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Advance care planning by proxy in German nursing homes: Descriptive analysis and policy implications

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Abstract

Background: Legally recognized advance directives (ADs) have to be signed by the person to whom the decisions apply. In practice, however, there are also ADs written and signed by legal proxies (surrogates) on behalf of patients who lack decision-making capacity. Given their practical relevance and substantial ethical and legal implications, ADs by proxy (AD-Ps) have received surprisingly little scientific attention so far.

Objectives: To study the form, content, validity, and applicability of AD-Ps among German nursing home residents and develop policy implications.

Methods: Secondary analysis of two independent cross-sectional studies in three German cities, comprising 21 nursing homes and 1528 residents. The identified AD-Ps were analyzed in parallel by three independent raters. Inter-rater agreement was measured using free-marginal multi-rater kappa statistics.

Results: Altogether, 46 AD-Ps were identified and pooled for analysis. On average (range), AD-Ps were 1 (1-7) year(s) old, 0.5 (0.25–4) pages long, signed by 1 (0–5) person, with evidence of legal proxy involvement in 35%, and signed by a physician in 20% of cases. Almost all the AD-Ps reviewed aimed to limit life-sustaining treatment (LST), but had widely varying content and ethical justifications, including references to earlier statements (30%) or actual behavior (11%). The most frequent explicit directives were: do-not-hospitalize (67%), do-not-tube-feed (37%), do-not-attempt-resuscitation (20%), and the general exclusion of any LST (28%). Inter-rater agreement was mostly moderate (kappa ≥0.6) or strong (kappa ≥0.8).

Conclusions: Although AD-Ps are an empirical reality in German nursing homes, formal standards for such directives are lacking and their ethical justification based on substituted judgment or best interest standard often remains unclear. A qualified advance care planning process and corresponding documentation are required in order to safeguard the appropriate use of this important instrument and ensure adherence to ethico-legal standards.

See related editorial by Cohen et al.

KEYWORDS

advance care planning, advance directives, healthcare proxy, nursing homes, surrogate decision-making

INTRODUCTION

Instructional advance directives (ADs) are an ethically and legally widely recognized instrument for safeguarding the patient's right to autonomy by documenting treatment preferences for potential future medical crises with acute or permanent loss of decision-making capacity.[1,2] Similarly, medical decision-making on behalf of incompetent persons by legitimate surrogates, designated previously by the person herself (durable power of attorney) or appointed by a court as legal guardian, is a well-established practice in many countries.[3–5] Surrogates (and healthcare professionals) may want and need to plan ahead for future medical crises arising in incompetent patients they are responsible for: May—or even should—they document the goals of care and treatment refusals in advance on behalf of the incompetent patients, based on the known or presumed preferences of the latter?

Almost 20 years ago, Ladislav Volicer and colleagues argued in a series of articles that what they termed "advance care planning by proxy" is both ethically justifiable (if not an obligation) and an empirical reality, though explicitly regulated in only a few U.S. state laws.[6–10] They suggested 11 "minimum criteria" for advance directives by proxy (AD-Ps), provided a form for "advance proxy planning," and called upon healthcare institutions to "develop their own policies and then evaluate their effect" as a step towards broader institutional or national standards for AD-Ps.[6]

However, our literature search reveals that this call has remained largely unanswered. We realize that such a search is challenging due to the lack of a standard terminology for AD-Ps. Nevertheless, we found very few papers specifically addressing AD-Ps,[11–14] or dealing with the ethical and legal issues related to advance care planning by proxies.[15] Moreover, a search in Pubmed and Scopus reveals that the paper of Volicer et al. has only been cited 10 times in the scientific literature.[11,12,16–22] The ethico-legal literature identified by us, including comprehensive standard works on surrogate decision-making[3] or advance care planning (ACP),[23] does not analyze or discuss the specific issues of AD-Ps.

