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## **Patient-physician communication at the end of life: a European perspective**

Evans, N.C.

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# Chapter 6

## **Life-sustaining treatment preferences: social support more important than health?**

Natalie Evans, H. Roeline W Pasman, Theo van Tilburgh, Dorly Deeg, Bregje Onwuteaka-Philipsen, on behalf of EURO IMPACT

Submitted

**Abstract**

This study examines Dutch older people's preferences for life-sustaining treatments and factors associated with a preference to forgo treatments. Participants from the Longitudinal Aging Study Amsterdam identified preferences for four life-sustaining treatments in hypothetical cases of cancer and dementia in a cross-sectional survey (n=1484). Preferences were described and associations examined using multivariable logistic regressions. A majority preferred to forgo a treatment in both cancer (78%) and dementia (85%) scenarios. Different elements of the multidimensional variable 'social support' influenced preferences in distinct ways: larger social networks were associated with forgoing treatment in the dementia scenario, whereas, in the cancer scenario, a live-in partner and greater emotional support were associated with preferring all treatments. Current health was not associated with preferences (except anxiety - associated with a preference for treatment in dementia). Understanding social support influences may encourage professionals to explore patients' expectations and fears about social support during advance care planning.

## Introduction

At the end of life, physicians and family members are frequently required to make decisions for patients who have lost decision-making capacity. Often these decisions are made without the benefit of prior knowledge of patients' end-of-life treatment preferences[1,2]. These situations can however be avoided by discussing medical end-of-life treatment preferences in a timely manner. Understanding life-sustaining treatment preferences and the factors that influence them can inform and facilitate end-of-life discussions.

Several studies, primarily from the United States, have examined attitudes towards medical end-of-life treatments, typically by ascertaining preferences for life-sustaining treatments in different end-of-life scenarios and the factors associated with these preferences. These studies have revealed that, in the case of terminal illness, people often do not want aggressive life-sustaining treatments[3-7]. Preferences, however, depend on the treatment in question: more invasive procedures, such as cardio-pulmonary resuscitation (CPR) and mechanical ventilation, are, in general, less acceptable than non-invasive treatments, such as antibiotics[3-5,8,9]. A number of personal characteristics associated with preferences for life-prolonging treatment have also been identified. For example, younger[5,8,10], male[9,11-14], less educated[3,14], more religious[3,14,15] and African American[12,14,16] participants more frequently prefer life-sustaining treatments compared with older, female, better educated, less religious and white American participants.

Aspects of individuals' physical and mental health have also been associated with treatment preferences: in hypothetical scenarios, the terminal condition influences treatment preferences[8,16-18] whereby treatments are less acceptable in the case of coma and dementia[18]. In addition, participants' current health has been associated with life-sustaining treatment preferences. Health-related associations with treatment preferences are of interest because health deteriorates towards the end of life and it is important to understand whether participants' preferences when they experience reasonable health remain the same if their health declines. Some studies that participants in worse health are *less* likely to forgo treatments [3,10]. The Prospect Theory of decision-making has been used to explain this apparent 'response shift'[10,19]: the process by which preferences change as they adapt to deteriorating health[20]. Prospect Theory postulates that pairs of distant prospects are less distinguishable than closer ones[21]. To people with poor health/functional limitations the difference between death and living in poor health would seem greater than to healthy people and acceptance of worse health outcomes, therefore, might be more acceptable in comparison to death. Other studies however suggest that

participants in worse health are *more* likely to forgo treatments[5,22]. The relationship between physical and mental health and preferences for life-sustaining treatment, therefore, remains unclear.

As well as health, social relationships and available social support can change towards the end of life. Social network size, for example, has been shown to decrease in old age[23]. ‘Fundamental Cause Theory’, posits that social conditions, including social support, mediate access to resources that can be used to enhance health[24]. Whereas the influence of social conditions such as gender and education level on life-sustaining treatment preferences have been well described, the influence of social support remains almost entirely unexplored. Expectations of informal practical and emotional support, or indeed the burden of such support on loved-ones, may influence participants’ preferences. Social support factors have been found to influence the management of chronic disease[25], advance care planning and surrogate decision-maker appointments[26]. However, as far as the authors are aware, just one study has touched upon the relationship between social support and medical end-of-life treatment preferences: Barnato *et al.*[14] found that participants with less-than-weekly contact with family or friends were less likely to want potentially life-shortening palliative drugs. In the same study, however, living alone was associated with not wanting mechanical ventilation.

