

Prevalence, symptoms and risk profiles of apathy at old age Koolhoven, I.

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# Chapter 6

Quality of life in community-dwelling older persons with apathy

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### **Abstract**

# **Objective**

To investigate the relationship between apathy and perceived quality of life in groups both with and without depressive symptoms or cognitive impairment.

#### Methods

We conducted a cross-sectional study comparing quality of life in older persons with and without apathy in 19 Dutch general practices. Participants were 1,118 older persons aged at least 75 years without current treatment for depression and a Mini-Mental State Examination score of at least 19. Perceived quality of life was determined using Cantril's Ladder for overall quality of life, EuroQol (EQ)-5D thermometer for subjective health quality, and De Jong-Gierveld Loneliness questionnaire for perceived loneliness. Apathy was assessed with the Apathy Scale.

#### Results

Of the 1,118 older persons, apathy was present in 122 (11%) of them. Overall, apathy was associated with having no work, lower level of education, presence of depressive symptoms, cognitive impairment, and decreased scores on all quality of life measures. Among the 979 (88%) older persons without depressive symptoms and cognitive impairment, apathy was present in 73 (7.5%) of them, showing similar associations as in the total population. In the 77 (7%) persons with cognitive impairment only, apathy was correlated to a lower score on the EQ-5D thermometer. However, in the 51 (5%) depressed persons without cognitive impairment, presence of apathy did not contribute to their decreased quality of life.

#### Conclusion

Apathy frequently occurred in community-dwelling older persons, also in the absence of depressive symptoms and cognitive impairment. In them, apathy contributed to the perception of a diminished quality of life in various aspects of daily life.

#### Introduction

Apathy is an important behavioral syndrome of several neuropsychiatric diseases, including depression and dementia, and is associated with reduced daily functioning,<sup>1-5</sup> caregiver distress <sup>6,7</sup> and poor functional outcome.<sup>3,4,8-14</sup> Consensus diagnostic criteria for apathy have been proposed<sup>15</sup> and tested in clinical populations suffering from different neuropsychiatric diseases.<sup>16</sup> Apathy is defined as a disorder of motivation that persists over time and is characterized by impairment of goal-directed behaviour, goal-directed cognitive activity, and/or emotions leading to functional impairments.<sup>2,15-19</sup> Of the few studies investigating apathy in community-based older populations,<sup>20-26</sup> the prevalence of apathy ranged from 6 to 51%. The various risk factors for apathy include increasing age,<sup>20,23,26</sup> although not consistently,<sup>21</sup> having no partner and/or living alone,<sup>21</sup> male gender,<sup>26</sup> cognitive impairment,<sup>21,27,28</sup> depressive symptoms,<sup>21,22,26</sup> and cardiovascular disease (CVD), including stroke and/or risk factors for CVD.<sup>22,29</sup> Apathy has also been associated with decreased daily functioning<sup>20,21</sup> and increased caregiver distress.<sup>21</sup>

It is often proposed that, in particular, caregivers of patients with apathy suffer more than the patients themselves due to the frequent presence of a lack of insight in apathy. However, few studies have investigated quality of life among older patients with apathy. One study found that among community-dwelling older persons who lived alone, apathy was not related to diminished quality of life,<sup>30</sup> which is in contrast to findings among clinical populations with dementia<sup>31,32</sup> and Parkinson disease.<sup>33</sup>

In the present cross-sectional study, we investigated whether apathy is associated with different aspects of perceived quality of life among community-dwelling older persons aged at least 75 years, both with and without comorbid depressive symptoms and cognitive impairment. Since depression and impaired cognition are well-known risk factors for both apathy and diminished quality of life, we were also interested in the additional effect of apathy on quality of life in this age group.