While the practice of ACP commonly does not explicitly distinguish between planning by persons with full decision-making capacity and planning by the proxies of persons lacking capacity, recent statements and trials on ACP explicitly exclude ACP by proxy.[24–27] Correspondingly, national legislation does not specifically address the issue of ACP by proxy or AD-Ps.[2,28]

Key Points

- Advance directives by proxy (AD-Ps) are a reality in nursing homes and respond to a need for advance care planning for individuals who have lost decision-making capacity.
- The AD-Ps identified in our study are highly variable, often vague or incomplete regarding relevant medical scenarios, and frequently lacking an explicit ethico-legal justification.
- An elaborated framework for AD-Ps should reflect established ethico-legal standards of decision-making and cover relevant clinical scenarios in an unambiguous manner, thus transforming factual reality into professional practice.

Why Does this Paper Matter?

Our study shows that advance directives by proxy (AD-Ps) are practically relevant, but of variable quality. Our recommendations for a standardized approach to medically relevant and ethically justified AD-Ps can contribute to patient-centered care for persons lacking decision-making capacity.

In contrast to the limited scientific research, scholarly discussion and professional reflection, there is ample evidence suggesting that AD-Ps are an empirical reality today. Two German studies conducted in long-term care facilities reported that approximately 10–20% of documents categorized as "advance directives" by staff were in fact signed by surrogates for persons without decisional capacity.[11,12] A large Canadian intervention study reported without further comment that "of 389 proxies of incompetent residents who expressed interest in completing advance directives for their relatives, 305 (78%) did so".[29] The physician orders for life-sustaining treatment ("POLST") form, widely distributed in various versions in the United States,[30] comes close to an AD-P since it is valid for incompetent patients if signed by a physician and (optionally) by the proxy, but not necessarily by the person concerned, who may already have lost decision-making capacity.[31] In a recent study, 25% of POLST forms were signed by surrogates.[32] The same applies to do-not-attempt-resuscitation (DNAR) orders for incompetent persons signed or consented to by physicians and proxies.[31,33,34]

We know from personal ADs that their effectiveness depends on their content, their comprehensiveness, the involvement of facilitating persons, and other contextual factors, in particular the presence of an advance care planning process.[35–37] Similarly, if AD-Ps are intended to be effective in guiding treatment decisions, they need to be thoroughly constructed, use precise wording, and specify their justification related to patient autonomy. Therefore, the objective of our study was to describe the form, content (e.g., expressed preferences), ethical validity, and (un)ambiguity of existing AD-Ps in German nursing homes, and to derive policy recommendations from the findings for an ethically and legally sound and practically effective use of this scholarly neglected, but highly relevant ACP instrument.

METHODS

Definition

In this paper, we define an AD-P as a written document aiming to guide medical care in potential future health crises that is signed by the legal proxy (surrogate decision-maker) because the person concerned lacks sufficient decision-making capacity.

Design and sample

This study identified and analyzed the pooled AD-Ps from two large studies conducted in German long-term care facilities: (1) In a survey carried out among all 11 nursing homes of a large city in Germany, 135 (12.4%) out of 1089 residents were reported to have an AD; for 119 of these residents, written informed consent was obtained in order to analyze their ADs. Of these 119 ADs, 15 (12.6%) were found to be AD-Ps.[11] (2) In the control group (439 residents) of a controlled intervention study on the effects of ACP, staff presented 116 ADs (26.4%) at follow-up, 33 (28.5%) of which were found to be AD-Ps.[12] Of the total of 48 AD-Ps, 46 were accessible and pooled for an in-depth analysis.

Analysis criteria

To describe the form, ethical justification and content of the documents, we used criteria derived from analogous analyses of ADs,[11] studies evaluating what is best to cover in ACP with individuals and their families,[38] and the 11 criteria suggested by Volicer et al., which are based on a focus group study.[6] The criteria used for analyses are described in detail below.

Form

To analyze the formal aspects of the documents, we retrieved the date, length, use of pre-existing forms, number of signees and their relation to the nursing home resident, involvement of health or legal professionals, and any formal evidence of an informed consent process.

