

## ORIGINAL ARTICLE

# Advance Directives in Nursing Homes

Prevalence, Validity, Significance, and Nursing Staff Adherence

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## SUMMARY

**Background:** The German Advance Directives Act of 2009 confirms that advance directives (ADs) are binding. Little is known, however, about their prevalence in nursing homes, their quality, and whether they are honored.

**Methods:** In 2007, we carried out a cross-sectional survey in all 11 nursing homes of a German city in the state of North Rhine–Westphalia (total nursing home population, 1089 residents). The ADs were formally analyzed and assessed by 3 raters with respect to 5 clinical decision-making scenarios. The specifications of the ADs were compared with what the nurses reported that they would do in each scenario.

**Results:** 11% of the nursing home residents had a personal AD, and a further 1.4% an AD by proxy. 52% of the 119 ADs that we analyzed contained no documentation of the patient's decision-making capacity and/or voluntariness, and only 3% contained documentation of a medical consultation. Most ADs failed to state what should be done in case the patient acutely became incapable of consenting to treatment (inter-rater agreement [IRA] >83%). For the case of permanent decisional incapacity, many ADs contained ambiguous information (IRA <43%). 23 directives stated that the patient should not have cardiopulmonary resuscitation in case an arrest occurred in the patient's current clinical condition, but the nurses reported a corresponding do-not-resuscitate agreement for only 9 of these 23 patients.

**Conclusion:** In 2007, ADs were rare in these German nursing homes, and most of the existing ones were invalid, of little meaning, and/or disregarded by the nursing staff. There is little reason to believe that the Advance Directives Act of 2009 will bring about any major change in this miserable status quo. Advance care planning, a system-oriented concept still uncommon in Germany, could give new impulses to promote a cultural change in this respect.

### ► Cite this as:

Sommer S, Marckmann G, Pentzek M, Wegscheider K, Abholz HH, in der Schmitten J: Advance directives in nursing homes: prevalence, validity, significance, and nursing staff adherence. *Dtsch Arztebl Int* 2012; 109(37): 577–83. DOI: 10.3238/arztebl.2012.0577

The third act amending German guardianship legislation (known as the Advance Directives Act) came into power on 1 September 2009. This new law essentially confirmed high-court jurisprudence on the subject of advance directives and the corresponding principles of the German Medical Association (1). The act strengthened the faith in due process of many involved in the creation and implementation of advance directives (2). As experience in the USA has shown, however (4), such legislation cannot be expected to have any far-reaching impact with regard to the prevalence and quality of the traditional advance directive—an instrument whose lack of effect has been demonstrated years ago (3). The Advance Directives Act has essentially not changed the law and neither provides incentives nor foresees resources for advisory consultations. In contrast to a draft bill that was defeated in parliament (5), the act contains—apart from stipulation of the written form—no criteria for the validity of patients' advance directives. As long as patently significant and valid advance directives remain the exception in daily clinical practice, it can hardly be expected that directives will be heeded by medical or non-medical staff.

Beyond questionnaire survey results (6, 7), there are no empirical data on the actual frequency of advance directives in Germany. Worldwide, there are only a handful of studies on the formal and substantive quality of advance directives and on whether they are observed (8–11). Advance directives are particularly relevant in nursing homes for senior citizens, where the elderly and mostly chronically multimorbid residents do not always wish unlimited use of life-prolonging measures, though here too empirical data are sparse (12).

Empirical evaluation of the effect of the new legislation in 2009 on the frequency and quality of advance directives is impossible without knowledge of the situation before passage of the Advance Directives Act. In 2007 we investigated the prevalence, significance, validity, and observation of advance directives in German nursing homes.