#### **Methods**

### **Subjects**

This sub-study was part of the PROMODE (PROactive Management Of Depression in the Elderly) study. The primary aim of this randomized controlled trial was to investigate the (cost-) effectiveness of a combined screening and treatment program for older persons aged at least 75 years with depressive symptoms, in general practices in the Leiden region (the Netherlands).<sup>34</sup>

The original study population consisted of 2,759 registered persons aged at least 75 years from 19 general practices (Figure 1). A total of 366 persons fulfilled the

following exclusion criteria: a life expectancy of no more than 3 months (n=22), current treatment for depression (n=141), loss of partner no more than 3 months ago (n=21), a diagnosis of dementia (n=114) and various other reasons (n=68). Of the remaining 2,393 persons who were invited to participate, 1,054 were non-responders (response rate 56%), and another 101 persons were excluded before/during the baseline interview due to current treatment for depression (n=37), decreased cognition (n=30), and other reasons (n=34). An additional 120 persons were excluded because of inadequate or missing data (Figure 1). This resulted in a total of 1,118 persons for inclusion in this substudy on apathy and quality of life.

The Medical Ethical Committee of the Leiden University Medical Centre approved the study.

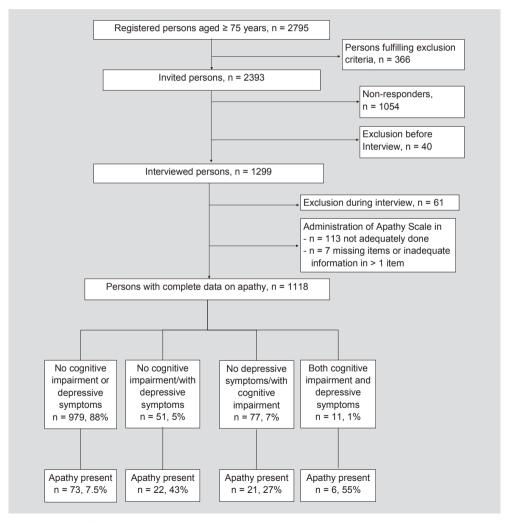


Figure 1. Flow chart PROMODE

#### Measures

# Assessment of apathy

Apathy was assessed during a face-to-face interview using the Apathy Scale, <sup>35</sup> which is an abbreviation of the Apathy Evaluation Scale (AES), <sup>36</sup> and measures apathetic symptoms present in the last 4 weeks. The Apathy Scale, that has good inter-rater reliability and internal validity in patients suffering from Parkinson disease, consists of 14 items with four possible answers ranging from 0 to 3 points. Higher scores indicate more severe apathy. <sup>35</sup> A score of at least 14 points is indicative for the presence of apathy. <sup>11,35,37</sup>

# Assessment of perceived quality of life

To assess (various aspects of) quality of life the following three measures were used: 1) Cantril's Ladder,<sup>38</sup> a visual analogue scale (VAS) ranging from 1 (very bad) to 10 (excellent) for overall quality of life; 2) the EuroQol (EQ)-5D thermometer,<sup>39</sup> ranging from 0 to 100 for subjective health quality, that is a valid measure for determining subjective health quality;<sup>40</sup> and 3) the De Jong-Gierveld Loneliness questionnaire for perceived loneliness.<sup>41</sup> This latter questionnaire consists of 6 items with a maximum score of six points; higher scores indicate more severe loneliness and a score of at least 2 indicates the presence of perceived loneliness.

# Assessment of depressive symptoms and cognitive function

The 15-item Geriatric Depression Scale (GDS-15) was administered by an interviewer as a screening instrument for depressive symptoms.  $^{42,43}$  The GDS-15 ranges from 0 to 15 points, with higher scores indicating more depressive symptoms. A score of at least five points is considered indicative for the presence of clinically relevant depressive symptoms in older persons in general practice, with a sensitivity of 92% and a specificity of 81%.  $^{44,45}$ 

Information on global cognitive functioning was assessed with the Mini-Mental State Examination (MMSE), which is a screening instrument with a good inter-rater and test-retest reliability. 46-48 Persons with an MMSE baseline score less than 19 points, indicating severe cognitive impairment, were excluded because this would compromise the reliability and validity of the measures used. A cut-off score of no more than 23 points was used for the presence of cognitive impairment.