Ethical validity

In Germany and other Western countries, legal proxies are expected to make treatment decisions for an incompetent person according to the substituted judgment standard or—if the patient's preferences are unknown—according to the best interest standard.[39] Substituted judgment can rely on current verbal statements or behavioral signs of the incompetent person, pre-existing advance directives, prior oral statements, and the person's attitudes and values. For the best interest standard, the surrogate must evaluate the person's current and future well-being, taking into account the person's suffering and functional impairment. We therefore analyzed whether the AD-Ps contained references to any of these criteria in order to justify the documented decisions.

Content: advance decisions

In order to assess the treatment preferences expressed in the AD-Ps, we looked for positive statements requesting (and consenting to) a certain type of care and negative statements refusing a certain type of care. Within the latter, we distinguished between refusals of care pertaining to the residents' current health status and refusals of care referring to a potential, deteriorated health status in the future. Furthermore, we distinguished between statements about life-sustaining treatment in general and statements about specific interventions: cardio-pulmonary resuscitation (CPR), ventilation, tube feeding, hospitalization, and others.

Inter-rater reliability as an indication of (un)ambiguity

To assess the applicability of the documents, we rated them according to three questions: Are they unclear? Are they medically unsound? Are they contradictory? The three raters (JidS, GM, RJJ) independently rated all documents for these three categories. In addition, the raters judged whether the documents included, clearly or vaguely, any of seven statements (1. global refusal of any

LST, 2. do not resuscitate, 3. do not ventilate, 4. do not hospitalize, 5. do not tube-feed, 6. any other specific refusals, 7. request for palliative care), differentiated for a. the currently given (i.e., at the time of signing the AD-P) or b. a potential future health status. Afterwards, inter-rater agreement was analyzed using free-marginal multi-rater kappa statistics,[40,41] as raters were not forced to allocate a fixed proportion to any category.[42] Values ≥0.60 indicate adequate levels of concordance. Analyses were performed with the software developed by Randolph.[43] Subsequently, the three raters discussed all diverging ratings, re-evaluated them, and then decided upon the items together—where necessary by a 2:1 majority.

RESULTS

Table 1 summarizes the basic demographic data of the residents to whom the documents applied as well as important characteristics of the AD-P documents.

AD-Ps varied considerably regarding their formal structure. Most of them were rather short (median 0.5 pages long, range 0.25–4) and used free wording, either as a separate document (61%) or a chart entry (24%). Just 6 out of 46 documents (13%) used either a general AD form (2) or a specific AD-P form (4). Only 35% provided evidence that they were signed by the legal proxy, in half of these cases by the residents' children (52%). An informed consent planning process was explicitly documented in only 2 cases (4%); 20% of the documents were signed by a physician, which may indicate that the AD-P was based on a physician-proxy conversation.

In contrast to conventional ADs, which are signed by the future patient herself, AD-Ps ought to indicate how the documented treatment preferences have been established with reference to the substituted judgment or best interest standard. Here we present the analysis of these elements of the ethico-legal justification which could be found in the documents (Table 2). While one-third of the AD-Ps provided no ethical justification at all, the remaining two-thirds did so in a highly variable and rather unsystematic manner. The justifications referred to:

- earlier oral statements (30%),
- the resident's current behavior (11%),
- presumed wishes (9%) or to
- the best interest standard, e.g., the resident's functional impairment (17%) or current suffering (15%), as judged by the signee.

Consequently, the documented advance decisions have a variable and often weak foundation in the values of patient autonomy or patient well-being.

