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› Advance (Meta-)Directives for Contented Dementia Patients?

Learning from a German Nationwide Survey

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Abstract

Background

Whether health care professionals should respect an advance directive (AD) refusing life support in late-stage dementia even if the patient seems contented, is an ethically contested issue. We conducted a nationwide study to assess this problem and to test a practical solution.

Methods

In a survey among Germans belonging to four stakeholder groups, participants were asked about their attitudes on medical decision-making in vignette cases of treatable pneumonia and for their agreement on standard ethical arguments.

Results

25 % of the respondents were unwilling to follow the AD. Respondents' unwillingness was significantly decreased (to 16.3 %), if the advance refusal explicitly indicated that it applied to the situation of contented dementia.

Conclusion

Persons executing ADs forbidding life support in late-stage dementia run some risk that these will not be followed if they later appear 'happy'. It seems ethically and practically advisable to incorporate an explicit meta-directive for this conflict.

Keywords

Advance directive; Advance care planning; Treatment refusal; Dementia; Alzheimer's disease; Precedent autonomy; Geriatrics; Pneumonia; Antibiotics; Tube feeding

1 Introduction

Advance directives (ADs) for medical treatment have become widely accepted in many Western societies and have been placed on a statutory basis (e. g. US since the 1990s; UK in 2007; 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 (Dworkin 1993). Mostly refusing life-prolonging interventions, such directives are increasingly used (up to 10% in the elderly) and their likelihood to be followed seems to have grown substantially over time, if only they clearly apply to the circumstances (University of Zurich 2014).

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 (e. g. 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-versus-present-interest conflict’ (PDPI conflict) has for years provoked heated expert controversy, mainly on ethical grounds (Dworkin 1993, Dresser 1995, Jaworska 1999, Quante 1999, McMahan 2002, Davis 2002, Sumner 2011): Should the directive take precedence over the ‘happy’ demented patient’s current interests, or vice versa?

Given the practical importance of stakeholders’ attitudes towards 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 conflict in their ADs (German National Ethics Council 2005, Lemmens 2012). To the best of our knowledge, this is the first empirical study about how stakeholders view the PDPI conflict (Lemmens 2012).

2 Methods

2.1 Recruitment of participants

We conducted a survey using a questionnaire - online or in print - among the four above mentioned groups (leaving out dementia patients for ethical reasons). It 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 outpatients’ departments 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 besides 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 subjects’ anonymity, completed questionnaires were not attributed to specific origin. Response rates could not be assessed, since we could not control approach rates.

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 missed formally checking whether to treat or not, but expressed a fully non-ambiguous, hence deducible position by their subsequent votes. We thus included 735 participants.

2.2 Design of the questionnaire

Respondents had to indicate which of the four 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 four- or five-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 recognising his next of kin anymore. Nevertheless, he often appears contented. For example, he likes playing with modeling clay or a dog. When the disease was diagnosed about four years ago, Mr Meyer, after detailed information and discussions with his close GP, executed an AD that he had twice reaffirmed before getting too incapacitated two 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 recognise 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,
- ventilators,
- artificial feeding (IV or tube),
- antibiotics in case of life threatening infections (e.g. pneumonia).”

Now 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 four 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 four-item Likert scale ranging from ‘fully agree’ to ‘full-disagree’.

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

Finally, respondents were asked for socio-demographic characteristics (age, gender, level of education) and for possession of an own AD.

2.3 Data Analysis

Statistical analysis was performed using IBM SPSS Statistics 22 for Windows. Beyond descriptive statistical analyses, differences between the four groups in their responses to certain questions were investigated using Fisher's exact test. Intra-individual differences in evaluation of the original Meyer-1 case and its variations were investigated using McNemar's 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 noticeable only if both the p-value $p \leq 0.05$ and additionally the corresponding effect were sufficiently meaningful and relevant.

3 Results

We received eligible 735 questionnaires (63 % female; age range 17 to 89 with a median of 44 years; educational range from high school to PhD; stakeholder groups: 161 physicians, 191 nurses, 197 next of kin, 186 dementia-inexperienced adults).

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).

3.1 Participants' attitudes on advance directives 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%). 25.4% of respondents indicated to have authored an AD by themselves. Regarding the Meyer case vignette 74.8% of all respondents favoured (and 25.2% opposed) following the AD (see Fig. 1).