No study has provided a thorough examination of the influence of socio-demographic characteristics, social support, physical and mental health on preferences for different life-sustaining treatments. To obtain a comprehensive understanding of preferences and associated factors it is important to examine preferences for multiple life-sustaining treatments and in different end-of-life scenarios (such as cancer or dementia).

This study examines medical end-of-life treatment preferences amongst participants of the Longitudinal Aging Study Amsterdam (LASA): a population-based study[27]. The specific objectives are:

- To determine Dutch older people’s preferences for artificial hydration and nutrition, antibiotics, cardio-pulmonary resuscitation (CPR) and mechanical ventilation in hypothetical cases of cancer and dementia.
- To examine the associations between older people’s preference to forgo one or more medical end-of-life treatments and socio-demographic characteristics, social support, physical and mental health.

## **Data and methods**

In 2008/9, older people participating in LASA identified preferences for four life-sustaining treatments in a self-administered questionnaire. This study, therefore, although part of a larger longitudinal study, takes a cross-sectional approach.

### *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)[27]. The samples were stratified for age and sex and there was a deliberate oversampling of men and older participants (in order to maintain some members from these high mortality groups throughout the study)[27]. 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, medical interview and self-administered questionnaire[27]. The LASA study has a low drop-out rate and most attrition is due to mortality, with much lower attrition due to frailty, refusal to participate and loss of contact[27]. In the 2008/09 data collection cycle 1818 people were still participating (985 people from the first and 833 from the second cohort)[27], of these 1484 (82%) completed the self-administered questionnaire.

### *Measurement instrument*

In the 2008/09 self-administered questionnaire, participants were asked to indicate their preferences for four medical end-of-life treatments in two end-of-life scenarios (cancer and dementia), Box 1. Vignettes concerning both cancer and dementia were chosen as previous research has shown distinct life-sustaining treatment preferences in cases of physical and cognitive decline[8,16-18].

Socio-demographics, social support and health characteristics were ascertained from population registries, face-to-face interview and medical interviews. Full details of the study have been published elsewhere[27]. The study was approved by the Medical Ethics Committee of the VU University Medical Center and all participants gave written informed consent.

### *Factors associated with treatment preferences*

Socio-demographic characteristics collected included: age; sex; ethnicity (self-defined by participants and categorized as 'white Dutch' or 'other'); membership of a religious organisation (Protestant, Roman Catholic or other); education level (low [ $\leq 6$  years], medium [7-11 years] or high [ $\geq 11$  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, income was then categorized into tertiles: low ( $\leq 1248$  euros), medium (1248-1929 euros) or high ( $> 1929$  euros).

Scenario 1. You are diagnosed with cancer, which has spread throughout your body. The disease is incurable. For some days you have not been responsive to any form of communication. You show clear signs of severe pain and agitation.				
Scenario 2. You suffer from dementia and no longer recognize your family or friends. You refuse to eat and drink and you are becoming increasingly withdrawn. It is no longer possible to discuss treatment options with you.				
<b>Preferences for four medical end-of-life treatments</b>				
	Yes	Probably yes	Probably not	No
Would you, in the above situation, wish to receive artificial hydration and nutrition (through a nasal gastric tube).	1	2	3	4
Would you, in the above situation, wish to be given antibiotics if you got pneumonia?	1	2	3	4
Would you, in the above situation, want cardiopulmonary resuscitation in the event of a cardiac arrest?	1	2	3	4
Would you, in the above situation, want mechanical respiration?	1	2	3	4

**Box 1.** End-of-life scenarios and questions on medical end-of-life treatment preferences.

Three dimensions of social support were measured. The first, 'structural characteristics', consisted of the partner status (co-residing with a partner or not) and the personal network size (the number of named people aged 18 or over with whom the participant had an important and regular contact [maximum 80])[28]. The second, 'functional characteristics of support', consisted of the practical and emotional support received from the nine most frequently contacted members of the participant's personal network. 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 (scores range from 0 to 11 with higher scores indicative of more intense loneliness)[29].

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 or rheumatoid arthritis; and cancer). Participants were also asked to rate their own health (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[30] 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 seven simple tasks (e.g. dress and undress yourself, sit down and stand up from a chair and walk outside during five minutes without stopping) (scores 0 [no difficulties] to 7 [all with difficulty]).