## Method

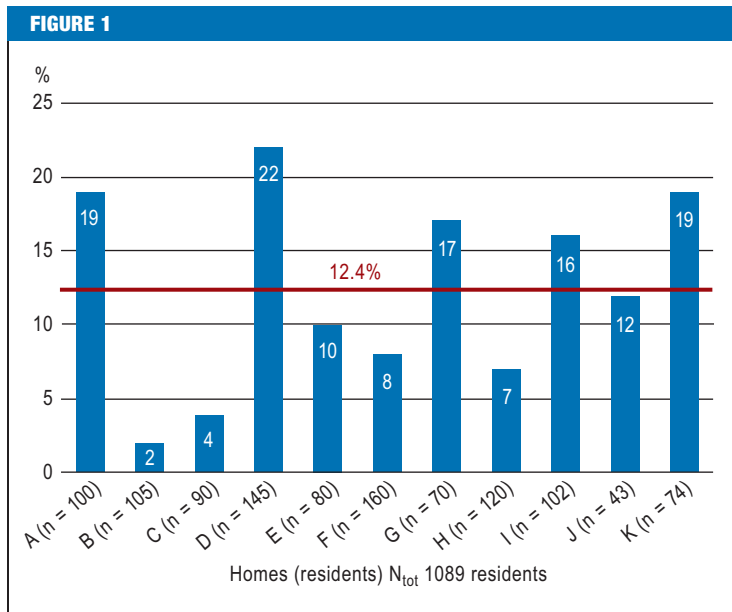
### Study type, sample, and survey period

We carried out a descriptive cross-sectional complete survey of all 11 nursing homes in a city in the German federal state of North Rhine–Westphalia (convenience

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**Prevalence of advance directives** (signed by the resident or by a proxy) in the 11 nursing homes studied

sample) covering the period from June to September 2007. Nine of these homes were run by the Christian church (some Protestant, some Catholic), one was private, and one was a community nursing home.

**Ethics committee approval**

The study was approved by the ethics committee of Düsseldorf University Hospital (no. 2997).

**Terminology**

We understand the term “advance directive” to mean a written statement signed by a person of legal age to cover the eventuality that they will lack decision-making capacity at some future time. This statement regulates whether the person concerned will agree, or not, to “certain investigations [...], treatments, or medical interventions, not yet planned at the time of the directive” (§ 1901a para. 1 of the German Civil Code).

In the course of our survey we were confronted with directives that were signed not by the individuals themselves but by their representatives according to § 1901a para. 2 of the German Civil Code, which implicitly provides for advance written specification of a nursing home resident’s presumed wishes (13). Such directives have been termed “advance care planning by proxy” (14) and will be referred to here as “proxy directives”.

**Prevalence, consent, and formal analysis**

In each nursing home members of staff informed us how many of the residents were covered by personally signed or proxy advance directives. With the consent of the residents or their legal representatives, their sociodemographic data were recorded and the form and content of the directives were analyzed.

**Comprehensibility of validity for third parties**

By validity we mean agreement (congruence) between what is directed in the AD and what the well-informed person meant to direct under the (actual or hypothetical) requirements for informed consent: decision-making capacity, voluntariness, information, and comprehension of the medical implications (15).

Demonstration that the necessary conditions for informed consent were fulfilled at the time the directive was written can be taken—as usual for written consent to medical treatments—to signify validity. In order for the validity, so defined, of a care directive to be comprehensible for the user (physician), as a surrogate parameter fulfillment of the above-mentioned requirements for informed consent must be documented in the advance directive. It should be noted that this definition of the comprehensibility of the validity of advance directives goes beyond the explicit minimal requirements laid down in the Advance Directives Act. We therefore investigated whether the directives were signed not only by their author but also by another person, and if so, by whom and with what additional text. We regard explicit documentation of informed consent by a physician—just as in the normal case of written consent to treatment—as the gold standard.

**Significance**

When we refer to the significance of a personal or proxy advance directive, we mean its applicability to critical treatment decisions typical for the nursing home setting, in the sense of the Advance Directives Act. We differentiated two relevant nursing home scenarios (A and B) and formulated three typical treatment decisions. Only two of these questions were applied to scenario A, so there were a total of five combinations of scenario and decision in which the directives could be tested (proxy directives: only scenario B):

**Scenario A:** Life-threatening health crisis with resulting loss of capacity to give valid consent in a patient previously able to do so

- A1 Resuscitation after circulatory arrest?
- A2 Hospital admission for treatment of dehydration resulting from infection with high fever?

