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Original Study

Advance (Meta-) Directives for Patients with Dementia who Appear Content: Learning from a Nationwide Survey

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A B S T R A C T

Objectives: Whether health care professionals should respect a properly executed advance directive (AD) refusing life support in late-stage dementia even if the patient seems contented, is an ethically contested issue. We undertook a nationwide survey to assess this problem and to test a practical solution.
Design: Nationwide survey using a questionnaire among 4 stakeholder groups.
Setting: Germany.
Participants: Adult Germans (n = 735), among them: dementia-experienced physicians (n = 161), dementia-experienced nurses (n = 191), next of kin (n = 197), and dementia-inexperienced adults (n = 186).
Measurements: Participants were asked about their attitudes on medical decision-making in a vignette case of treatable pneumonia, for their agreement or disagreement on standard ethical arguments in this debate, and for their views on modified versions of the case. One such modification was an explicit anticipation of the conflict in question by the patients themselves.
Results: Of our 735 eligible respondents, 25% were unwilling to follow the patient's AD. Standard arguments for and against respecting the directive were endorsed to different degrees. Respondents' unwillingness to follow the directive was significantly decreased (to 16.3%, $P < .001$), if the advance refusal of pneumonia treatment explicitly indicated that it applied to a patient who appears content in his demented state. Only 8.7% of respondents would disregard an advance refusal of tube feeding.
Conclusions: Persons executing ADs forbidding life support in late-stage dementia run some risk that these will not be followed if they later appear "happy" in their dementia. It seems ethically and practically advisable to incorporate an explicit meta-directive for this conflict.

Advance directives (ADs) for medical treatment have become widely accepted in many Western societies and have been placed on a statutory basis (eg, United States since the 1990s; United Kingdom in 2007; and Germany in 2009). Legally and ethically, ADs are widely regarded as a tool to execute "precedent autonomy" concerning medical treatment decisions in situations of lost decision-making competency.[1] Mostly refusing life-prolonging interventions, such directives are increasingly used and their likelihood to be followed seems to have grown substantially over time, provided they clearly apply to the circumstances.

Controversial, however, is the specific situation where a still-competent person has executed an advance treatment refusal for the case of her own later end-stage dementia (eg, not to treat an intercurrent pneumonia with antibiotics), and where the later patient, though mentally severely incapacitated, appears "happy" in his demented state. This "past-directive-vs-present-interest" (PDPI) conflict has for years provoked heated expert controversy, mainly on ethical grounds.[1–7] Should the directive take precedence over the "happy" demented patient's current interests, or vice versa?

Given the practical importance of stakeholders' attitudes toward the PDPI conflict, we were interested in their relevant views and whether they agreed or disagreed with standard arguments on both sides of the debate. Finally, we were interested in the potential success of a pragmatic solution, namely to have patients themselves anticipate the PDPI

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conflict in their ADs.[8,9] To the best of our knowledge, this is the first empirical study about how stakeholders view the PDPI conflict.

Methods

Recruitment of Participants

We conducted a survey using a questionnaire (online or in print) among 4 stakeholder groups (dementia-experienced physicians, dementia-experienced nurses, next of kin, and dementia-inexperienced adults, excluding patients with dementia because of ethical reasons). The survey was conducted in Germany from late 2010 to fall 2012. Respondents were recruited via dementia networks, a systematic request of 190 relevant hospitals across Germany, waiting rooms of a blood donation institution, and several outpatient clinics of the University Hospital in Muenster (primarily for the dementia-inexperienced). We contacted each hospital and regional office of the dementia network and sent several print questionnaires, including the URL of the alternative online version. For the waiting rooms, print questionnaires were placed beside a drop-off box. Altogether, we delivered approximately 1650 questionnaires (sent about 950 to hospitals, 170 to dementia networks, dropped 420 at the waiting rooms of the University, delivered 112 at a congress of the German Alzheimer's Association in late 2010). In order to assure participant anonymity, completed questionnaires were not attributed to specific origin. Because of this method of distribution, the response rate was approximated to be at about 40%.

We included only questionnaires with complete data (drop-out number: 155 respondents), with the notable exception of about 140 respondents who, in the case vignette, did not formally check whether to treat or not but expressed a nonambiguous, hence, "deducible" position by their subsequent votes. We, thus, included 735 participants.