#### Additional measures

For all persons, sociodemographic characteristics were obtained. Abuse of alcohol was defined as drinking at least 14 consumptions per week. Presence of anxiety was measured using the 7-item anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A), with scores ranging from 0-21 points, and at least 8 points suggesting the presence of an anxiety disorder. This cut-off has a sensitivity and specificity of 90%.<sup>49;50</sup>

# Statistical analyses

Data are presented as numbers with percentages, medians with interquartile ranges (IQR), or means with standard deviations (SD) where appropriate. Using univariate logistic regression analyses, older persons with and without apathy were compared on all three quality of life measures, and on sociodemographic, neuropsychiatric, and clinical characteristics. Median scores of Cantril's Ladder and the EQ-5D thermometer were used as cut-off scores. Multivariate (logistic) regression analysis, thereby entering variables with a p-value < 0.05 as well as age and gender, was used to determine independent correlates for apathy. Multivariate analyses were performed in two models because of multicollinearity: one model with all variables except Cantril's Ladder (data presented) and one model with all variables except EQ-5D (only odss ratios and statistics of EQ-5D presented).

The relationship between apathy and quality of life measures in older persons with and without comorbid clinically relevant depressive symptoms (GDS-15  $\geq$  5) and cognitive impairment (MMSE  $\leq$  23) was investigated in four groups of older persons: 1) without both clinically relevant depressive symptoms and cognitive impairment, 2) with depression but without cognitive impairment, 3) without depression but with cognitive impairment, and 4) with both depression and cognitive impairment. Because the group of older persons with both depression and cognitive decline appeared to include only 11 persons, no further analyses regarding this subgroup were done, given the small sample size. Post hoc bivariate analyses within subgroups were computed with Pearson chi-square testing. Missing values were imputed with values representing a good Quality of Life (Cantril's ladder  $\geq$  8 and EQ-5D thermometer score  $\geq$ 75).

A p-value < 0.05 was considered statistically significant. Statistical analyses were performed with SPSS 17.0 for Windows 7 (IBM).

#### **Results**

# Sociodemographic and clinical characteristics

Table 1 presents the sociodemographic and clinical characteristics of the total study population (n=1,118). Mean age was 82 (SD: 5, range: 74-103) years. The median score on the Apathy Scale for the total population was 7 (IQR: 4-10), whereas 122 older persons (11%) had a score of at least 14, indicative for having apathy. A total of 62 (6%) persons had depressive symptoms based on a GDS score of at least 5, and 88 (8%) showed cognitive impairment based on an MMSE score of no more than 23.

Figure 1 shows the presence of apathy in the four subgroups of older persons. Among older persons without both clinically relevant depressive symptoms and cognitive impairment 73 (7.5%) showed apathy. In almost half of the older persons with depressive symptoms apathy was present, whereas apathy was present in more than one-fourth of older persons with cognitive impairment. Also, in more than half of the

99

older persons with both depressive symptoms and cognitive impairment, apathy was present. Because this latter subgroup comprised only 11 persons, no further analyses regarding this subgroup were done, given the small sample size.