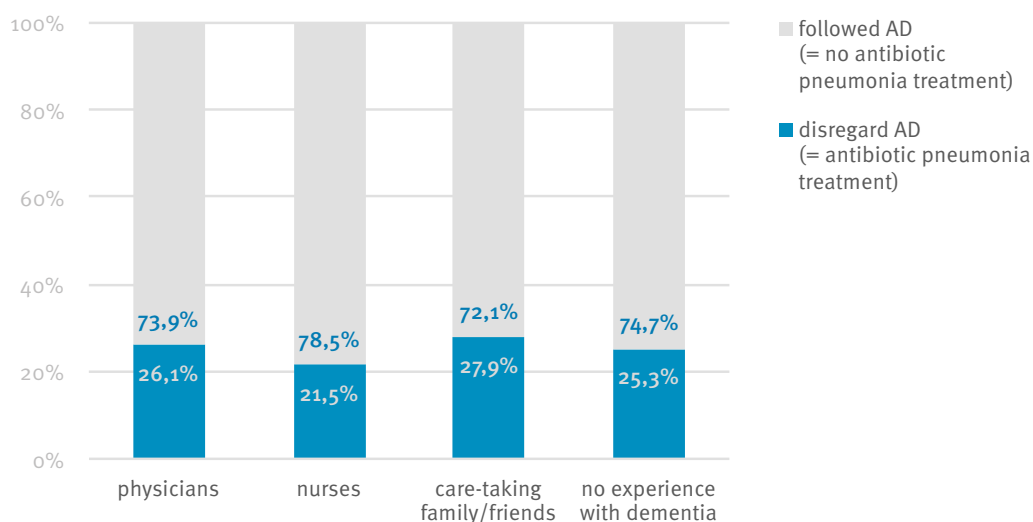


Fig. 1: Treatment decisions in the Meyer-1 case (M1).

3.2 Participants' agreement on standard ethical arguments

Next, we asked the participants whether they approved or disapproved of what we take to be the four standard arguments A1–A4 in the PDPI debate.

A vast majority of AD-followers agreed with each of the four offered arguments (*Fig. 2*). 96.4% affirmed (A1) that personal identity is preserved between early and late Mr Meyer ('fully agree': 78.9%; 'rather agree': 17.5%). 95.8% agreed with (A2) that the difficulties in anticipating how it would feel to be severely demented should be shouldered by the patient himself ('fully agree': 66%; 'rather agree': 29.8%). 82.7% held (A3) that the experience of

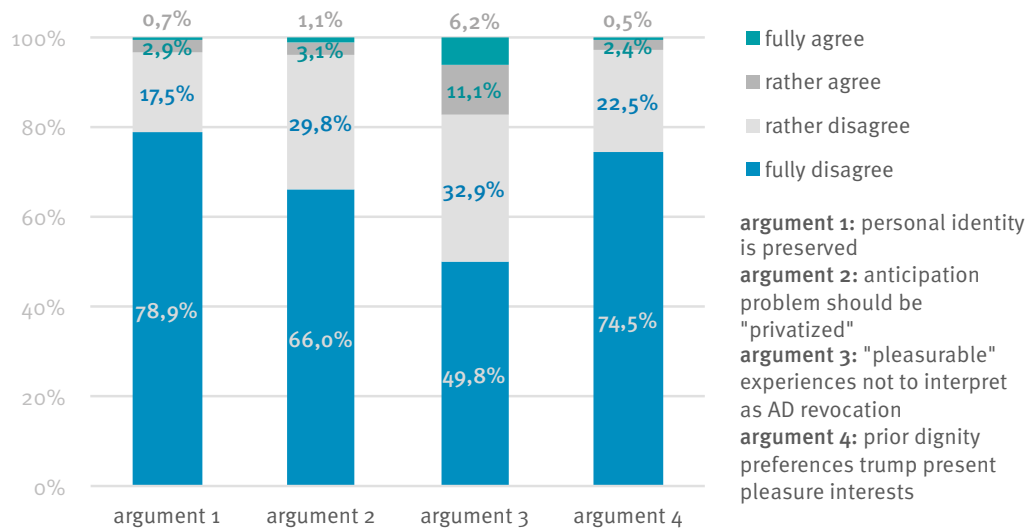


Fig. 2: Degree of approval of the four standard arguments for following the AD in the M1 case (mean of all respondents who opted to follow the AD).