Design of the Questionnaire

Respondents had to indicate which of the 4 groups they belonged to as well as their experience with dementia. After some preliminary questions on the desired and experienced authority of ADs in general (using a 4- or 5-item Likert scale), the questionnaire presented the hypothetical case of Mr Meyer:

> Mr Meyer, 78 years old, suffers from late-stage Alzheimer's dementia. Otherwise, he has so far been of good health. Living in a dementia-specialized nursing home, he has meanwhile developed severe language deficits and disorientation, regularly not recognizing his next of kin anymore. Nevertheless, he often appears content. For example, he likes playing with modeling clay or a dog. When the disease was diagnosed about 4 years ago, Mr Meyer, after detailed information and discussions with his close family doctor, executed an AD that he had twice reaffirmed before getting too incapacitated 2 years ago.
>
> In this document the patient requested:
>
> "Should I, in the course of my Alzheimer's dementia, lose my competency and my capability to reliably recognize my family, I do not wish to be kept alive by medical interventions. Acting otherwise would violate my views of an end of life in dignity. In particular, I do not wish to be treated by CPR, with ventilators, artificial feeding (IV or tube), or antibiotics in case of life threatening infections (eg, pneumonia)."
>
> Mr Meyer does get life-threatening pneumonia that could, however, be treated with antibiotics, involving minimal risks and burden to the patient.

First, respondents were asked whether Mr Meyer should be treated with antibiotics or not, thereby following his AD. In addition, we inquired about participants' approval or disapproval to what we take to be the 4 standard arguments in the PDPI debate. We presented these arguments in short formulas and offered them (positively or negatively phrased) as potential justifications for the very treatment decision each respondent had come to make in the Meyer case. Participants were asked to use a 4-item Likert scale ranging from "fully agree" to "fully disagree."

Next, we asked for respondents' treatment decision (yes/no) on 3 variations of the original Meyer case (M1). In variation M2, the patient with late-stage dementia does not appear content, but rather anxious and depressed. In variation M3, the patient appears content (as in the M1 case), but his AD contains an explicit anticipation of the potential conflict and a clear nontreatment directive for this special case. In variation M4, the patient appears content, but the decision that has to be made is whether or not to use tube feeding by percutaneous endoscopic gastrostomy (PEG), which Meyer had also ruled out in his AD.

Finally, respondents were asked for sociodemographic characteristics (age, gender, level of education) and whether they themselves possessed an AD.

Data Analysis

Statistical analysis was performed using IBM SPSS Statistics 22 for Windows (IBM Corporation, Somers, NY). Beyond descriptive statistical analyses, differences between the 4 groups in their responses to certain questions were investigated using Fisher's exact test. Intra-individual differences in evaluation of the original M1 case and its variations were investigated using the McNemar test. The association of responses with age was investigated using Student's *t*-test. The correlation of responses with gender and education was investigated using Fisher's exact test. *P* values were regarded exploratory, not confirmatory. No adjustment for multiple testing was performed. An overall significance level was not determined and cannot be calculated. In order to exclude chance findings in inferential statistical analyses, results were considered significant if both the *P* value was $\leq .05$ and the corresponding effect were sufficiently meaningful and relevant.

Results

We received 735 eligible questionnaires (63% female; median age 44 years; educational range from secondary education to PhD). Sizes of subgroups were comparable (161 physicians, 191 nurses, 197 next of kin, 186 dementia-inexperienced adults). Gender and age are detailed in Table 1.

For none of the elicited answers presented in the following did we find any significant and relevant difference associated with stakeholder group, age, gender, or education, with the exception of case variation M4 (see below).

Participant Attitudes on ADs and on Decision-Making in the Case Vignette

Asked whether ADs should in general be binding for the medical staff, 98.7% of the 735 participants answered in the affirmative (fully agree: 77.6%; rather agree: 21.1%); 97.6% judged ADs as helpful in general (fully agree: 66.0%; rather agree: 31.6 %); and 25.4% of respondents indicated to have authored an AD by themselves.

Regarding the Meyer case vignette, 74.8% of all respondents favored (and 25.2% opposed) following the AD (Figure 1).