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Chapter 8

Older Dutch people's advance directive possession before and after the enactment of the euthanasia law: a time trend study (1998- 2011)

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Submitted

Abstract

This time trend study describes 'euthanasia' and 'care' advance directive (AD) possession amongst representative samples of Dutch older people from 1998 to 2011 and factors associated with possession. Euthanasia ADs represent a request for euthanasia under specific circumstances, whereas care ADs outline an opposition to euthanasia. The data can provide insight into the influence of the 2002 Dutch euthanasia law on 'euthanasia' and 'care' AD possession. A total of 2576 participants were asked about AD possession in face-to-face interviews during one or more data collection cycle (1998, 2005, 2008 and 2011). Possession of 'euthanasia' and 'care' ADs in each collection cycle was described and associations with personal characteristics analysed with multivariable logistic regression using generalized estimating equations. 'Euthanasia' AD prevalence was 6.8%, 4.3%, 6.4% and 6.2%, and 'care' AD prevalence was 1.3%, 0.2%, 0.1% and 0.4% in 1998, 2005, 2008 and 2011 respectively. The odds of possession 'euthanasia' and 'care' ADs were significantly lower in 2005 and 2008 compared with 1998. There were, however, no significant differences in the odds of possessing a 'euthanasia' or a 'care' AD between 1998 and 2011. Health factors had little or no influence on AD possession. This suggests a stability of preferences in various states of health and supports the legitimacy of ADs. The findings also suggest that the 2002 euthanasia law negatively influenced the possession of euthanasia and care ADs in the period directly following its enactment.

Introduction

Advance directives (ADs), documents that outline end-of-life preferences in case of future loss of decision-making capacity, are frequently promoted as a way to extend patient participation and autonomy at the end of life. Despite a general strengthening of their legal status in Europe[1-3], surveys reveal low uptake in general and older populations across Europe (between 2 and 10%[4-10]). Compared with the United States, these figures are low (uptake from American studies range from 20 to 55%, depending on the population)[11-13].

Attempts to understand the factors that influence AD possession have often focussed on the influence of personal characteristics[7,9,14-20], the effect of (macro-level) societal influences, such as the legal and policy context, are however less well understood. For example, in the US, the implementation of the 1991 Patient Self-Determination Act, which required health care institutions to inform patients about ADs, led to increased documentation of people's ADs, although not actual AD possession[11,21,22].

Advance directives can be instructional directives, which outline end-of-life treatment preferences, or proxy directives, which name a surrogate decision-maker[1]. Broadly, three types of instructional ADs are available in the Netherlands: non-treatment ADs, which detail unwanted treatments, such as cardio-pulmonary resuscitation; euthanasia ADs, which outline a desire for euthanasia under certain circumstances; and value-based 'care' ADs, which explicitly oppose euthanasia and state support for palliative care. Non-treatment ADs are legally binding under the 1995 Medical Treatment Contract Act[1]. Euthanasia ADs are covered by the 2002 Law on Euthanasia and Assisted Suicide and are not legally binding[1]. Euthanasia ADs first received legal recognition in the 2002 euthanasia law, they were however encountered in clinical practice before that date because euthanasia and assisted suicide had been tolerated and exempt from prosecution since the early 1990s, if conducted by a physician within prescribed standards of care[23]. These standards required an explicit request for euthanasia from the patient; the 2002 law however clarified that this request could also be made in the form of a euthanasia AD[24]. Stating an opposition to euthanasia in a care AD is, judicially, unnecessary as euthanasia is only legal with an explicit request, but reflects a desire never to request euthanasia.

This study describes the trend over time in AD possession amongst older Dutch people, participants of the Longitudinal Aging Study Amsterdam (LASA), and identifies the socio-demographic, social support, physical and mental health factors associated

with possession. The data, spanning from 1998 to 2011, are well-suited to study the impact the 2002 euthanasia law had on AD possession. As such the article focuses on the two ADs related to this law: euthanasia and care ADs. Time trend research can shed light on the effect of ageing, participants' personal characteristics and macro-level influences. Specific objectives include: to describe any trend in the possession of 'euthanasia' and 'care' ADs amongst older people in the Netherlands using data collected in 1998, 2005, 2008 and 2011; and to analyse and compare associations between older peoples' socio-demographic, social support and health characteristics and possession of 'euthanasia' and 'care' ADs.

Methods

LASA is a population based, longitudinal cohort study examining 'predictors and consequences of changes in physical, emotional, and social functioning in older people'[25].