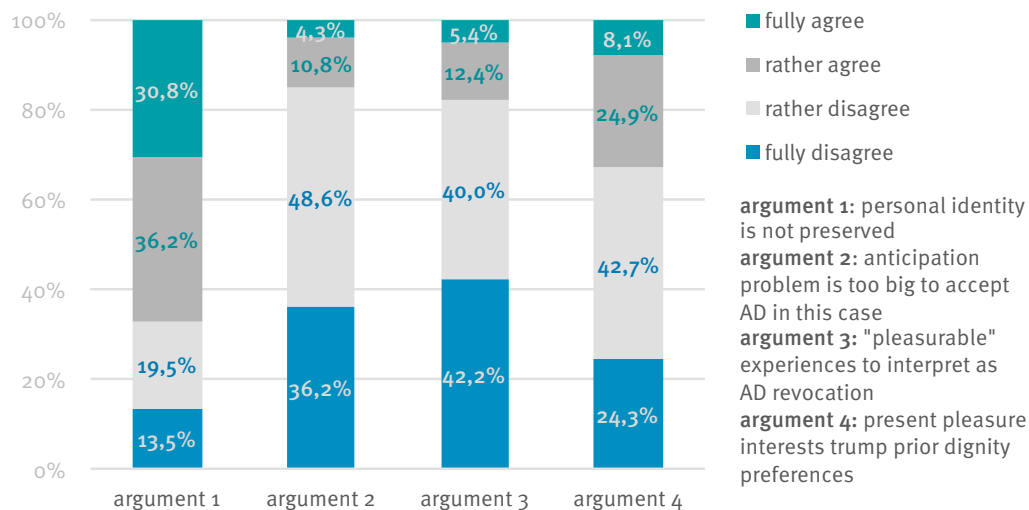


Fig. 3: Degree of approval of the four standard arguments against following the AD in the M1 case (mean of all respondents who opted not to follow the AD).

pleasure by severely demented Mr Meyer does not revoke the AD ('fully agree': 49.8%; 'rather agree': 32.9%). Finally, 97% of AD-followers agreed with (A4) that the patient's prior ideas of dignity should trump his later pleasure interests ('fully agree': 74.5%; 'rather agree': 22.5%).

Of those 25.2% participants who opposed following Mr Meyer's AD, a majority agreed with three of the above four arguments' contradictions, although to a lesser extent than their opponents held to their (reverse) justifications (see Fig. 3). 84.8% agreed that the difficulties in anticipating how it feels to be severely demented should invalidate the AD ('fully agree': 36.2%; 'rather agree': 48.6%). 82.2% considered the experience of pleasure by severely demented Mr Meyer as revoking the AD ('fully agree': 42.2%; 'rather agree': 40.0%). 67% of them supported the view that the prior patient's ideas of dignity should not trump his later pleasure interests ('fully agree': 24.3%; 'rather agree': 42.7%). Only 33.0% of them voted for a personal non-identity relation between early and late Mr Meyer ('fully agree': 13.5%; 'rather agree': 19.5%).

Cumulative agreement among followers and non-followers of Mr Meyer's AD amounted to: 89.0% in favour of preserved personal identity (A1); 75.5% against letting the anticipation problem invalidate the AD (A2); 66.4% against taking pleasure interests to revoke the AD (A3); and 81.0% in favour of the patient's former dignity preferences trumping his later pleasure interests (A4).

3.3 Modified versions of the case vignette

Asking for respondents' views on the three variations of the original case, we got different results (see Fig. 4). In each variation, significantly more respondents followed the AD. In variation M2 (the patient does not appear pleasant), 83% of participants were willing and 17% unwilling to follow Mr Meyer's AD, thus to let him potentially die from untreated pneumonia