TABLE 1 Basic characteristics of residents and AD-P documents ($n = 46$)

Demographic data of the residents	
Median age in years (mean; SD; range)	86 (84; 10.6; 50–101)[a]
Female gender, *n* (%)	35 (76)
Median years since signature (mean; SD; range)	1 (1.7; 1.5; 0–7)
Median number of pages (mean; SD; range)	0.5 (0.66; 0.67; 0.25–4.0)
Signatures	
Median number of signees (range)	1 (0–5)
Number of documents without a signature, *n* (%)	4 (9)
Number of documents signed by an adult child of the resident, *n* (%)	24 (52)
Number of documents with (some) evidence that the signee is the legal proxy, *n* (%)	16 (35)
Evidence of informed consent	
Attestation by the physician's signature	9 (20%)
Informed consent process explicitly documented	2 (4%)
Format	
Own words, *n* (%)	28 (61)
Pre-set phrases compiled, *n* (%)	1 (2)
Free text in chart entry, *n* (%)	11 (24)
Specific AD-P form (2 types), *n* (%)	4 (9)
AD form, *n* (%)	2 (4)

Abbreviation: SD = standard deviation.

[a] For age, there was 1 missing, i.e., $n = 45$.

The core of the AD-Ps consists of the documented advance decisions (cf. Figure 1). In general, the analysis showed that AD-Ps are formally analogous to conventional ADs: Certain types of medical interventions are usually refused or, occasionally, consented to or requested. Almost all AD-Ps aimed at limiting life-sustaining treatment (LST); the specific advance decisions, however, varied considerably and usually covered just a subset of relevant LST. The interventions most frequently covered were: do-not-hospitalize (67%), do-not-tube-feed (37%), do-not-attempt-resuscitation (20%), and the global exclusion of any LST (28%). Most of the advance decisions applied to the resident's current health status while only a minority referred to a potential future deteriorated health status of the resident specified in the

TABLE 2 Elements of ethico-legal justification found in the AD-Ps ($n = 46$)

Type of justification	*n (%)*[a]	kappa[b]
Any attempt of ethical justification (at least one of the following)	29 (63)	0.841
Justification by substituted judgment (of resident's preferences)		
Reference to current verbal statements	4 (9)	0.884
Reference to non-verbal (behavioral) indications for resident's wishes	5 (11)	0.885
Reference to a pre-existing advance directive	0 (0)	0.942
Reference to relevant earlier oral statements	14 (30)	0.681
Reference to presumed wishes of the resident	4 (9)	0.623
Reference to attitudes or values of the resident	1 (2)	0.884
Justification based on the resident's best interest		
Reference to current suffering of the resident as judged by the signee	7 (15)	0.797
Reference to the resident's functional impairment as judged by signee	8 (17)	0.739
Reference to poor prognosis as judged by the signee	3 (7)	0.797

Note: multiple answers possible.

[a] Numbers reflect the consensus reached between the three raters.

[b] Mean overall free-marginal multi-rater kappa for all types of justification; measure for inter-rater agreement; kappa ≥0.6 indicates moderate agreement, kappa ≥0.8 indicates strong to perfect agreement.

AD-P. Inter-rater agreement before consensus was moderate (≥ 0.6) or strong (≥ 0.8) for the identification of most of these interventions (cf. Figure 1).

As the individual AD-Ps often comprised several advance decisions, we strived to rate the applicability of these decisions by identifying those documents whose content was unclear, contradictory, or medically unsound (cf. caption to Table 3 for the definitions we used). The three independent raters agreed rather strongly on which documents were contradictory (kappa = 0.79) or medically unsound (kappa = 0.70), but only very little on which were unclear (kappa = 0.10) (data not shown). After inter-rater discussion yielded consensus, 4 AD-Ps (9%) were classified as contradictory, 3 (7%) as medically unsound and 21 (25%) as unclear. Mean overall kappa was 0.82 for all advance decisions referring to the current health status, and 0.74 for those referring to a potential future health status.

Table 3 illustrates the three categories (unsound, unclear, contradictory) with selected quotes from the AD-Ps; for a collection of all pertinent quotes with comments by the authors, see Table S1.