**Scenario B:** Life-threatening health crisis, patient permanently unable to give valid consent owing to advanced dementia

- B1 Resuscitation after circulatory arrest?
- B2 Hospital admission for treatment of dehydration resulting from infection with high fever?
- B3 Percutaneous endoscopic gastrostomy in progressive dysphagia with weight loss?

The significance of the advance directives in these five situations was assessed independently by each of three qualified raters with different professional backgrounds (S. Sommer, G. Marckmann, J. in der Schmitt) and classified as follows:

- 1. The patient implicitly or explicitly wishes the intervention.

2. The directive permits no statement regarding the patient's will with respect to this scenario and/or this decision.
3. The intervention is implicitly or indirectly rejected.
4. The intervention is explicitly or directly rejected.

To measure agreement among the three raters, we calculated Cohen's kappa coefficient for each decision and each pair of raters. The kappa values and their means are reported here.

### Nursing staff adherence

We asked the head nurses whether arrangements had been made for the residents with regard to resuscitation attempts in the case of a cardiac arrest, and took this to indicate knowledge of the existence of advance directives and the potential need to observe them.

The information provided by the nursing staff was compared with the stipulations of the directives with regard to resuscitation: situation A1 for residents acutely unable to give consent, situation B1 for those permanently unable to give consent.

To this end, the rating categories 3 and 4 (implicit and explicit rejection respectively) were amalgamated and rejection of a CPR attempt was assumed when at least two of the three raters so decided (majority vote).

The nursing home residents were classified as acutely or permanently unable to give consent by the nursing staff, using the seven-point Global Deterioration Scale (GDS) (16). We adopted a conservative approach and assumed permanent incapacity to give consent with respect to the decision regarding resuscitation only for those residents with GDS scores of 6 or higher.

## Results

### Participation rate and sample size

The directors of the 11 nursing homes all agreed to take part in the study and all reported 100% occupancy (n = 1089 residents) on the appointed day.

### Prevalence of advance directives

Altogether, the nursing homes reported that 135 of their residents (12.4%, range 2% to 22%) had a personal or proxy advance directive (Figure 1). Of these 135 residents (or their representatives), 119 (88%) consented to analysis of the directive.

Thirteen (11%) of these 119 directives had been signed by patients' representatives (proxy directives). Extrapolating this ratio of 11% (proxy) to 89% (personal) to the total of 135 advance directives reported by the nursing homes yields 15 proxy and 120 personal directives. This corresponds to rates of 11% for personally signed advance directives and 1.4% for proxy advance directives among the 1089 residents on the day of the survey.

### Sociodemographic characteristics, formal analysis, validity

Table 1 shows the sociodemographic characteristics of the nursing home residents with advance directives and the results of formal analysis of the directives.

TABLE 1

**Sociodemographic characteristics of the residents with advance directives and formal analysis of the directives (n = 119)**

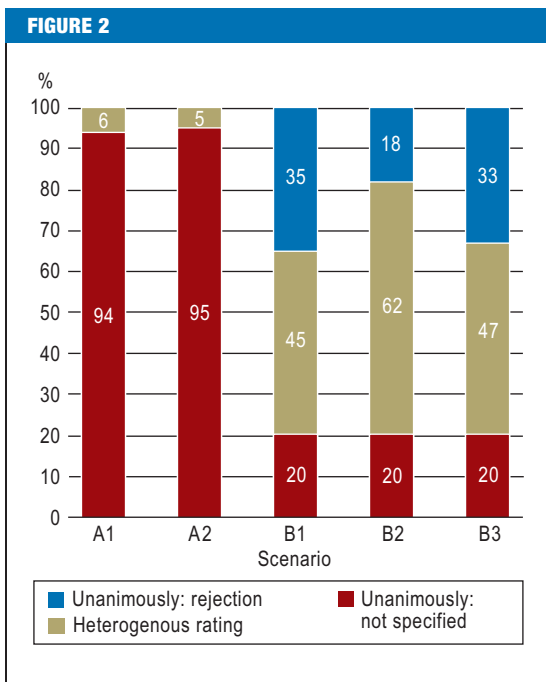
Age and sex	
Age (mean)	86 years (range: 60–100)
Age when directive written	83 years (range: 67–99)
Women	65%
Time of writing of directive	
Before moving into the nursing home	50%
In the year of moving in	10%
Later	40%
Type of directive	
Proxy directive (signed by the resident's representative, not by the resident)	11%
Form	80%
Personally written text	12%
Mixed or unclear	8%
Length of directive	
Less than ½ page	31%
½–2 pages	54%
>2 pages	14%
Validity according to the criteria of informed consent	
a) Documentation of advice on completing the directive and of ability to give consent by a physician (gold standard)	3%
b) Documentation of ability to give consent by a physician	3%
c) Documentation of ability to give consent by a lawyer	20%
d) Documentation of ability to give consent (unclear by whom)	3%
e) Signature of a (any) third party with no reference to ability to give consent or similar	19%
→ Signed by a (any) third party (Σ a–e)	48%