Sample

To date, two nationally representative cohorts of older people have been included in LASA. The cohorts were selected via random stratified sampling from population registers of eleven Dutch municipalities, chosen to represent Protestant, Catholic and secular areas and different levels of urbanisation[25]. The samples were stratified for age and sex and there was a deliberate oversampling of men and older participants to maintain some members from these high mortality groups throughout the study[25]. The first cohort, aged 55-85, was recruited in 1992/93 and the second, aged 55-64, in 2002/03. Data were collected from both cohorts at three year intervals through a face-to-face interview, followed, 2-6 weeks later, by a medical interview and a self-administered questionnaire[25]. The LASA study has a low drop-out rate: most attrition is due to mortality and much lower attrition results from frailty, refusal to participant and loss of contact[25]. The Medical Ethics Committee of the VU University Medical Center approved LASA and all participants gave written informed consent.

Although the missing values for the question regarding AD possession were low (between 0.3 and 3.6%, depending on the year), across the collection years, non-responders were found to be significantly older (Pearson's chi-square, $p < 0.001$), more frequently female ($p < 0.05$) and more frequently non-church members ($p < 0.001$).

Measurement instrument

A question on AD possession was asked during face-to-face interviews in 1998, 2005, 2008 and 2011. Participants' ADs were categorized as 'non-treatment', 'euthanasia', 'care' or 'other' (a diffused group including, where specified, proxy ADs, instructions

for leaving the body to medical science and financial wills amongst others). 'Non-treatment' and 'other' ADs were not included in analyses.

Socio-demographics, social support and health characteristics were ascertained from population registries, face-to-face interviews and medical interviews, respectively. Socio-demographic characteristics included: age; gender; membership of a church/religious organisation (Protestant, Roman Catholic or other); education level (low [≤ 6 years], medium [7–11 years] or high [≥ 11 years]); and monthly net household income. Household income was multiplied by 0.7 if participants lived with a partner to make it comparable to that of a single person household. Using the data collection year's modal income, household income was categorized into 'below modal' and 'above modal' income.

Three dimensions of social support were measured. The first, 'structural characteristics', consisted of the partner status (co-residing with a partner or not) and personal network size. Personal network size was defined as the number of named persons aged 18 or over with whom the participant had important and regular contact [maximum 80][26]. The second, 'functional characteristics of support', consisted of the practical and emotional support received from frequently contacted personal network members. Participants were asked how often they received practical or emotional support from the nine members of the participant's personal network with whom they had most contact in the previous year. Possible responses were: never (0), rarely (1), sometimes (2), and often (3). The mean practical and emotional support received from the nine relationships was calculated (ranging from 0-3). The final dimension of social support, 'perceived support', was a measure of participants' sense of loneliness. Loneliness was defined as the discrepancy between what one wants and what one has in terms of interpersonal affection and intimacy. This was measured using De Jong Gierveld's loneliness scale, with scores ranging from 0 to 11 and higher scores indicative of more intense loneliness[27].

Aspects of physical health measured included: chronic disease; perception of own health; experience of pain; and physical limitations. Chronic disease was determined by asking participants if they had one or more of seven common chronic diseases (chronic non-specific lung disease; cardiac disease; peripheral arterial disease; diabetes mellitus; cerebrovascular accident (CVA)/stroke; osteoarthritis/rheumatoid arthritis; and cancer). Participants were also asked to rate their own health as very good (1), good (2), fair (3), sometimes good/sometimes poor (4) and poor (5). Experience of pain was measured using Hunt *et al.*'s[28] pain scale abbreviated to five items. Scores were dichotomized, resulting in the categories 'no pain' (score 0) and

'any pain' (scores 1–5). Finally, physical limitations were measured by asking participants if they had difficulty carrying out six activities of daily living, e.g. dress and undress oneself, sit down and stand up from a chair and walk outside during five minutes without stopping (scores 0 [no difficulties] to 6 [all with difficulty]). Mental health measures included cognitive functioning and depressive symptoms. Cognitive functioning was measured with the Mini-Mental State Examination (MMSE), with scores ranging from 0 to 30 and scores of 23 or under indicating lower cognitive functioning[29]. Depressive symptoms were measured with the 20-item Center for Epidemiologic Studies Depression (CESD) Scale, with scores ranging from 0 to 60, with higher scores indicating more depressive symptoms[30]. Independent continuous variables (such as the MMSE) were used as nominal variables if they violated the assumption of linearity of the logit.