Mental health measures included cognitive functioning, anxiety and depressive symptoms. Cognitive functioning was measured with the Mini-Mental State Examination (MMSE) (scores range from 0 to 30, with scores of 23 or under indicating lower cognitive functioning)[31]; Anxiety was measured with the Hospital Anxiety and Depression Scale-Anxiety (HADS-A) (scores range from 0 to 21, with higher scores indicating more anxiety symptoms)[32]. Depressive symptoms were measured with the 20 item Centre for Epidemiologic Studies Depression (CESD) Scale (scores range from 0 to 60, with higher scores indicating more depressive symptoms)[33].

### *Analysis*

Sample characteristics and preferences for life-sustaining treatments were analysed using descriptive statistics. Percentages, means and standard deviations weighted for sex and age (standard: Dutch 1<sup>st</sup> January 2009 population[34]) in order to adjust for the over sampling of older and male participants. The relationships between participants' desire to forgo pairs of different life-sustaining treatments (nasal and gastric tubes, antibiotics, CPR and mechanical respiration) were determined using Spearman's rho correlations.

A factor analysis revealed that responses concerning the four medical end-of-life treatments formed one component in both the cancer and dementia scenarios



(analysis not shown). It was therefore possible to create one dichotomous variable from the four variables for each scenario: preference for all four life-sustaining treatments vs. preference to forgo one or more end-of-life treatments. Associations between preference to forgo one or more medical end-of-life treatment and socio-demographic characteristics, social support, physical and mental health were examined through univariate and multivariable logistic regressions. A forced enter procedure was used for the multivariable regressions. Residuals were examined and multicollinearity tests conducted.

#### *Non-responders and missing data*

The 334 participants who did not complete the self-administered questionnaire were older (Pearson's chi-square,  $p < 0.001$ ), more frequently female ( $p < 0.001$ ), and had lower educational attainment ( $p < 0.001$ ) than those who completed the questionnaire. Ethnicity and religious group membership did not differ significantly between responders and non-responders; however few participants identified as non-white Dutch (1%).

In addition to non-participation in the questionnaire, there was a relatively high proportion of missing data regarding treatment preferences (ranging from 8.2-10.9%). Furthermore, missing values for the variable 'all four treatments', a combination of individual preference responses, were 11.9% cancer and 13.5% dementia scenario. In the cancer scenario, participants for who the variable 'all four treatments' was missing were older (Pearson's chi-square,  $p < 0.001$ ), more frequently female ( $p < 0.05$ ) and had lower education ( $p < 0.001$ ). Similarly, in the dementia scenario, participants for who the variable 'all four treatments' was missing were older (Pearson's chi-square,  $p < 0.001$ ), more frequently female ( $p < 0.05$ ), had lower education ( $p < 0.001$ ), and were church members ( $p < 0.001$ ).

## **Results**

### *Sample characteristics*

Participants, aged between 61 and 101, had a mean age of 70.85 (SD 7.88). Just over half were female (53%) and the vast majority identified as white Dutch (99%) (Table 1).

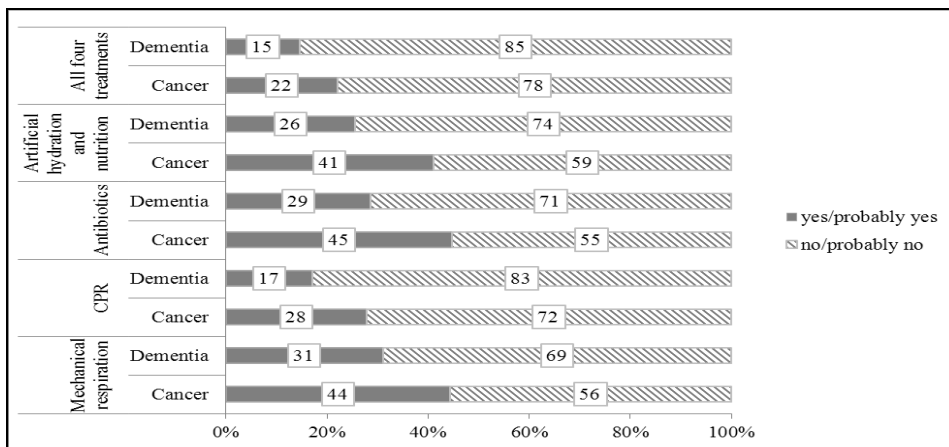
**Table 1.** Sample characteristics (n=1484).