Strikingly, most of the directives lacked documentation of validity criteria in the sense of informed consent. More than half of the directives were signed only by their author. Six percent of them were co-signed by a physician, and in only 3% medical advice was documented.

### Significance

The three raters' assessments of the advance directives with regard to the five treatment decisions A1, A2, and B1–3 are shown in Figure 2. Table 2 shows the agreement between the raters.

With regard to the treatment questions in scenario A (nursing home resident previously able to give valid consent, but currently unable to do so due to a



life-threatening health crisis), inter-rater agreement was high (mean kappa >0.8) and the vast majority of directives gave no answer (94% and 95%).

The findings were quite different for pre-existing (permanent) inability to give valid consent owing to advanced dementia (scenario B). The inter-rater agreements were low overall (mean kappa <0.43), and the ratings of the directives were often mixed (45% to 67%). The raters agreed that one fifth of the advance directives contained no answers to the three treatment questions in this scenario, and that one fifth to one third of the directives rejected the various interventions.

TABLE 2

Inter-rater agreement (measured using Cohen's kappa coefficient) by treatment decision (n = 117)

Scenario	Kappa Rater 1 vs 2	Kappa Rater 1 vs 3	Kappa Rater 2 vs 3	Arithmetic mean
A1	0.849	0.823	0.828	0.833
A2	0.883	0.850	0.858	0.864
B1	0.358	0.386	0.525	0.423
B2	0.154	0.337	0.205	0.232
B3	0.439	0.436	0.353	0.409

A kappa value of 1 shows perfect inter-rater agreement; a kappa value of 0 shows purely random results.

Scenarios A1, A2: Resuscitation after cardiac arrest (A1); hospital admission for management of infection (A2) in the case of acute inability to give consent.

Scenarios B1–B3: Resuscitation after cardiac arrest (B1); hospital admission for management of infection (B2); percutaneous endoscopic gastrostomy for dysphagia (B3) in the case of permanent inability to give consent.

The three raters' interpretation of the wording of the advance directives analyzed with regard to five treatment scenarios. "Implicit" and "explicit" rejection were combined into a single category.

Sample (out of a total of 119 directives analyzed):

**A1–A2:**

98 (13 proxy directives, 8 ratings missing)

**B1:**

115 (4 ratings missing)

**B2–B3:**

116 (3 ratings missing)

**Scenarios A1 and A2:**

Patient temporarily unable to give valid consent: resuscitation after cardiac arrest (A1), hospital admission for management of infection (A2)

**Scenarios B1 to B3:**

Patient permanently unable to give valid consent: resuscitation after cardiac arrest (B1), hospital admission for management of infection (B2), percutaneous endoscopic gastrostomy in dysphagia (B2)