Analysis

To ensure that in all four data collection years the age range of participants was comparable, those under the age of 65 and over the age of 91 (the age of the oldest participant in 1998) were excluded from analyses.

Sample characteristics were analysed separately for each of the four data collection cycles using descriptive statistics. The percentages of participants in possession of a 'euthanasia' or 'care AD' in each of the four collection cycles were described. Due to the over-sampling of older and male participants and to aid interpretation, true values were reported but percentages were adjusted for sex and age (weighting standards: the Dutch population on January 1st of 1999, 2006, 2009 and 2012[31]).

Differences in possession of 'euthanasia' and 'care' ADs over time were examined with logistic regressions using generalised estimating equations (GEE) with time as the main independent variable. This accounted for intra-personal correlation in responses as measurement occasions were nested within individuals[32]. Because a non-linear relationship between data collection year and AD possession was observed, and due to the uneven time intervals between sampling, time was included as a discrete variable in the analysis [32]. The variables age and sex (used to create the weights), as well as the interaction between them, were included as main effects in the GEE to control for the over-sampling of male and older participants but still giving unbiased estimates and standard errors. Model specifications included a logit link function, exchangeable correlation matrix and a robust covariance matrix estimator [32].

Associations between possession of a 'euthanasia' or 'care' AD, and socio-demographic, social support, physical and mental health factors were estimated with multivariable logistic regression using GEE (using the same model specifications as above)[32]. Multicollinearity tests were conducted and interactions between age and the data collection year examined. Analyses were carried out in SPSS20 (IBM Software).

Results

A total of 2576 individual participants were asked about their AD possession between one and four times over the fourteen year study period, corresponding to the question being asked 5068 times and responded to on 4988 (98%) occasions. The characteristics of people participating in each data collection cycle are shown in Table 1.

Advance directive possession over time

Possession of a 'euthanasia AD' declined from 6.8% in 1998 to 4.3% in 2005 before increasing to 6.4% in 2008 and remaining at a similar proportion (6.2%) in 2011. The odds of possession were significantly lower in 2005 compared with 1998, although there were no significant differences in 2008 and 2011 compared with 1998 (Table 2, Graph 1).

Possession of a 'care AD' declined from 1.3% in 1998 to 0.2% in 2005 and 0.1% in 2008 before increasing slightly to 0.4% in 2011. The odds of possession were significantly lower in both 2005 and 2008 when compared with 1998. There were no significant differences in the odds of possessing a 'care AD' in 2011 compared with 1998 (Table 2, Graph 1).

Table 1. Participant characteristics during each of the four data collection cycles.

		1998-1999 N=1584	2005-2006 N=1207	2008-2009 N=1158	2011-2012 N=1119
		n (adjusted %)	n (adjusted %)	n (adjusted %)	n (adjusted %)
		Adjusted mean (SD)	Adjusted mean (SD)	Adjusted mean (SD)	Adjusted mean (SD)
Age	Youngest old (65-74)	765 (59.3)	650 (59.5)	632 (59.1)	633 (67.9)
	Middle old (75-84)	576 (32.5)	430 (33.4)	421 (33.5)	376 (25.0)
	Oldest old (85-91)	243 (8.2)	127 (7.0)	105 (7.5)	110 (7.0)
	Mean (SD)	74.38 (6.61)	74.10 (6.42)	74.31 (6.57)	72.76 (6.76)
Gender	Male	698 (40.6)	530 (44.3)	515 (45.2)	501 (46.8)
	Female	886 (59.4)	677 (55.7)	643 (54.8)	614 (53.2)
Religious affiliation	None	579 (37.2)	472 (39.1)	469 (40.8)	454 (41.8)
	Protestant	517 (32.2)	365 (30.0)	353 (30.3)	332 (29.2)
	Catholic	467 (29.2)	356 (29.7)	321 (27.6)	310 (27.2)
	Other	21 (1.4)	14 (1.1)	15 (1.3)	19 (1.9)
Education	Low	651 (40.3)	367 (29.7)	303 (25.4)	255 (21.7)
	Medium	502 (31.9)	411 (34.1)	407 (35.1)	420 (38.6)
	High	431 (27.7)	429 (36.2)	448 (39.5)	440 (39.8)
Household income	Below average	1037 (74.3)	701 (65.6)	664 (63.8)	625 (60.7)
	Above average	346 (25.7)	357 (34.4)	365 (36.2)	367 (39.3)
Partner status	Partner co- residing	820 (54.5)	730 (62.4)	703 (62.4)	707 (66.8)
	No partner co- residing	764 (45.5)	477 (37.6)	455 (37.6)	412 (33.2)
Total network size		14.63 (8.76)	16.41 (9.30)	16.47 (9.75)	16.25 (9.69)
Practical support		0.82 (0.70)	0.88 (0.69)	0.90 (0.67)	0.84 (0.64)
Emotional support		1.62 (0.76)	1.67 (0.74)	1.71 (0.72)	1.69 (0.68)
Loneliness score		2.36 (2.66)	1.96 (2.51)	1.98 (2.52)	1.94 (2.53)
Chronic disease	None	350 (23.3)	245 (21.3)	226 (20.2)	226 (22.5)
	One or more	1224 (76.7)	962 (78.7)	932 (79.8)	893 (77.5)
Own perception of health		2.40 (0.86)	2.46 (0.91)	2.40 (0.89)	2.36 (0.89)
Experience of pain	Yes	515 (36.0)	433 (37.0)	373 (33.7)	386 (33.4)
	No	871 (64.0)	718 (63.0)	717 (66.3)	666 (66.6)
Physical limitations		1.59 (1.88)	1.69 (1.89)	1.57 (1.86)	1.43 (1.78)
Cognitive functioning	Low	200 (9.8)	104 (7.6)	84 (6.6)	68 (5.0)
	Normal	1384 (90.2)	1103 (92.4)	1074 (93.4)	1051 (95.0)
Depressive symptoms		8.69 (7.65)	8.51 (7.30)	7.63 (6.72)	7.83 (7.05)