**Table 1.** Sociodemographic and clinical characteristics of all 1,118 older persons

Sociodemographic characteristics	02	(5.74.100)
Age in years, mean (SD, range)	82	(5, 74-103)
Female sex, n (%)	684	(61)
Income social security only, n (%)	141	(13)
No volunteer or paid work, n (%)	909	(81)
Living alone, n (%) <sup>a</sup>	641	(57)
Independent living, n (%) <sup>b</sup>	1074	(96)
Low level of education, n (%) <sup>c</sup>	333	(30)
Clinical characteristics		
Alcohol use > 14 drinks/week, n (%)	99	(9)
Quality of life		
Cantril's Ladder score, median (IQR)	8	(7-8)
Cantril's Ladder score < 8, n (%)	469	(42)
EQ-5D thermometer score, median (IQR)	75	(64-80)
EQ-5D thermometer score < 75, n (%)	518	(46)
De Jong-Gierveld Loneliness score, median (IQR)	1	(0-2)
De Jong-Gierveld Loneliness score ≥ 2, n (%)	338	(30)
Neuropsychiatric characteristics		
Apathy Scale score, median (IQR)	7	(4-10)
Apathy Scale score ≥ 14, n (%)	122	(11)
Geriatric Depression Scale score, median ( IQR)	1	(0-2)
Geriatric Depression Scale score ≥ 5, n (%)	62	(6)
Hospital Anxiety Scale-Anxiety score, median (IQR) <sup>d</sup>	2	(0-3)
Hospital Anxiety Scale-Anxiety score ≥ 8, n (%)	48	(4)
Mini Mental Status Examination score, median (IQR)	8	(27-29)
Mini Mental Status Examination score ≥19≤ 23, n (%)e	88	(8)

Notes: Data are presented as numbers (percentages), means (standard deviations) or medians (interquartile ranges), where appropriate.

<sup>&</sup>lt;sup>a</sup> Being widowed/divorced;

b not living in an elderly home or nursing home;

<sup>&</sup>lt;sup>c</sup> maximum of 6 years of schooling;

<sup>&</sup>lt;sup>d</sup> anxiety subscale of the Hospital Anxiety Depression Scale;

<sup>&</sup>lt;sup>e</sup> subjects with Mini-Mental Status Examination < 19 were excluded.

# Comparison of older persons with and without apathy

Using univariate analysis, Table 2 shows that older persons with apathy more often had a diminished perceived quality of life compared with those without apathy, as assessed with Cantril's Ladder, the EQ-5D thermometer, and the De Jong-Gierveld Loneliness questionnaire. Also, older persons with apathy more often showed clinically relevant depressive symptoms and cognitive impairment. Furthermore, older persons with apathy less often had volunteer or paid work, less often lived alone and independently, and more often had a low level of education. Using multivariate analysis, all quality of life measures and neuropsychiatric characteristics as well as having no (volunteer or paid) work and a low level of education appeared to be independent correlates for apathy (Table 2).

# Comparison of subgroups of older persons with and without apathy

Figure 2 and table 3 show perceived quality of life according to the different measures used, in subgroups of older persons with and without apathy.

In the 979 older persons without both cognitive impairment and depressive symptoms, apathy was associated with a diminished quality of life as assessed with Cantril's Ladder the EQ-5D thermometer and the De Jong-Gierveld Loneliness questionnaire. Furthermore, among these older persons, apathy was associated less with often having volunteer (or paid) work and more often with having a low level of education.

Among the 77 older persons with cognitive impairment, the presence of apathy did not affect quality of life. Among the 51 older persons with depressive symptoms, quality of life was low and did not differ between older persons with and without apathy. Remarkably, in depressed older persons, the presence of apathy did not further affect their already poor quality of life.

For sensitivity analysis, all analyses for Table 3 were repeated using the continuous scores of Cantril's Ladder, the EQ-5D thermometer, and the De Jong-Gierveld Loneliness questionnaire; cut-off scores 5/6 and 6/7 for Cantril's Ladder, less than 70 and less than 80 for the EQ-5D thermometer, and at least 3 for the De Jong-Gierveld Loneliness questionnaire; and by excluding missing values for Cantril's ladder and the EQ-5D thermometer. These yielded similar results, except for the EQ-5D thermometer in the cognitively impaired older persons: a cut-off score less than 70 and excluding missing values showed a lower quality of life in the subgroup with apathy compared to the subgroup without apathy. Furthermore, in the depressed older persons a cut-off score 5/6 for Cantril's ladder showed a lower quality of life in the subgroup with apathy.