		n	Adjusted mean (SD) or %
<b>Socio-demographics</b>			
Age (range 61-101)		1484	70.85 (7.88)
Gender	Male	670	47
	Female	814	53
Ethnicity	Dutch/Netherlands	1468	99
	Other	16	1
Religious affiliation	None	626	43
	Protestant	436	29
	Catholic	398	26
	Other	24	2
Education	Low	367	23
	Medium	542	37
	High	575	40
Household income	Low	454	32
	Medium	451	34
	High	415	34
<b>Social support characteristics</b>			
<i>Structural network</i>			
Partner status	Partner co-residing	961	69
	No partner co-residing	522	31
Total network size		1405	16.69 (9.66)
<i>Functional receipt of support</i>			
Practical support		1405	0.85 (0.66)
Emotional support		1402	1.72 (0.71)
<i>Perceived receipt of support</i>			
Loneliness score		1454	1.81 (2.41)
<b>Physical health</b>			
Chronic disease and co-morbidity	No chronic disease	334	25
	Has one or more chronic diseases	1149	75
Own perception of health		1481	2.31 (0.90)
Experience of pain	Yes	466	30
	No	1000	70
Physical limitations		1483	1.34 (1.93)
<b>Mental health</b>			
Cognitive functioning	Low cognitive functioning	89	5
	Normal cognitive functioning	1394	95
Anxiety		1482	2.69 (3.02)
Depressive symptoms		1479	7.29 (6.81)
True n, adjusted valid percentages and adjusted mean and standard deviation reported (SD) reported (adjusted = weighted for age and sex). Percentages have been rounded to whole numbers; therefore some totals are not exactly 100%.			
Missing values 0-11.1%. Variables with missing values >5%: household income (11.1%), network size (5.3%), practical support (5.3%) and emotional support (5.5%)			

Participants who claimed membership of a Protestant church made up 29% of the sample; 26% were members of the Catholic church, whereas just under half (43%) were non-church members. Just under a quarter of the sample had no more than primary school education (23%), whereas 37% had achieved a high level (11 years or more) of education. As participants' monthly household income was categorized into tertiles, there was an even distribution over the income categories. Participants resided with a partner made up 69% of the sample and the mean number of people in participants' personal network was 16.69 (SD 9.66). The mean support received was 0.85 (SD 0.66) for practical and 1.72 (SD 0.71) for emotional support. Loneliness was, on average, low (mean 1.81, SD 2.41). Although the majority of participants reported one or more chronic conditions (75%), mean self-perceived health (2.31, SD 0.90) was good to fair. The vast majority demonstrated normal cognitive functioning (95%). The mean anxiety score was 2.69 (SD 3.02) (indicating low anxiety) and the mean depressive symptom score was 7.29 (SD 6.81) (indicating few depressive symptoms) (Table 1).

#### *Treatment preferences*

The majority of participants preferred to forgo one or more life-sustaining treatments: 78% and 85% in the cancer and dementia scenario respectively. Treatment preferences, however, depended on the end-of-life scenario and the specific treatment in question: in the dementia scenario, more participants wanted to forgo all treatments. In the cancer scenario, a similar proportion of people desired antibiotics (45%), mechanical respiration (44%) and artificial hydration and nutrition (41%). The least frequently desired treatment was CPR, preferred by 29% of participants. Likewise, in the dementia scenario, similar proportions of people desired antibiotics (29%), mechanical respiration (31%) and artificial hydration and nutrition (26%). The least frequently desired treatment was CPR, preferred by 17% of participants (Graph 1). Responses for life-sustaining treatment preferences correlated highly with each other. Correlation coefficients were lower in the cancer scenario (ranging from 0.55 to 0.73), however, compared with the dementia scenario (ranging from 0.66 to 0.79) (data not shown).



**Graph 1.** Older people's preferences for each life-sustaining treatments (n=1484). Adjusted valid percentages reported (weighted for age and sex). Missing values for treatment preferences were 8.2-9.4% cancer and 9.2-10.9% dementia scenario. Missing values for the variable "all four treatments", a combination of individual preference responses, were 11.9% cancer and 13.5% dementia scenario.

### *Factors associated with forgoing treatment*

Factors associated with the desire to forgo one or more end-of-life treatments in univariate and multivariable analyses are shown in Table 2 for the cancer scenario and Table 3 for the dementia scenario. Factors significant in multivariable analysis are discussed below.

#### Socio-demographic characteristics

Increasing age was negatively associated with the desire to forgo one or more end-of-life treatments in multivariable analysis in the cancer scenario only (OR 0.97).