True n, adjusted valid percentages and adjusted mean and standard deviation reported (SD) reported (adjusted = weighted for age and sex).

Missing value 0-12.7%. Variables with missing values over 5% for years 1998/99, 2005/06, 2008/09 and 2011/12 - n (%):

Household income 201 (12.7), 149 (12.3), 129 (11.1), 127 (11.3);

Network size 135 (8.5), 79 (6.5), 58 (5.0), 6 (5.5);

Practical support 139 (8.8), 79 (6.5), 58 (5.0), 61 (5.5);

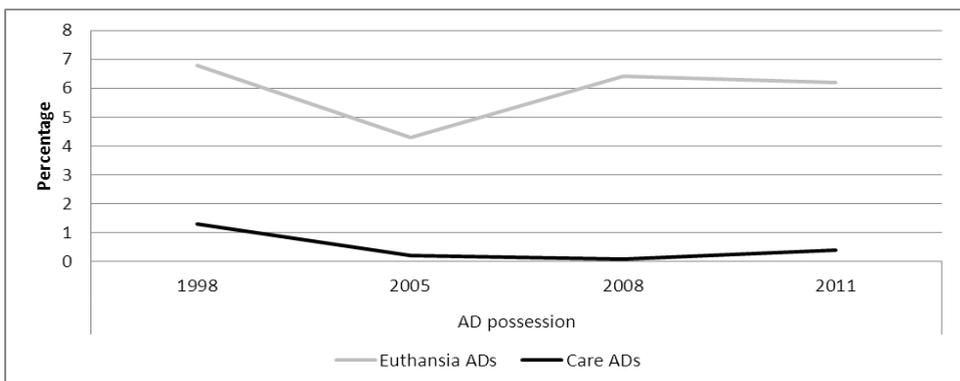
Emotional support 141 (8.9), 56 (4.6), 68 (5.9), 67 (6.0);

Pain 198 (12.5), 60 (4.9), 75 (6.3), 71 (6.2).

Table 2. Trends in older people’s advance directive possession over time.

		AD possession			
		1998-1999 N=1584	2005-2006 N=1207	2008-2009 N=1158	2011-2012 N=1119
Euthanasia AD	n unadjusted	106	54	74	80
	Adjusted %	6.8	4.3	6.4	6.2
	OR (CI) †	1	0.71 (0.55, 0.92)*	0.95 (0.74, 1.24)	1.11 (0.85, 1.46)
Care AD	n unadjusted	20	2	1	6
	Adjusted %	1.3	0.2	0.1	0.4
	OR (CI) †	1	0.13 (0.02, 0.66)*	0.08 (0.01, 0.52)**	0.46 (0.19, 1.10)

Unadjusted numbers and adjusted valid percentages reported (adjusted = weighted for age and sex).
 Missing values: 1998-1999 - 16 (1%); 2005-2006 - 44 (3.6%); 2008-2009 - 17 (1.5%); 2011-2012 - 3 (0.3%).
 †Logistic regression using generalised estimating equations (GEE). The variables age, sex and age*sex were included as main effects in the GEE (ORs not shown) to control for the over-sampling of male and older participants.
 *, **, and *** indicate significance at the $p < .05$, $p < .01$, and the $p < .001$ levels, respectively.