**Nursing staff adherence**

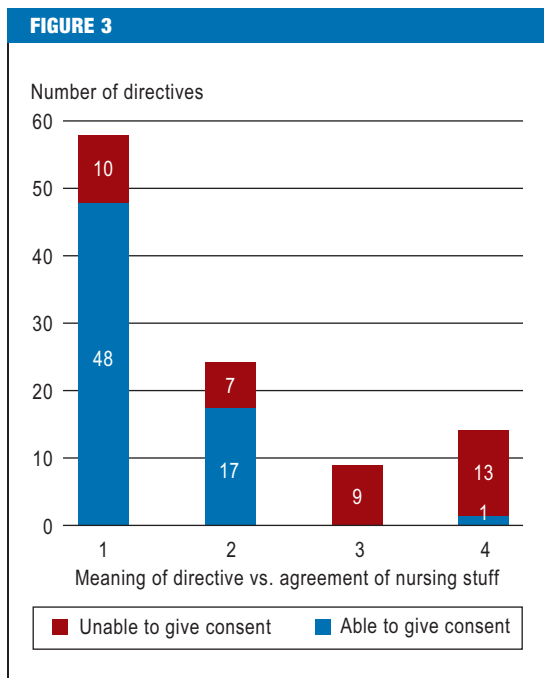
The raters judged that 23 of the 119 advance directives analyzed implied that the nursing home resident did not wish to be resuscitated (categories 3 and 4 in Figure 3). This assessment was unanimous in 14 cases and a majority decision in 9 cases. In 14 (61%) of these 23 cases (including 8 with unanimous agreement) there was no corresponding arrangement on the part of the nursing staff (category 4 in Figure 3); thus, in the event of a cardiac arrest the standard procedure would have had to be followed, i.e., these residents would have had to be resuscitated against their documented will.

**Discussion**

This study was the first in Germany to investigate the prevalence and the quality criteria of advance directives in nursing homes for the elderly, and to our knowledge the first worldwide to examine nursing staff adherence to such directives. In 2007 we succeeded in carrying out a complete survey of all 11 nursing homes in a city in the German federal state of North Rhine–Westphalia, with a total of 1089 residents.

The lively public discussion of the Advance Directives Act since its inception is likely to have somewhat increased the prevalence of such directives. For the reasons described at the beginning of this article, however, the new legislation can hardly be expected to bring about quantitative or qualitative improvement. Our survey offers a methodologically robust platform for investigation of the effect of the legislation passed in 2009 on the dissemination and quality of advance directives.

Almost 9 out of 10 nursing home residents in the city we surveyed had no advance directive. This corresponds



**Nursing staff adherence to advance directives as exemplified by attempted resuscitation in the event of cardiac arrest (n = 105).**

Eleven directives could no longer be attributed to the correct residents owing to errors in pseudonymization, and in three further cases the nursing staff could not evaluate the severity of dementia.

- 1:** Advance directive and nursing staff (congruently):  
No instructions / no arrangement → resuscitation
- 2:** Advance directive: no instructions;  
nursing staff: “do not resuscitate” arrangement
- 3:** Advance directive and nursing staff (congruently):  
Instruction / arrangement: “do not resuscitate”
- 4:** Advance directive: “do not resuscitate”;  
nursing staff: no arrangement → resuscitation

to figures previously reported from surveys in Germany (7) and elsewhere (17). The present study therefore supports the finding that advance directives are completed by only a small proportion of the population—even in nursing homes, where around one third of the residents die each year. The prevalence of such directives varies considerably from home to home, indicating that local factors play a large part.

For 1.4% of the nursing home residents we found so-called proxy advance directives. These have been sporadically described in the USA (14), but not yet in Germany. Proxy directives merit and urgently require closer attention from researchers.

Too little heed has been paid to the validity of advance directives, here understood as a documentation of a medical consultation. Given that the documentation of a process of explanation and comprehension is acknowledged as a basic requirement for informed consent to medical treatments, it seems ethically dubious, not to mention perilous for the patient (albeit legally permissible according to the German Advance Directives Act), to regard advance directives as binding even if they feature no indication that such a process took place. The present survey demonstrates, in agreement with data from the USA (18), that this was the exception in 2007: only 3% of the directives contained documentation of medical advice.

The fact that the validity of many advance directives cannot be assessed makes it difficult for decision-makers to take irreversible actions based on their content. This may contribute to the still widespread professional skepticism with regard to these documents.

Inability to assess the validity of advance directives will continue to have no consequences in practice,

however, until their significance with regard to clinically relevant decisions increases from its hitherto very low level. Thus, the case of a sudden health crisis with acute (new) incapacity to give valid consent remains completely unaddressed in the majority of directives (80% of which are written using established, widely available forms)—as if all nursing home residents were in agreement with receiving the standard acute medical treatment, i.e., all feasible life-prolonging interventions. However, surveys of senior citizens on the subject of treatment limitation (8, 19), as yet unpublished data from a study of our own (20), and findings from emergency medical care (21) indicate that many seniors prefer considerable restriction of life-prolonging treatment.