Although gender was not significantly associated with the desire to forgo in univariate analysis in either scenario, female gender was positively associated with forgoing in the multivariable analysis in the cancer scenario (OR 1.76), indicating a possible suppressor effect. Entering other independent variables individually into a forced enter regression with gender (analysis not shown) revealed that female gender was significantly positively associated with forgoing in the case of cancer when any of the following were controlled for: church membership; education; income; and emotional support.

**Table 2.** Associations between participant characteristics and the desire to forgo one or more end-of-life treatments in case of cancer.

		<b>Cancer</b>		
		<b>Prefer to forgo treatments n (%)§</b>	<b>Univariate OR (95% CI)</b>	<b>Multivariable† OR (95% CI)</b>
<b>Socio-demographics</b>				
Age		1005 (78)	<b>0.97 (0.95, 0.98)***</b>	<b>0.97 (0.94, 0.99)**</b>
Gender	Male	454 (77)	1	1
	Female	551 (79)	1.19 (0.92, 1.54)	<b>1.76 (1.23, 2.51)**</b>
Ethnicity	Dutch/Netherlands	999 (78)	1	1
	Other	6 (38)	<b>0.22 (0.08, 0.64)**</b>	<b>0.09 (0.02, 0.34)***</b>
Religious affiliation	None	493 (88)	1	1
	Protestant	241 (66)	<b>0.26 (0.19, 0.36)***</b>	<b>0.23 (0.16, 0.34)***</b>
	Catholic	257 (74)	<b>0.39 (0.28, 0.55)***</b>	<b>0.38 (0.26, 0.57)***</b>
	Other	14 (81)	0.50 (0.16, 1.57)	0.44 (0.12, 1.57)
Education	Low	210 (70)	1	1
	Medium	344 (75)	1.28 (0.93, 1.75)	1.09 (0.73, 1.62)
	High	451 (85)	<b>2.37 (1.70, 3.32)***</b>	<b>1.58 (1.01, 2.48)*</b>
Household income	Low	257 (66)	1	1
	Medium	318 (81)	<b>2.00 (1.44, 2.76)***</b>	<b>1.85 (1.27, 2.67)**</b>
	High	330 (87)	<b>3.07 (2.15, 4.38)***</b>	<b>2.46 (1.59, 3.81)***</b>
<b>Social support</b>				
<i>Structural network</i>				
Partner status	Partner co-residing	661 (78)	0.91 (0.69, 1.19)	<b>0.61 (0.42, 0.90)*</b>
	No partner co-residing	343 (78)	1	1
Total network size		963 (78)	1.01 (1.00 <sup>a</sup> , 1.03)	1.02 (1.00 <sup>a</sup> , 1.04)
<i>Functional receipt of support</i>				
Practical support		805 (78)	<b>0.79 (0.65, 0.96)*</b>	0.90 (0.70, 1.15)
Emotional support		928 (78)	0.83 (0.69, 1.01)	<b>0.75 (0.59, 0.96)*</b>
<i>Perceived support</i>				
Loneliness score (scores >3)		555 (77)	0.97 (0.92, 1.02)	0.98 (0.91, 1.05)
<b>Physical health</b>				
Chronic disease	No chronic disease	228 (78)	1.06 (0.77, 1.44)	0.67 (0.45, 1.01)
	Has one or more chronic diseases	776 (78)	1	1
Perception of health		1004 (78)	<b>0.85 (0.73, 0.97)*</b>	0.93 (0.75, 1.15)
Pain	Yes	307 (77)	0.94 (0.71, 1.24)	1.28 (0.86, 1.92)
	No	693 (78)	1	1
Physical limitations		541 (75)	<b>0.94 (0.88, 1.00<sup>a</sup>)*</b>	0.99 (0.89, 1.10)
<b>Mental health</b>				
Cognitive functioning (MMSE, cut off 23/24)	Low functioning (<24)	40 (59)	1	1
	Normal functioning	964 (79)	<b>2.45 (1.49, 4.05)***</b>	1.38 (0.69, 2.75)
Anxiety (HADS-A, cut-off 7/8)		708 (76)	0.97 (0.93, 1.01)	0.94 (0.87, 1.01)
Depressive symptoms (CESD, cut-off 15/16)		897 (77)	0.99 (0.97, 1.01)	1.03 (0.99, 1.07)

§ True n and adjusted valid percentages reported (adjusted = weighted for age and sex).  
† Multivariable logistic regressions (forced enter – two tailed). Dependent variable: 0 – desire to have all four life-sustaining treatments, 1 - desire to forgo one or more end-of-life treatments  
\*, \*\*, and \*\*\* indicate significance at the p < .05, p < .01, and the p < .001 levels, respectively.  
<sup>a</sup> Value less than 1.00 at 3dp.  
Multicollinearity tests – 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.