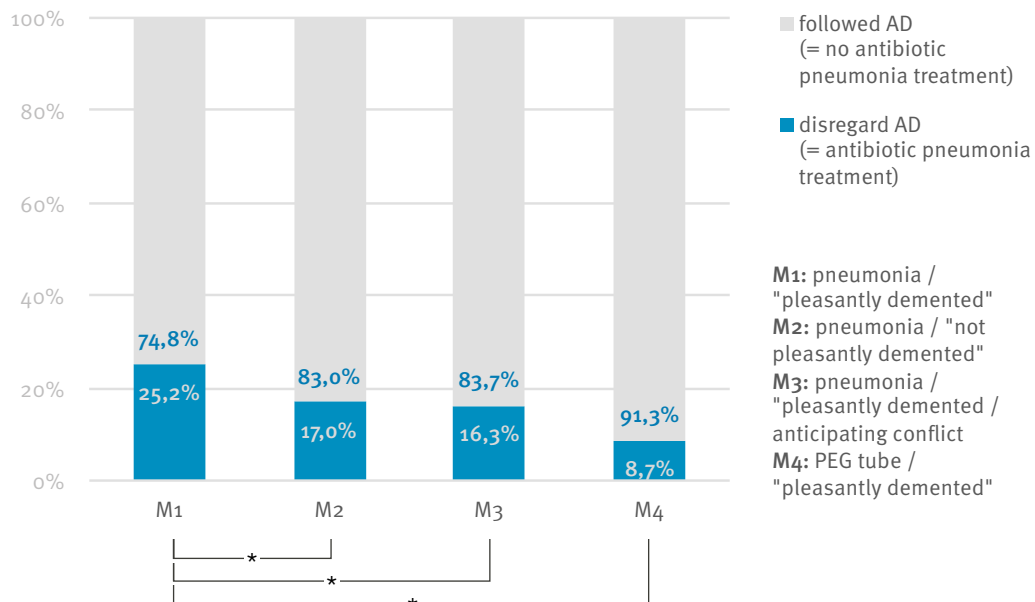


Fig. 4: Treatment decisions (mean of all respondents) in Meyer case variations (M1-M4). Asterisks mark significant differences between M1 and each variation (* $p < 0.05$).

($p < 0.0005$). In variation M3 (the patient's AD contains an explicit anticipation of the potential PDPI conflict), 83.7% of our participants were willing and 16.3% unwilling to follow Mr Meyer's AD ($p < 0.0005$). Finally, in variation M4 (decision on feeding by PEG tube), 91.3% of the participants were willing and 8.7% unwilling to forgo tube feeding ($p < 0.0005$). Moreover, M4 was the only case with a significant difference in inter-group comparison ($p < 0.05$, data not shown in a diagram): Significantly less professionals (5.1% of physicians plus nurses) than non-professionals (12.0% of next of kin plus dementia-inexperienced lay persons) were unwilling to follow the AD in this regard.

4 Discussion

Conceivably, a growing number of people might want in advance to refuse treatment for what they personally consider a state of bewildering indignity (Dworkin 1993). In the context of advance directives (ADs) for late-stage dementia a 'past-directive-versus-present-interest conflict' (PDPI conflict) is a specific problem. It involves a properly executed advance refusal of life support and a seemingly 'happy' patient who has permanently lost the capacities for decision-making as well as for understanding, let alone for confirming his prior directive, but for whom clinical benefit could be realised if care providers did not follow his prior directive. This situation, especially difficult in ethical terms, has been long debated among bioethicists, but largely neglected in the growing body of empirical research (De Boer/Hertogh/Droes/Jonker/Eefsting 2010, Denning/Jones/Sampson 2011, Dickinson/Bamford/Exley/Emmett/Hughes/Robinson 2013, Jox/Denke/Hamann/Mendel/Foerstl/Borasio 2012, Hartog/Peschel/Schwarzkopf et al. 2014, Vandervoort/Houttekier/Van den Block/van der Steen/Stichele/Deliens 2014) or policy proposals (Alzheimer's Society UK 2014, Royal College of Physicians of London 2009) regarding dementia-related Advance Care Planning (ACP) – with some notable exceptions, such as the 2009 Nuffield Council Report (Nuffield Council on Bioethics 2011).

As a first result, our study demonstrates that the PDPI conflict is a relevant practical issue in the care of persons with advanced dementia, obviously not rooted in skepticism about ADs in general. Whereas 98.7% of respondents affirmed the general authority of ADs, Mr Meyer's unambiguous AD was not deemed binding by 25% of respondents. For persons who want to control end-of-life decisions in the late stage of their own dementia through reliance on their ADs, this might be a shocking finding. The shock will be a little softer with regard to Mr Meyer's tube refusal. In this case (Meyer-4), only 8.7% of all respondents insisted (surely or probably) on placing and using such a tube against the patient's explicit prior wish. Moreover, this was the only question where we found a significant inter-group difference: 5.1% of physicians plus nurses versus 12.0% of next-of-kin plus dementia-inexperienced persons opted for tube feeding). These results correspond well with more general empirical data. Obviously, there is growing scepticism about the overall benefits of such invasive devices in persons with late-stage dementia, promoted primarily in the professional community (Gillick 2000, Sampson/Candy/Jones 2009). However, from the patient's perspective even 8.7% AD-disregarding persons might be way too many.

As a second result, we found for the Meyer-1 case high approval rates for the four standard arguments – mirror-inverted on both sides of the conflict. From this we formulate four crucial points:

(1) Opting against personal identity between the competent and the later severely demented person is not uncommon among bioethicists who then view Meyer's AD as a heteronomous directive without authority (Dresser 1995). However, a 89.0%-majority of all respondents

(including 67 % of those disrespecting Meyer's AD) do not take issue with the single-person assumption which also underlies our social and legal conventions with regard to persons before and after major changes in their personality (Sumner 2011).