Table 2. Sociodemographic and clinical characteristics of older persons with and without apathy

		Apathy	thy			Univariate analyses	analyses			Multivariate analyses	te analys	S
	Ab	Absent	Pre	Present								
	n=	966=u	n=	n=122	OR	95% CI	Wald	p-value	OR	95% CI	Wald	p-value
Sociodemographic characteristics												
Age, Years, mean (SD)	82	(5)	82	(5)	1.0	(0.98-1.06)	1.298	0.255	0.98	(0.9-1.0)	0.431	0.511
Female sex, n (%)	610	(61)	74	(61)	1.0	(0.7-1.4)	6.0	6.0	0.7	(0.4-1.1)	2.988	0.084
No volunteer or paid work, n (%)	792	(80)	117	(96)	6.6	(3.1-31.6)	<0.005	<0.005	8.5	(2.6-27.8)	12.374	<0.005
Living alone, n (%)	561	(99)	80	(99)	1.5	(1.0-2.2)	0.052	0.052	8.0	(0.5-1.3)	1.007	0.316
Independent living, n (%) <sup>a</sup>	961	(26)	113	(63)	0.5	(0.2-0.98)	0.043	0.043	1.0	(0.4-2.5)	0.055	0.814
Low level of education, n (%) <sup>b</sup>	275	(28)	28	(48)	2.4	(1.6-3.5)	<0.005	<0.005	1.9	(1.2-2.9)	8.818	0.003
Clinical characteristics												
Alcohol use > 14 drinks/week, n (%)	87	6)	12	(10)	1.2	(0.6-2.2)	0.601	0.601	١	1	1	1
Quality of life												
Cantril's Ladder score < 8, n (%)	392	(39)	77	(63)	2.8	(1.9-4.1)	<0.005	<0.005	1.7	(1.1-2.7)	5.785	0.016
EQ-5D thermometer score < 75, n (%)	439	(44)	79	(65)	2.5	(1.7-3.8)	<0.005	<0.005	1.7	(1.1-2.6)	5.305	0.021
De Jong-Gierveld Loneliness score ≥ 2, n (%)	273	(27)	65	(53)	3.0	(2.1-4.4)	<0.005	<0.005	2.1	(1.3-3.3)	13.376	<0.005
Neuropsychiatric characteristics												
Geriatric Depression Scale score ≥ 5, n (%)	34	(3)	28	(23)	8.4	(4.9-14.5)	<0.005	<0.005	4.8	(2.7-9.0)	25.393	<0.005
Hospital Anxiety Scale score ≥ 8, n (%) °	42	(4)	9	(5)	1.2	(0.5-2.8)	0.722	0.722	1	ı	ı	1
Mini Mental State Examination score $\geq$ 19 $\leq$ 23, n (%) <sup>d</sup>	19	(9)	27	(22)	4.4	(2.6-7.2)	<0.005	<0.005	2.3	(1.3-4.2)	7.478	900.0
		;		,								

Notes: Data are presented as numbers (percentages) or means (standard deviations) where appropriate;

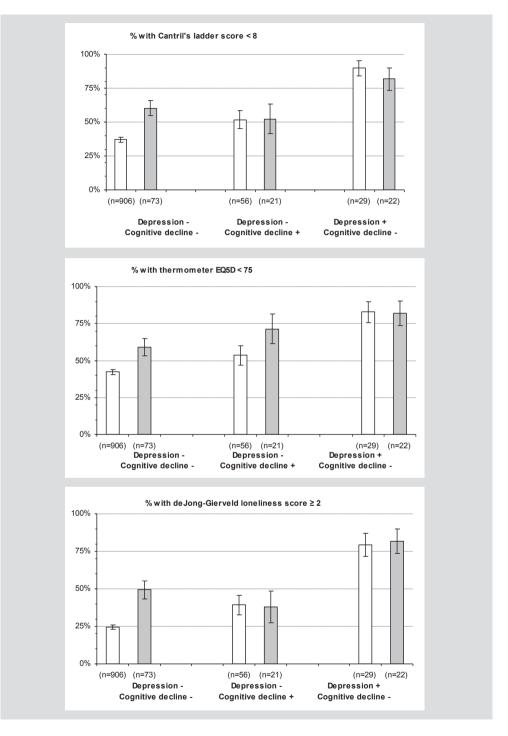
Univariate and multivariate logistic regression analyses with df=1 for all variables, Odds ratios (OR) with 95% confidence intervals (CI), and Wald chi-square statistics;

anot living in a residential home or nursing home;

b maximum of 6 years of schooling;