**Table 3.** Associations between participant characteristics and the desire to forgo one or more end-of-life treatments in case of dementia.

		<b>Dementia</b>		
		<b>Prefer to forgo treatments n (%)§</b>	<b>Univariate OR (95% CI)</b>	<b>Multivariable† OR (95% CI)</b>
<b>Socio-demographics</b>				
Age		1088 (85)	<b>0.97 (0.96, 0.99)**</b>	0.98 (0.96, 1.01)
Gender	Male	504 (85)	1	1
	Female	584 (86)	1.07 (0.79, 1.45)	1.40 (0.93, 2.10)
Ethnicity	Dutch/Netherlands	1080 (86)	1	1
	Other	8 (56)	<b>0.28 (0.09, 0.87)*</b>	<b>0.18 (0.04, 0.74)*</b>
Religious affiliation	None	523 (93)	1	1
	Protestant	266 (74)	<b>0.21 (0.14, 0.31)***</b>	<b>0.17 (0.10, 0.26)***</b>
	Catholic	284 (84)	<b>0.37 (0.24, 0.56)***</b>	<b>0.39 (0.24, 0.63)***</b>
	Other	15 (85)	0.37 (0.10, 1.34)	0.32 (0.08, 1.30)
Education	Low	237 (81)	1	1
	Medium	379 (82)	1.08 (0.75, 1.56)	0.88 (0.56, 1.39)
	High	472 (91)	<b>2.22 (1.48, 3.33)***</b>	1.32 (0.77, 2.24)
Household income	Low	286 (77)	1	1
	Medium	346 (87)	<b>1.84 (1.27, 2.66)**</b>	<b>1.69 (1.11, 2.58)*</b>
	High	346 (91)	<b>3.02 (1.97, 4.64)***</b>	<b>2.32 (1.39, 3.88)**</b>
<b>Social support</b>				
<i>Structural network</i>				
Partner status	Partner co-residing	721 (85)	1.00 (0.73, 1.38)	0.73 (0.47, 1.12)
	No partner co-residing	366 (85)	1	1
Total network size		1035 (85)	<b>1.02 (1.00, 1.04)*</b>	<b>1.02 (1.00, 1.05)*</b>
<i>Functional receipt of support</i>				
Practical support		869 (85)	<b>0.71 (0.56, 0.89)**</b>	0.82 (0.61, 1.09)
Emotional support		1000 (86)	0.83 (0.66, 1.04)	0.83 (0.63, 1.10)
<i>Perceived support</i>				
Loneliness score (scores >3)		591 (84)	<b>0.94 (0.89, 1.00<sup>a</sup>)*</b>	0.97 (0.89, 1.05)
<b>Physical health</b>				
Chronic disease	No chronic disease	251 (87)	1.17 (0.81, 1.70)	0.72 (0.44, 1.17)
	Has one or more chronic diseases	836 (85)	1	1
Perception of health		1087 (85)	<b>0.82 (0.70, 0.97)*</b>	1.04 (0.81, 1.33)
Pain	Yes	322 (82)	0.75 (0.55, 1.03)	1.08 (0.68, 1.71)
	No	760 (87)	1	1
Physical limitations		580 (82)	<b>0.87 (0.81, 0.93)***</b>	0.90 (0.80, 1.01)
<b>Mental health</b>				
Cognitive functioning (MMSE, cut off 23/24)	Low functioning (<24)	44 (72)	1	1
	Normal functioning	1043 (86)	<b>2.40 (1.35, 4.24)**</b>	1.67 (0.80, 3.51)
Anxiety (HADS-A, cut-off 7/8)		765 (84)	<b>0.93 (0.89, 0.97)**</b>	<b>0.91 (0.83, 0.99)*</b>
Depressive symptoms (CESD, cut-off 15/16)		971 (85)	<b>0.98 (0.96, 1.00<sup>a</sup>)*</b>	1.04 (1.00 <sup>a</sup> , 1.09)

§ True n and adjusted valid percentages reported (adjusted = weighted for age and sex).  
† Multivariable logistic regressions (forced enter - two tailed). Dependent variable: 0 - desire to have all four life-sustaining treatments, 1 - desire to forgo one or more end-of-life treatments.  
\*, \*\*, and \*\*\* indicate significance at the p < .05, p < .01, and the p < .001 levels, respectively.  
<sup>a</sup> Value less than 1.00 at 3dp.  
Multicollinearity tests - 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.