DISCUSSION

This study is one of the few that specifically address the issue of ACP by proxy, and in particular the anticipatory written documents which we call AD-Ps. The secondary analysis of all ADs derived from a large sample of nursing home residents in Germany revealed that 20% of these documents were in fact AD-Ps. The population of residents to which these AD-Ps applied exhibited gender and sex characteristics typical for nursing home residents and similar to all participants in the two underlying studies.[11,12]

One of the most striking features of the AD-Ps, both with respect to form and content, was their diversity. The documents ranged from short one-sentence notes in nursing charts to separate 4-page documents, most of them using free wording and only a few employing preworded advance directives or even specific AD-P forms. The same diversity applies to the number of signees, the kinds of decisions made, and the extent to which ethico-legal justifications were explicitly documented.

This huge diversity reflects the fact that there are to date no national or international guidelines on AD-Ps, no explicit legal or professional norms in Germany (or most other countries) and not even a professional debate on AD-Ps in the literature or at conferences. Many empirical studies report on “ADs,” clearly referring to both ADs and AD-Ps without explicitly differentiating between the two.

One of the particular ethical requirements for AD-Ps—in contrast to regular ADs completed by the person him- or herself—is the fact that AD-Ps need to specify the justification of the anticipatory decisions based on the substituted judgment or best interest standard. As the person concerned has lost decision-making capacity and cannot validate the content by her signature, it is not self-evident that the documented decisions really represent that person's true treatment preferences.[15] It is all the more troubling that more than one-third of the AD-Ps in our study lacked any explicit reference to this justification. But even when it was present, our analysis revealed a wide variety of cited justifications, ranging from earlier oral statements of the person, his/her values and attitudes or his/her current non-verbal behavior to best interest considerations focusing on perceived suffering and functional impairment of the person as well as on a poor prognosis.

Most AD-Ps in our sample refer to the resident's current health status and provide orientation as to what should—or should not—be done in an acute medical crisis of the