<sup>&</sup>lt;sup>c</sup> Anxiety subscale of the Hospital Anxiety and Depression Scale;

<sup>&</sup>lt;sup>d</sup> subjects with Mini Mental Status Examination < 19 were excluded.



**Figure 2.** Poor quality of life in subgroups without apathy (white bars) and with apathy (grey bars), as measured with Cantril's ladder, thermometer EQ5D and deJong-Gierveld loneliness scale. Vertical lines in the bars represent the 95% confidence limits.

Table 3. Characteristics of apathy in older persons without cognitive impairment and with or without depressive symptoms.

	Dep	ressive	sympte	Depressive symptoms absent	it of		Depress	sive syl	mpton	Depressive symptoms absent	+ ب	ПС	Depressive symptoms present	ve sym	ptoms	presen	, ,
	Apathy	Apathy	thy			Apa	Apathy	Apathy	hy			Apathy	hy	Apathy	ht.		
	absent	present	ent	$Test^a$	Ь	abs	absent	present		$Test^a$	Д	absent	nt	present		$Test^a$	Д
	n=906	n=73	73			=u	n=56	n=21	1			n=29	66	n=22	2		
Sociodemographic characteristics																	
Age in years, mean (SD)																	
Female sex, n (%)	82 (5)	83	(5)	2.380	0.123	84	(5)	82	(5)	2.881 0.094	0.094	81	(5)	81 (	(5)	0.004 0.952	.952
No volunteer	548 (61)	41	(99)	0.526	0.468	36	(65)	15	(71)	0.348 0.555	0.555	21	(72)	14 (	(64) (	0.448	0.503
or paid work, n (%)	713 (79)	70	(96)	12.294	0.000	52	(63)	20 (	(66)	1.508 0.219	0.219	24	(83)	21 (9	696)	4.023 0.045	.045
Low level of education, n (%) b																	
	277 (25)	32	32 (44)	12.471 0.000	0.000	36	36 (64)	13 (62)		0.037 0.847	0.847	6	(31)	∞	) (98)	0.160 0.689	689.
Clinical characteristics																	
Quality of life																	
Cantril's Ladder score <8, n (%)	335 (37)	44	(09)	15.395	0.000	29	(52)	11	(52)	0.030 0.861	0.861	76	(06)	18 (8	(82) (	0.649 0.421	.421
EQ-5D thermometer score <75, n (%)	383 (42)	43	(69)	7.602	900.0	30	(54)	15 (	(71)	2.005 0.157	0.157	24	(83)	18 (8	(82) C	0.008 0.930	.930
DJG Loneliness score ≥2, n (%)	224 (25)	36	(49)	20.945	0.000	22	(38)	8	(38)	0.009 0.924	0.924	23	(62)	18 (8	(83) (	0.050 0.823	.823
Notes: Data are presented as numbers (percentages) or means (standard deviations) where appropriate. <sup>a</sup> Pearson Chi-square testing for dichotomous variables, and analysis of variance testing for continuous variables. <sup>b</sup> maximum of 6 years of schooling	centages) or 1	means , and a	(standa nalysis	rd deviat of varian	ions) wh	ere app g for co	oropriat	e. ius var	iables.								

### Discussion

In this study, the presence of apathy among community-dwelling older persons was 11%. Although apathy in older persons often co-occurs with depressive symptoms and cognitive impairment, in 7.5% of the community-dwelling older persons, symptoms of apathy occurred in their own right without comorbid depressive symptoms or cognitive impairment. In these older persons, apathy was independently associated with decreased overall quality of life and subjective health quality and with increased perceived loneliness. Furthermore, apathy was associated with having no volunteer or paid work and a lower level of education.