Membership of a minority ethnic group was negatively associated with the desire to forgo treatments in multivariable analysis in case of cancer (OR 0.09) and dementia (OR 0.17). Religious affiliation was also significant: multivariable analysis showed membership of the Catholic or a Protestant church to be negatively associated with the desire to forgo treatments, compared with no religious affiliation in the cancer (Protestant OR 0.23, Catholic OR 0.38) and dementia scenario (Protestant OR 0.17; Catholic OR 0.39).

Multivariable analysis indicated that, in the cancer scenario, a high level of education (11 years or more) was positively associated with the desire to forgo, compared with a low level of education, (OR 1.60). Also in the cancer scenario, higher monthly household income categories were positively associated with the desire to forgo, compared with the low income category, in the case of cancer (medium OR 1.84, high OR 2.45) and dementia (medium OR 1.69, high OR 2.30).

#### Social support

Partner status was not significantly associated with forgoing treatments in univariate analysis. However, multivariable analysis indicated that living with a partner, compared with living without a partner, was negatively associated with the desire to forgo treatments in the cancer scenario (OR 0.61) – again, a potential suppressor effect. Further analysis (not shown) revealed that living with a partner was significant when either age or personal network size was controlled for.

Personal network size was positively associated with the desire to forgo treatments in multivariable analysis in case of dementia (OR 1.02).

Emotional support was not significantly associated with forgoing treatments in univariate analysis. However, it showed a protective effect in multivariable analysis for the cancer scenario (OR 0.75) (Table 2). Further analysis (not shown) demonstrated that when age, sex, ethnicity, education or network size was controlled for, emotional support was significant.

#### Health

In multivariable analysis, only one health related factor was significantly associated with a desire to forgo treatments once other factors had been controlled for: anxiety was negatively associated with the desire to forgo treatments for the dementia scenario only (OR 0.91).

## **Discussion**

The findings illustrate that, when faced with end-of-life scenarios involving cancer and dementia, the majority of older people prefer to forgo a life-sustaining treatment. Treatments were desired less frequently in the dementia compared to the cancer scenario and participants' preferences to forgo treatments were also most consistent in the dementia scenario. This suggests that older people find cognitive impairment less acceptable than physical cancer pain, even when such pain is accompanied with an inability to communicate.

Although previous research has found that more invasive procedures are, in general, less acceptable than non-invasive treatments, such as antibiotics, that was not the case in this study. Mechanical ventilation, an intensive and invasive intervention, was the second most frequently preferred treatment in the cancer scenario and the most frequently preferred treatment in the dementia scenario. This may reflect specific fears surrounding suffocating or choking to death[35-37] or participants' understanding of what the treatment entails, which may have been influenced, for example, by media representations that depict ventilation as part of a 'controlled death' in which family members are able to say goodbye before ventilation is withdrawn. Cardio-pulmonary resuscitation, the burdens of which are perhaps more commonly understood, was however the least preferred treatment.

Preferences for forgoing treatments differed in relation to participants' characteristics. The complex relationship between the multidimensional 'social support' variable and treatment preferences was perhaps the most novel finding. Personal network size was positively associated with forgoing treatments in the dementia scenario. A potential explanation is linked to the greater possibility of encountering end-of-life situations involving friends, family or acquaintances that a larger social network brings. These encounters and the resultant awareness of the suffering experienced at the end of life may engender negative attitudes towards life-sustaining treatments, particularly in the case of cognitive decline. Living with a partner and receipt of higher levels of emotional support from one's personal network, in contrast, were associated with a preference to have all four treatments in the cancer scenario. A live-in partner is commonly the most important source of practical and emotional support, and an emotionally supportive and close network may dampen any desire to hasten death when faced with cancer. In contrast, mental deterioration might be perceived as damaging to close personal relationships, which may prove less acceptable. Within a Fundamental Cause Theory framework, the findings suggest that those with more immediate or emotionally supportive social



resources are more likely to wish to extend their lives in poor physical, but not mental, health.

In contrast, participants' physical and mental health – often considered important determinants of treatment preferences – were not associated with end-of-life treatment preferences once other factors had been controlled for (with the exception of anxiety and a preference for all four treatments in dementia). This suggests that, contrary to the predictions of Prospect Theory, in general, they are of limited importance to people's preference choices. Moreover, it is possible that participants suffering from anxiety have exaggerated fears about the withholding of treatments in the case of cognitive decline.