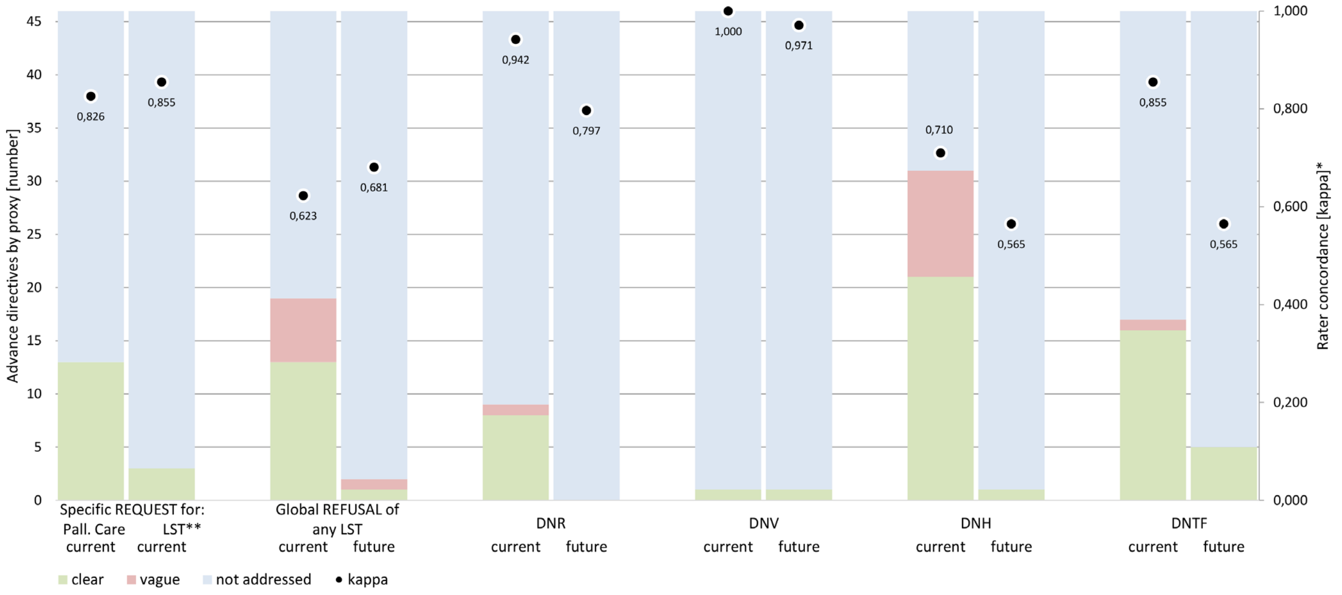

FIGURE 1 Advance decisions documented in the AD-Ps referring to the currently given and/or a possible future health status ($N = 46$) * Free-marginal multirater kappa between three raters before consensus discussion (inter-rater agreement ≥0.60 moderate, ≥0.80 strong to perfect agreement). ** In three cases, specific forms of LST were requested: (1) "In case of circulatory or respiratory problems the emergency medical team should be called." (2) "The resident should be hydrated (e.g., fluids s.c.) in periods of somnolence when he or she is not able to eat and drink." (3) "Do provide subcutaneous fluid if oral intake is less than 1000 ml/d". "Current" refers to the currently given, "future" to a possible future health status. A request/refusal was judged "clear" if it was explicitly or otherwise unequivocally stating the preference; "vague" refers to implicit or otherwise undefined statements like "no heroic / distressing / unnatural measures". Abbreviations: DNR, do-not-resuscitate; DNV, do-not-ventilate; DNH, do-not-hospitalize; DNTF, do-not-tube-feed; LST, life-sustaining treatment; Pall. Care, palliative care

resident. In acute health crises, the need for an AD-P is certainly highest because the surrogate decision-maker may not be available to inform the care team rapidly enough about the patient's (presumed) treatment preferences. In such crises, moreover, medical and nursing staff usually cannot determine whether emergency treatment including CPR is medically futile or not. Two-thirds of the AD-Ps in our study expressed a refusal of hospitalization; others included refusals of artificial nutrition, CPR or any life-sustaining interventions. These anticipatory decisions are similar to those covered by physician orders for life-sustaining treatment (POLST).[31] However, most AD-Ps in our study did not use standardized forms. Rather, we found vague and incomplete treatment directives, often lacking a clear statement of the intended treatment goal. For example, if a refusal of hospitalization is documented, CPR should also be excluded because successful CPR usually requires subsequent intensive care treatment in the hospital. As a result, there remains considerable ambiguity in the application of the AD-Ps, resulting in uncertainty among healthcare professionals—and potential disregard of patients' (presumed) treatment preferences. Similar conceptual and application problems are also known for ADs,[11] although these tend to be more standardized in Germany due to the limited number of widely used, similarly worded AD forms.[44] The varying quality of ADs is indeed a major argument for a comprehensive, standardized, high-quality approach to ACP that includes uniform documentation.[11]

While the need for AD-Ps is most obvious for acute medical crises, it also seems advisable to plan ahead for non-emergency medical decisions like artificial nutrition in the case of a deteriorating patient with dysphagia. There are good reasons for such advance care planning by proxy even though proxies may likely be available to make these decisions in real-time: First, it can be helpful to elicit and document the resident's relevant prior oral statements or attitudes regarding future medical treatment while it is still possible to do so. In addition, surrogate decision-making will be more reliable if the proxy is supported by a process of professionally facilitated ACP ("professionally facilitated" referring to an ACP facilitator specifically trained for this role who is either a member of the treatment team or an external facilitator specialist), and is not caught in an emotionally burdensome acute care situation. Last but not least, proxies may not be available for a longer time due to a vacation or serious illness. In our sample, however, treatment directives for future (deteriorated) health states or non-acute medical decisions were documented only in a small portion of the AD-Ps.