(2) With regard to the problem of anticipation (how does it feel to be severely demented?), followers and non-followers of Meyer's AD seem to have a decidedly different perspective. Among followers, 95.8 % see this as the patient's own risk. Among non-followers, 84.8 % disagree. We suggest that the argument from defective anticipation gets its force from evidence about hedonic adaptation that occurs in many persons following disabling illnesses or accidents (Ubel/Loewenstein/Jepson 2003). Such persons – e.g. when they suddenly become wheelchair-bound – often find new sources of contentment even though they did not expect to do so. In doing so, they not only contradict their own advance prophecies, but also may change their “critical interests” (Dworkin 1993) – that is, their views on how to lead their life. In contrast, late-stage dementia does not induce a change of critical interests, but, rather, their complete loss. Whether or not this is a normatively decisive difference seems a central dispute. It can reasonably be assumed that patients' advance treatment refusals for late-stage dementia are motivated by one or more of three major concerns: to avoid a possibly miserable life-span, to avoid burdening their loved-ones, or to preserve dignity at the end of their life. All three are legitimate critical interests. But where the last ones involve indisputable matters of whom one wants to be and how one wants to be seen, the first concern might rest on false beliefs about the quality of life in late-stage dementia (Gillick 2012). Surely, such possibly false beliefs should be prevented, amounting to a first argument for requiring an explicit mention of PDPI conflicts in dementia related ADs (as done in our Meyer-3 case).

(3) The third contested thesis about PDPI conflicts holds that the dementia patient's pleasure expressing behaviour (“natural will” in the German debate, Jox/Ach/Schoene-Seifert 2014) amounts to a revocation of his directive. Among respondents, 82 % on both sides of the conflict subscribe or rather object to the revocation thesis. The thesis can, however, be read in two ways. The natural will – difficult to interpret as it is – may be seen as an expression of patient self-determination, so to say, as autonomy's ‘little brother’. This seems unconvincing in the eyes of all of those who link the attribution and the value of autonomy to substantial competency. The alternative reading takes the natural will as one important parameter in assessing patients' well-being. In this case, the revocation thesis boils down to affirming that pleasure interests of late-stage demented patients should outweigh their past autonomous wishes, and vice versa. This is identical with what we have called the fourth standard argument.

(4) Our fourth standard argument is less an argument than an explicit position on the central disputed point: Should or should not the critical preferences of a formerly competent patient trump his pleasure interests in late-stage dementia? 97 % of AD-following respondents affirm the authority of former ‘dignity preferences’, whereas 67 % of their opponents stress the authority of present pleasure interests. These opposed views cannot easily be reconciled. Emphasis on a moral right to be the author of one's life' throughout bluntly conflicts with an alleged duty not to “permit competent persons to exercise tyranny over their lives as incompetent patients.” (Dresser 1994)

As a final result, we obtained some evidence that the PDPI solution suggested by some (German National Ethics Council 2005, Lemmens 2012) – namely, to let the patient himself anticipate and ‘solve’ the conflict – might be a realistic option. After all, respondents' readiness to follow Meyer's treatment refusal rose from 75 % in the original Meyer-1 case to 83.3 % in the Meyer-3 case where the treatment refusal is reaffirmed for a hypothetically anticipated PDPI conflict. Yet unsurprisingly, not everybody was convinced to follow Meyer's directive

even under these enriched conditions. Rather, categorical opponents of persons' advance authority in medical treatment decisions regarding their later demented selves might accept this 'meta-directive' solution only as a pragmatic way of dissent management.

4.1 Limitations

Our data do not provide a representative picture of stakeholder groups in Germany, but they do constitute a powerful enough sample for valid inter-group comparisons. While physicians, nurses and next of kin were recruited throughout Germany, the dementia-inexperienced were recruited only in Muenster. A bias caused by the inclusion of questionnaires where the treatment decision in the Meyer-1 case was deduced cannot be ruled out.

4.2 Conclusion

Persons who – by means of an advance directive – want to authorise a refusal of life sustaining treatment in the final stage of dementia, cannot rely on their AD being followed. Should they become severely demented but 'happy' patients, a substantial number of people, professional or lay, would see an ethical obligation to prolong these patients' lives with non-burdensome treatments (e. g. antibiotics in pneumonia). In the absence of an ethical consensus on this issue, it has been suggested that persons make an explicit meta-directive for the conflict in question. Based on our own normative outlook and the evidence from our data, we strongly recommend this pragmatic solution.

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