Older age was negatively associated with the desire to forgo treatments in the cancer scenario. In contrast, previous studies amongst older people from the United States have found age to be positively associated with a desire to forgo treatments[4,5,10]. In addition to an age effect, however, a cohort effect may be considered. The younger old in the current study may have been particularly influenced by the intense public debate concerning end-of-life care that occurred six years prior to data collection, around the time of the legalization of euthanasia[38,39]. To date, the item regarding life-sustaining treatment preferences has only been included in one round of LASA data collection, future use of this item would provide the longitudinal data necessary to determine if this finding is a result of a specific cohort effect or the effect of ageing on preferences.

Other socio-demographic characteristics were associated with end-of-life treatment preferences in ways that, in general, supported previous research. Women were more likely to express a preference to forgo treatments in the cancer scenario and this finding is consistent with those of other studies that have found women to prefer less aggressive end-of-life care[3,8,9,13,17,22]. Arber *et al.*[7], in a qualitative study of older people's attitudes towards life-prolonging technology, related women's preference to forgo life-sustaining treatments to their greater life-time involvement in caring for others and putting the concerns of others before their own.

Membership of a minority ethnic group was strongly associated with a preference for all four life-sustaining treatments. Although the Netherlands is a multicultural society, mass immigration only began in the late 1960s and the age structure of the minority ethnic population is younger than that of the Dutch white population[40]. Due to the age of the LASA participants, few participants were members of a minority ethnic group; this makes the magnitude and significance of the association even more

remarkable. De Graaff *et al.*[41], in a qualitative study amongst patients and carers of Turkish and Moroccan descent (two of the largest minority ethnic groups in the Netherlands), revealed that patients and families prefer starting life-sustaining treatments to maintain hope of recovery.

Another important socio-demographic variable was church affiliation. Protestant and Catholic affiliations were negatively associated with forgoing life-sustaining treatments. Although neither the Catholic nor the major Dutch Protestant churches oppose forgoing 'extraordinary' life-sustaining measures[42-44], the churches' vitalist rhetoric in connection to the euthanasia debate may have created ambiguity regarding their position amongst their members.

Forgoing treatments was also associated with a high level of education (11 years or more). Garrett *et al.*[3], in a survey of older patients concerning treatment preferences, observed a similar association. Better-educated participants may be more informed about the burden of life-sustaining treatments and, therefore, choose to forgo them.

Higher monthly household income was positively associated with the desire to forgo treatments. The importance of income, even when education and other socio-demographic variables were controlled for, is striking. Carr *et al.*[45] found a similar association between net worth and advance directive possession and hypothesized that those with greater financial resources may be more inclined to write a will and, in doing so, be encouraged to carry out health care planning.

### *Strengths and limitations*

This is the first study to examine older Dutch people's preferences for different life-sustaining treatments within a representative sample of the older population. Moreover, it is the first to comprehensively examine the influence of social support next to socio-demographic, physical and mental health factors on preferences for life-sustaining treatments.

There were, however, some limitations. Participants were asked about treatment preferences but were not provided with detailed descriptions of the treatments or associated burdens. It is, therefore, unclear how informed preferences were. Furthermore, preferences in hypothetical scenarios may not reflect decisions in situations of actual illness. Advance directive documents, however, often require people to identify preferences regarding specific treatments in hypothetical situations.

There was a relatively high proportion of missing data regarding treatment preferences. Non-responders and participants for whom the main outcome variable was missing also had statistically different characteristics to those who did complete the items. These findings may reflect the challenges older and less educated participants faced answering a self-administered questionnaire or indeed the difficulty many people have thinking about end-of-life preferences. As responders and non-responders differed on variables found to be associated with treatment preferences (age, sex, church membership and education), this may have led to a slight underestimation in the preference for each life sustaining treatment.

### **Conclusions**

In light of findings that many older people would prefer to forgo life-sustaining treatments at the end of life, particularly in the case of dementia, it is imperative that preferences are discussed with relatives and healthcare professionals in a timely manner to avoid unwanted interventions.

In this population, social support had a greater influence on preferences than participants' current physical, cognitive and emotional health. As social structures continue to change, it is important to understand how social support might influence medical end-of-life treatment preferences. This, together with awareness of the more commonly recognized influences of socio-demographic characteristics and health, may enhance the advance care planning process by encouraging healthcare professionals to explore patients' expectations and fears about social support at the end of life.

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