TABLE 3 Selected examples of unclear, unsound, or contradictory Advance Directives by Proxy (AD-Ps) (A comprehensive list of examples, together with comments by the authors, can be found in Table S1)

ID	Quotations from AD-Ps
R16	“Life-prolonging interventions may only be initiated and my father may only be transferred to hospital after consultation with my father's GP and with myself.” [a]
S11	“This do-not-hospitalize order is, of course, invalid in case there is a life-threatening [!] situation, i.e. if she suffered pain, could not eat any more, or suffered a trauma that necessitated a hospital stay. “[a,b]
R14	“I forgo [!] the performance of resuscitative interventions and operations that would prolong her suffering . “[b]
R32	“... transfer to hospital only if the situation is life-threatening “[a]
R24	“Transfer to hospital should be avoided with respect to the patient and her progressive disease. ... Only in case of problems that cannot be mastered in the ambulatory setting, a transfer to hospital may be considered. “[b]
R12	“In consultation with [relatives], further life-prolonging interventions have been [!] forgone, including a feeding tube insertion via PEG. Alternatively, fluids are substituted subcutaneously. Please be cautious with hospital referrals.” [a,c]
R29	“It has been decided that a transfer to hospital related to our mother's health is refused. However, in case of an emergency [!] we agree with the decision of the attending physician. “[c]

Note: Translated from German into English by the authors. Added notes in brackets [] point to or comment on the critical quote. ID: internal study identification.

[a] “Unsound” was defined as: “The AD-P contains assumptions, conditions, scenarios or directives that are medically unsound.”

[b] “Unclear” was defined as: “The AD-P contains assumptions, conditions, scenarios or directives that remain unclear (=in need of interpretation) in relevant details.”

[c] “Contradictory” was defined as: “The AD-P contains assumptions, conditions, scenarios or directives that contradict each other (logically).”

Limitations

We performed a secondary analysis of the documents of two regional studies, which therefore limits the generalizability of the results to other regions of Germany or to other countries. Furthermore, we tried to assess the validity of the documents; however, we were limited to surrogate parameters for an underlying informed consent or refusal process, such as the physician's or the surrogate's signature, because a more detailed account of the (potential) conversation underlying the AD-Ps was not documented.

CONCLUSIONS AND POLICY IMPLICATIONS

The results of our study show that AD-Ps are a reality in German nursing homes and respond to a need for advance care planning on behalf of individuals who have lost decision-making capacity. Our study also demonstrates, however, that the identified AD-Ps are highly variable, often vague or incomplete regarding relevant medical scenarios, and lacking explicit ethico-legal justification, which renders their validity questionable. At the same time, our results confirm that AD-Ps can be an important, even necessary tool for implementing patient self-determination and delivering patient-centered care. Even if an AD has been completed, however, an additional AD-P can be a helpful complementary tool if the existing AD is vague or incomplete (especially for emergency situations), or if an existing AD mandates to forgo certain (or all) life-sustaining treatments in a chronic state of irreversible decisional incapacity, e.g. severe dementia, that at the time when the AD was signed constituted a possible (hypothetical) future scenario, but that has now indeed become the current situation. Furthermore, AD-Ps can promote trust and reduce the burden on patients, proxies, families, and care teams.[6] ACP with the patient's proxy therefore seems ethically and legally justified and clinically favorable.

There are several significant differences between conventional ADs and AD-Ps which have to be taken into account in the concept and implementation of proxy ACP (Table S2). In AD-Ps, patient autonomy is re-constructed rather than actually constructed or co-constructed in a joint conversation with the patient. The surrogate and not the patient is the legally responsible person in an AD-P. In Germany, as in other countries, there is no explicit legal foundation for these documents. However, authoritative legal assessments conclude that the surrogate is entitled or even obliged to document the incompetent patient's treatment preferences in advance so that they can be reliably respected in future health crises, especially when the surrogate then is unavailable to decide on behalf of the patient in acute situations including emergencies.[45] Therefore, if AD-Ps are based on an appropriate substituted judgment or best interest assessment, they should in fact be considered an ethically and legally valid form of an advance treatment request or refusal.