Graph 1. Trend in older people’s possession of euthanasia and care advance directives over time (adjusted percentages).

Factors associated with AD possession

Revisiting the time trend, and controlling for all sample characteristics, the odds of possessing a ‘euthanasia AD’ were significantly lower in 2005/06 and 2008/09 compared with 1998/99 (Table 3). There were still no significant differences in the odds of ‘euthanasia AD’ possession in 2011 compared with 1998. ‘Euthanasia AD’ possession was positively associated with increasing age, female gender, higher educational attainment and higher household income (Table 3); possession was negatively associated with membership of the Catholic or a Protestant church compared with no religious affiliation (Table 3).

Table 3. Associations between participant characteristics and possession.

		Euthanasia ADs	Care ADs
		Multivariable	Multivariable
		OR (95% CI)†	OR (95% CI)†
Study period §	1998-99	1	1
	2005-06	0.50 (0.36, 0.69)***	0.17 (0.03, 0.82)*
	2008-09	0.72 (0.52, 0.99)*	0.11 (0.01, 0.79)*
	2011-2012	0.78 (0.57, 1.07)	0.56 (0.23, 1.34)
Age category §	Youngest old (65-74)	1	1
	Middle old (75-79)	1.71 (1.29, 2.28)***	1.36 (0.53, 3.51)
	Oldest old (80+)	2.53 (1.57, 4.09)***	4.69 (1.51, 14.56)**
Gender	Male	1	1
	Female	2.09 (1.45, 3.00)***	1.41 (0.52, 3.84)
Religious affiliation	None	1	1
	Protestant	0.16 (0.10, 0.28)***	0.93 (0.33, 2.64)
	Catholic	0.10 (0.05, 0.17)***	0.94 (0.32, 2.78)
	Other	0.26 (0.04, 1.63)	2.65 (0.42, 16.89)
Education §	Low	1	1
	Medium	2.36 (1.45, 3.83)***	1.20 (0.53, 2.73)
	High	3.05 (1.86, 4.98)***	0.54 (0.15, 1.91)
Household income §	Below average	1	1
	Above average	1.41 (1.01, 1.97)*	0.34 (0.09, 1.34)
Partner status	Partner co-residing	1	1
	No partner co-residing	1.32 (0.94, 1.85)	1.27 (0.50, 3.28)
Total network size		1.00a (0.98, 1.01)	1.00a (0.96, 1.04)
Practical support		0.83 (0.67, 1.03)	0.93 (0.45, 1.92)
Emotional support		1.12 (0.92, 1.36)	0.90 (0.47, 1.73)
Loneliness score		1.02 (0.96, 1.09)	1.06 (0.88, 1.29)
Chronic disease	None	1	1
	One or more	1.24 (0.82, 1.88)	1.24 (0.42, 3.67)
Own perception of health		1.15 (0.96, 1.37)	0.87 (0.48, 1.57)
Experience of pain	Yes	1	1
	No	0.80 (0.59, 1.08)	0.67 (0.32, 1.40)
Physical limitations		0.92 (0.83, 1.02)	0.73 (0.56, 0.95)*
Cognitive functioning	Low	1	1
	Normal	5.76 (0.83, 40.27)	2.34 (0.29, 19.21)
Depressive symptoms		0.99 (0.97, 1.02)	1.02 (0.95, 1.10)

†Logistic regression using generalised estimating equations: Dependent variable: 0 – does not possess AD, 1 – possesses AD.

^aValue less than 1.00 at 3dp.

*, **, and *** indicate significance at the $p < .05$, $p < .01$, and the $p < .001$ levels, respectively.

Tests for multicollinearity revealed no tolerance values less than 0.1 and no VIF values greater than 10, no big difference in eigenvalues or variables with high proportion loadings on the same eigenvalue. No significant interactions were found between participants' age and the data collection year (analysis not shown) therefore interaction terms were not included in the multivariable analysis.