Our results show that, contrary to the clinical impression, patients with apathy themselves also suffer from diminished quality of life, not only their caregivers as reported earlier.<sup>21</sup> In older persons with depressive symptoms, quality of life was already low and the presence of apathy was not additionally associated with any of the quality of life measures. This may be related to a ceiling effect.

The results of this study are in contrast with the only other community-based study on quality of life in apathy, performed among 96 older persons aged at least 70 years who lived alone in a rural Japanese town.<sup>30</sup> In this latter study, remarkably, an extremely high prevalence of apathy (almost 98%) was found as assessed with the Apathy Scale, without any relationship to quality of life. Possibly, demographic and cultural differences had an impact on the very different outcomes compared to our study.

However, our results are very consistent with those of several studies among clinical populations including Alzheimer dementia and Parkinson disease, reporting the presence of apathy to be associated with a diminished quality of life, 31,32,40,51,52 in particular in nursing home residents with a relatively good cognition (MMSE ≥ 18).<sup>52</sup> Still, in these studies, it is unclear whether and to what extent apathy was also associated with diminished quality of life among persons without depressive symptoms or cognitive impairment (which we studied). Nevertheless, in two other studies among patients with Parkinson disease, apathy was independently associated with different dimensions on a self-report questionnaire assessing the impact of Parkinson disease on quality of life. 33,53 To our knowledge, this is the first study among a large population of community-dwelling older persons that investigated the relationship of apathy and perceived quality of life using various (self-rated) measures for quality of life, including overall quality of life according to a visual analogue scale, subjective health quality, and perceived loneliness. Apathy was assessed by trained research nurses using a validated apathy scale and analyzed in stratified samples of older persons with and without depressive symptoms and/or cognitive impairment.

This study has some limitations that need to be addressed. First, our study had a cross-sectional design, making it impossible to determine the temporal relationship of apathy

and quality of life and therefore to draw causal inferences. Also, selection bias may have occurred because older persons with more severe depression and serious cognitive impairment or dementia were lacking, because current treatment for depression, an MMSE score less than 19 points, or presence of a clinical diagnosis of dementia were exclusion criteria for the PROMODE study. Furthermore, due to the low response rate in the original study, the overall presence of apathy of 11% found in this study is probably an underestimation, because older persons with apathy more likely did not participate. In addition, we had no information on neurological disorders such as Parkinson disease and stroke or on objective health status and psychotropic medication use, which are all possible confounders for the association between apathy and our quality of life measures.

Although apathy is commonly a behavioral syndrome of various neuropsychiatric diseases, our study confirms that symptoms of apathy may also occur in their own right in community-dwelling older persons without depressive symptoms and cognitive impairment. This is an important finding because it has been shown, in mostly clinical studies, that apathy is related to decreased daily functioning, a lack of social contacts, and poor functional outcome. Evidence-based effective treatment of apathy, however, is largely lacking and the scarce studies that investigated the effect of pharmacologic and psychosocial interventions were all done in clinical populations with neuropsychiatric diseases such as depression and dementia. As far as we know, no studies have been done in community-dwelling older persons with apathy without neuropsychiatric comorbidity. Nonetheless, education and information about apathy and its possible concomitants may result in a better understanding of and coping with apathy, by the older persons themselves and their caregivers.

#### Conclusion

In community-dwelling persons aged at least 75 years with no comorbid depressive symptoms or cognitive impairment, apathy as a syndrome in its own right frequently occurred in over 7%. In those persons, apathy was associated with a perception of diminished overall quality of life and subjective health quality as well as increased loneliness. No additional effect of apathy on the already low quality of life in depressed older persons was found, whereas in older persons with merely cognitive impairment, apathy was only associated with diminished subjective health quality.

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