made significant contributions to the questionnaire and to the data interpretation and helped correcting the manuscript.

Hans Gruber initiated und supervised the preliminary interview study (not published), the results of which have been integrated into the questionnaire. He supervised the statistical data analysis, made major contributions to the questionnaire and to the data interpretation in particular with respect to educational and learning aspects, and helped writing and correcting the manuscript.

Competing interests

All authors have completed the ICMJE uniform disclosure form and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

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Data Sharing Statement

All authors agree to make the relevant anonymised patient level data available for all researchers on reasonable written request to the corresponding author.

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Table 1 | Characteristics of participants enrolled in the study, separately for outpatients of a university clinic and outpatients from private practices. 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 (standard deviation in brackets) in years are given. For all other variables the numbers of participants (percentages in brackets) are given.

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 (9 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)

Table 2 | Familiarity with and presence of AD (separate for living wills and for health care proxies), separately for outpatients from a university clinic and for outpatients form private practices. 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.

	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 health care 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 health care proxy (n_1 = 1366; n_2 = 443)	467 (34)	150 (34)

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

	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)

Table 4 | Prior experience with own life-threatening diseases or family members in need for care and presence of AD. For all variables the numbers of participants (percentages in brackets) are given.

	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.

Table 5 | Motives in favour of completion of AD (multiple answers possible). For all variables the numbers of participants (percentages in brackets) are given.

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.

Table 6 | Motives against completion of AD (multiple answers possible). For all variables the numbers of participants (percentages in brackets) are given.

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 *N* due to missing values.

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract **[within the title page 1 and design section of the abstract page 2]**
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found **[page 2]**
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported **[pages 5 - 6]**
Objectives	3	State specific objectives, including any prespecified hypotheses **[page 6]**
Methods		
Study design	4	Present key elements of study design early in the paper **[page 6]**
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection **[pages 6 - 7]**
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants **[pages 6]**
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable **[page 7]**
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group **[page 7]**
Bias	9	Describe any efforts to address potential sources of bias **[N/A]**
Study size	10	Explain how the study size was arrived at **[N/A]**
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why **[pages 7 - 8]**
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding **[pages 7 - 8]**
		(*b*) Describe any methods used to examine subgroups and interactions **[pages 7 - 8]**
		(*c*) Explain how missing data were addressed **[N/A]**
		(*d*) If applicable, describe analytical methods taking account of sampling strategy **[N/A]**
		(*e*) Describe any sensitivity analyses **[N/A]**
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers

		potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed **[page 8]**
		(b) Give reasons for non-participation at each stage **[N/A]**
		(c) Consider use of a flow diagram **[N/A]**
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders **[pages 8]**
		(b) Indicate number of participants with missing data for each variable of interest **[N/A]**
Outcome data	15*	Report numbers of outcome events or summary measures **[pages 8 - 13]**
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included **[pages 8 - 13]**
		(*b*) Report category boundaries when continuous variables were categorized **[N/A]**
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period **[N/A]**
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses **[pages 8 - 13]**
Discussion		
Key results	18	Summarise key results with reference to study objectives **[pages 14 - 17]**
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias **[page 18]**
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence **[pages 14 - 15]**
Generalisability	21	Discuss the generalisability (external validity) of the study results **[]**
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based **[page 21]**

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.