Controlling for all sample characteristics, the odds of possessing a care AD were significantly lower in 2005/06 and 2008/09 compared with 1998/99. There was no significant difference in the odds of possessing a 'care AD' in 2011 compared with 1998. The odds of possessing a 'care AD' were higher amongst the oldest old compared with the youngest old, and lower with increasing physical limitations (Table 3).

Discussion

This study is the first to assess AD possession over time in a representative sample of older people from a European country. The findings illustrate that in the two data collection cycles following the enactment of the 2002 Dutch euthanasia law, there was a significant decrease in possession of 'euthanasia' and 'care' ADs. In the third data collection cycle following the euthanasia law's enactment, however, possession of 'euthanasia' or 'care' ADs had increased so that there were no significant differences with pre-law levels. These findings suggest that legal changes in the status of euthanasia ADs actually negatively affected possession in the first instance. This decrease in euthanasia AD possession mirrors decreases in both euthanasia requests and incidence that occurred shortly after the enactment of the euthanasia law[33,34] and that have been ascribed to uncertainty regarding the functioning of the new law[33]. A parallel decline in AD possession suggests that older people, undoubtedly aware of the widely debated new law, may have been unsure about how a euthanasia AD might be interpreted in this new legal context. The subsequent increase in euthanasia AD possession to a level not significantly different from pre-euthanasia law levels suggests increasing public confidence in their use and interpretation by physicians.

Surprisingly, possession of care ADs also declined after the enactment of the 2002 euthanasia law. A Dutch mixed-methods study amongst AD holders found that those who had drafted a care AD did so mainly due to fear that physicians might hasten their death against their wishes[35]. The intense public debate surrounding the new law may have convinced some people that such fears were unfounded and that, in particular, the patient must actively request euthanasia. This may also explain why the prevalence of care ADs remains low and does not experience an increase of the same magnitude as euthanasia directives in the years following the initial decline.

The characteristics of participants in possession of 'euthanasia' or 'care' ADs also differed. Euthanasia AD possession was associated with increasing age, female gender, higher education and higher household income, and negatively associated with Catholic or Protestant church membership. The association with increasing age may reflect an increasing relevance and experience of death and dying, both motivating factors in drafting an AD[35]. A lack of interaction between age and data collection year indicates all age groups were affected equally by time factors. Women's greater direct involvement in caring roles[36] and awareness of the burden of care, or more proactive approach to health care[37], may explain their more frequent possession of euthanasia ADs. The negative association with Catholic or Protestant affiliation and euthanasia AD possession reflects the opposition to euthanasia from the Catholic and

many Protestant churches. A higher level of education may be related to greater awareness of ADs and end-of-life options. Independent of educational attainment, higher household income was associated with euthanasia AD possession. In the US, higher income or net worth has also been linked with AD possession[14,18,38,39] and has been explained by wealthier participants' greater need to organise financial end-of-life affairs that might motivate end-of-life care planning[18]. Possession of a care AD was higher amongst the oldest old compared with the youngest old. Older people with more physical limitations were also less likely to possess a care AD.

Previous studies have associated indicators of poor health, such as hospital admittance, number of illnesses, functional limitations, experience of pain and use of prescription medicines with AD possession[9,14,16-18,38-40]. In contrast, health factors had no influence on possession of a euthanasia AD, and limited influence on possession of a care AD, in this study.

Strengths and limitations

The findings are strengthened by the use of data on AD possession and a range of socio-demographic, social support and physical and mental health factors from a representative sample of older people spanning fourteen years. There are, however, also limitations. The first measurement sampled only the first cohort, whereas subsequent measurements sampled both the first and second cohorts. Some degree of cohort effect is therefore possible. Also, although there was, in general, a low level of attrition and missing data, missing values for some independent variables often considered sensitive topics, such as household income, social support (network size, practical and emotional support) and experience of pain were relatively common. Although the missing values for AD possession were low, non-responders were significantly older, more frequently female and non-church members. Because these characteristics are associated with possessing an AD, possession estimates may have been slightly underestimated.

Conclusions

This time trend study suggests an influence of the legal context on AD possession. Whereas legal changes had no significant effect on the possession of ADs in the US, the Dutch 2002 euthanasia law, which clarified the use of euthanasia ADs was actually followed by a decline in euthanasia and care ADs in the Netherlands. Strengthening the legal status of ADs may not, therefore, result in an increase in AD possession. Health factors' lack of influence on euthanasia AD possession, and very limited influence on care AD possession suggests that preferences remain stable in different health states and supports the legitimacy of ADs.

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