Regarding permanent incapacity for consent, the three raters varied greatly in their judgment of advance directives with respect to their significance for concrete treatment questions—meaning that many such directives will be of little assistance in deciding on the appropriate treatment if and when the time comes. This unsatisfactory state of affairs is not likely to improve until advance directives are regularly formulated on the basis of discussions with a professional. And besides validity, it is important to modify the forms used for directives so that they contain statements specifying what should be done (or left undone) in practically relevant situations.

As a way of determining how closely the terms of advance directives are observed, we investigated whether nursing home residents’ wishes not to be resuscitated were reflected by corresponding arrangements on the part of the nursing staff. For 14 of the 23 residents whose directives stated that no attempt at

resuscitation should be made if they suffered a cardiac arrest, no such arrangement existed. Therefore it has to be assumed that in the event of a cardiac arrest the standard nursing home procedure would be followed and these residents would be resuscitated against their documented will.

Although the method we used—and the imprecise wording of many directives (in only 8 of the 14 cases were all three raters in agreement)—enables only a first approach to the question of the adherence to advance directives in care facilities for the elderly, it can be stated—confirming the experience of family physicians—that observation of a clearly formulated advance directive by nursing home staff is not the rule. This experience points to far-reaching structural deficits in the handling of advance directives in nursing homes.

**Limitations**

Our study has a number of limitations. For instance, although we succeeded in carrying out a complete survey of all of the nursing homes in the city in question and achieved a participation rate of 88% of the residents with advance directives, variation among the homes was high and the results may not be representative for other German regions. Furthermore, some directives may not have come to light—although one would have to wonder what function advance directives have at all if they can be overlooked when expressly sought by nursing home administrators.

**Conclusion**

This survey carried out in 2007, four decades since advance directives began to be widely propagated (22), paints a disturbing picture of the implementation of

such directives in nursing homes. Since no substantial change in the status quo can be expected following the passage of the German Advance Directives Act in 2009, the question is what needs to be done so that elderly and multimorbid persons, in particular, are regularly given the opportunity to place valid, effective limits on life-prolonging treatment according to their wishes. The following options are being discussed:

- Visits to nursing home residents by physicians (or non-physicians) trained to offer advice on advance directives to interested residents and their relatives (23)
- Regional standardization of the forms used for advance directives and physician orders for life-sustaining treatment (POLST) (24)
- Measures to ensure adherence to advance directives by those at all stages of the care chain (25).

The concept of regional advance care planning programs (26, 27) meets these demands but is not yet widespread in Germany. It should be investigated whether such initiatives can succeed in creating the necessary conditions for significant, valid advance directives and their implementation.

**Acknowledgment**

We are grateful to Prof. Stephan Rixen (University of Bayreuth) for critical perusal of the manuscript and for valuable suggestions.

**Conflict of interest statement**

The authors declare that they have no conflict of interests.

Manuscript received on 30 January 2012, revised version accepted on 22 May 2012.

Translated from the original German by David Roseveare.

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**KEY MESSAGES**

- The prevalence, quality and observation of advance directives in German nursing homes for senior citizens have not yet been empirically studied.
- A complete survey of the 11 nursing homes in one city in 2007 revealed that 12.4% of the residents possessed advance directives, including 1.4% whose directives had been signed not by them personally but by their representatives (proxy directives).
- The validity of the directives, in the sense of documentation of an informed consent process, was mostly not readily clear to third parties, and the significance of the directives was limited; in particular, typical emergency situations involving acute inability to give consent are usually not regulated.
- In 14 of the 23 cases in which the advance directive was interpreted as meaning that resuscitation should not be attempted in the case of cardiac arrest, there was no corresponding arrangement on the part of the nursing staff; we regard this as a sign of structural deficits in the implementation of such directives in nursing homes.
- Little indicates that the Advance Directives Act of 2009 will bring about any substantial lasting improvement in this unsatisfactory state of affairs. However, new impulses could be provided by regional advance care planning programs that take a process- and system-oriented approach.

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