Given the practical need, the ethico-legal justification and the limitations of current AD-P practice, a conceptual framework for AD-Ps should be developed that complies with ethico-legal standards for medical decision-making and covers relevant clinical scenarios in a precise and unambiguous manner. The experience gained with the widely established Physician Orders for Life-

Sustaining Treatment (POLST) indicates to some extent that such concise advance care planning (ACP) is feasible.[46] In a recent study, however, 24% of POLSTs contained at least one pair of incoherent orders which may limit their effectiveness in many acute care scenarios.[47] Furthermore, even with correctly completed POLSTs, the care delivered may still turn out to be discordant with the POLSTs—in a current study to up to 38%.[32,48] This indicates that any documentation of advance decisions via POLSTs or other formats (and regardless of whether used for personal ADs or AD-Ps) needs to be embedded in a more comprehensive ACP framework. Professional facilitation of ACP discussions will likely increase the coherence and validity of the documented preferences,[24] and the system-wide implementation of ACP standards can promote care consistent with the documented care preferences.[49] While it is beyond the scope of this paper to develop a comprehensive AD-P framework, we would like to suggest some of its basic elements building on our empirical data, our own experience with ACP in nursing homes,[12] and prior work[6,50] (cf. Table 4).

TABLE 4 Core elements of a conceptual framework for advance care planning (ACP) by proxy

1. ACP by proxy should be considered for all individuals who have lost decision- making capacity, including those who have already issued an AD.
2. If there is an existing personal AD, in principle ACP by proxy and the resulting AD-Ps have to be consistent with the former AD. The AD-Ps may specify, complement or implement the advance decisions documented in the AD, but may not contradict or revoke it unless on the grounds of specific, more recently stated wishes of the individual concerned.
3. The proxy should be supported by a qualified facilitator in the advance planning process, as has become the standard for comprehensive ACP programs,[24,25] in order to promote the quality of the resulting advance directive by proxy (AD-P). Members of the care team, including nurses and the treating physician, should be involved in the ACP conversation.
4. Standardized forms should be developed for the AD-Ps. These forms can help structure the proxy ACP conversation and facilitate precise documentation of the elicited advance care plan.
5. The AD-P should contain an explicit statement about the source of the documented advance treatment decisions, e.g. references to the patient's previously expressed values and treatment preferences, earlier or current oral statements and non-verbal behavior, or assessment of the patient's well-being.
6. The AD-P should clearly state the current treatment goal as the basis for future emergency care decisions. In addition, it should cover advance decisions on CPR, mechanical ventilation, intensive care treatment, hospitalization and life-sustaining treatment in the outpatient setting, ideally documented on a concise physician order for life-sustaining (emergency) care.
7. It seems advisable to also consider decisions in acute medical crises in case of potential future health states (e.g. after defined disease progression), and for non-acute medical decisions (like artificial nutrition and hydration) during the planning process. Such preparation can facilitate patient-centered treatment decisions on behalf of the patient in psychologically burdensome situations.
8. The AD-Ps should be signed by the proxy, the responsible physician and – if applicable – the qualified professional who has facilitated the ACP process.
9. The AD-Ps should be re-evaluated and updated regularly, especially if the patient's health status changes.
10. Even if a valid AD-P has been completed, the proxy must be involved in the current medical care decision-making whenever possible. The AD-P must not be a substitute for the ongoing communication between the patient (if possible), the surrogate (and family), and the care team[6]

In conclusion, ACP by proxy has the potential to fill an important gap in realizing patient-centered care for patients who have lost decision-making capacity. It thereby can help surrogate decision-makers comply with their ethical and legal obligations. Scholarly debate in medical law and ethics should explicitly recognize the legitimacy of AD-Ps, and contribute to more elaborated concepts of ACP by proxy, thus transforming factual reality into professional practice.

FINANCIAL DISCLOSURE

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

All authors meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Jürgen in der Schmitten, Ralf J. Jox, Georg Marckmann: conception and design of the study. All authors: analysis of data; Jürgen in der Schmitten, Ralf J. Jox, Georg Marckmann: interpretation of data. All authors: preparation of the manuscript and final approval of the version to be published.

SPONSOR'S ROLE

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

Table S1 All cases of unclear, unsound, or contradictory advance directives by proxy (AD-P), with comments by the authors
Table S2: Comparison of personal advance directives and advance directives by proxy.

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