



# Apathy and health-related quality of life in nursing home residents

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Accepted: 31 October 2018 / Published online: 7 November 2018  
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## Abstract

**Purpose** To explore the association between apathy and health-related quality of life (HRQoL) from resident and proxy perspectives and whether cognition and depression moderate this relationship.

**Methods** Secondary analyses with baseline data from a cluster randomized trial on the effects of a care program for depression in Nursing Homes (NHs) were conducted. For HRQoL, the Visual Analogue Scale (VAS) and the Dutch version of the European Quality of Life (EQ-5D) were administered to 521 NH residents, and to professional caregivers reporting from the perspective of the NH resident (Resident–Proxy) and from their own perspective (Proxy–Proxy). Utility scores (U) were calculated for the three perspectives. Apathy, depression, and cognition were measured using the 10-item Apathy Evaluation Scale, the Cornell Scale for Depression in Dementia, and the standardized Mini-Mental State Examination, respectively.

**Results** Mixed models adjusted for clustering within NH units revealed that apathy was negatively associated with HRQoL both from the Resident–Proxy perspective (EQ-5D VAS: estimated effect,  $-0.31$ ,  $P < 0.001$ ; EQ-5D Utility:  $-0.30$ ,  $P < 0.001$ ) and from the Proxy–Proxy perspective (VAS:  $-0.29$ ,  $P < 0.001$ ; U:  $-0.03$ ,  $P < 0.001$ ), but not from the Resident–Resident perspective (VAS:  $-0.05$ ,  $P = 0.423$ ; Utility:  $-0.08$ ,  $P = 0.161$ ). Controlling for depression and cognition and their interaction terms with apathy did not change the results.

**Conclusion** Apathy is negatively associated with NH resident HRQoL as reported by proxies. Depression and cognitive functioning do not moderate this association. NH residents do not self-report a relationship between apathy and HRQoL. More research is needed to understand caregiver and NH resident attitudes and underlying assumptions regarding apathy and HRQoL.

**Keywords** Apathy · Quality of Life · Nursing home · Depression · Cognition

## Introduction

Apathy is a very prevalent neuropsychiatric symptom (NPS) in people with neurological or neurodegenerative diseases such as dementia, stroke, and Parkinson's disease [1–5]. The core features of apathy are reduced interest or reduced participation in activities of daily living, early withdrawal from activities, diminished initiative, flattening of affect, and indifference [6–8]. Apathy is associated with adverse outcomes such as increased dependence on and burden in caregivers, earlier institutionalization, more rapid cognitive decline, and increased mortality [5, 9–13].

Predictably, apathy is very common in Nursing Home (NH) residents. Selbaek et al. [5] found that in dementia NH residents, the weighted mean prevalence of apathy was 36% (range 17–82). Although apathy has been shown to be associated with several adverse outcomes in NH residents,

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the relationship between Apathy and QoL is still unclear [14–16]. Mjorud [17] found a negative relationship between proxy-rated apathy and self-reported QoL in NH residents with severe dementia. Gerritsen [18] found that cognition played a moderating role in the relationship between proxy-rated apathy and self-reported QoL: apathy was negatively related with general QoL in NH residents with a high level of cognitive functioning, and positively related with QoL in those with a lower level of cognitive functioning. Accordingly, Yeager [19] found that increased apathy based on proxy rating was associated with worse self-reported QoL, but only for those community-dwelling people with Alzheimer dementia with better cognitive functioning.

The relationship between apathy, cognition, and depression is complex. Fronto-subcortical circuits are involved in apathy, and different anatomical and neural networks relate to different dimensions of apathy such as reduced goal-directed cognitive activity, i.e., cognitive apathy; diminished spontaneous or reactive emotional expression, i.e., emotional apathy; or impaired goal-directed behavior, i.e., auto-activating or behavioral apathy [20–22]. Therefore, cognition needs to be accounted for when exploring the relationship between QoL and apathy [2, 17, 23, 24]. But so does depression, especially given its overlapping features with (emotional) apathy that may (partially) explain the relationship between apathy and QoL [7, 25, 26], and the negative association that exists between depression and QoL in NH residents with dementia [14–16].

QoL is a multidimensional concept. Two approaches are commonly used to measure QoL, the first of which is more general and considers life as a whole. Frameworks that are based on a broad approach are for instance Lawton's framework and social production functions (SPF) theory [27]. Especially for people with dementia, several measurement instruments based on a broad approach exist, such as the Qualidem [28] and the QOL-AD [29]. The second approach looks specifically at health-related QoL (HRQoL) and those dimensions of life affected by disease or treatment [27, 30]. Inconclusive results in previous studies about the relation between QoL and apathy might be due to different conceptual approaches. Results may also differ depending on whose perspective is being considered: QoL measurements can be based either on proxy reports or on self-report. In proxy-based measurement, the informal or professional caregiver estimates the resident's QoL. In self-report measurement, the patient is asked to report his/her own QoL. The self-report measurement is commonly considered the gold standard, but self-reports are not always possible or reliable, as, for instance, in patients with severe dementia [31].

This study was conducted using a health-related QoL approach and its aim was (1) to explore the relationship between apathy and HRQoL using self-reports and proxy reports in NH residents and (2) to explore the possible

influence of depression and cognition on the relationship between apathy and HRQoL from a resident perspective and a proxy perspective.

## Methods

### Participants and design

In this study, residents' baseline data from a large multi-center study on the effect of a multidisciplinary care program for depression management in NHs were used [32, 33]. Within the stepped-wedge cluster randomized trial of the parent study, randomly selected clustered groups cross over to the intervention condition at several time points (T1–T4). All clusters were in the control condition at T0, and at T5 all clusters were in the intervention condition. Within the Nijmegen University Network of NHs, 16 Dementia Special Care (DSC) units (specializing in dementia care), and 17 Somatic Care (SC) units (providing special care for somatic and physically frail NH residents with or without cognitive complaints) provided data from May 2009 to April 2011. At the start of the parent study, all patients residing on participating units at that time were approached for participation. Written informed consent was obtained from each patient or a relative/representative when a resident could not provide informed consent. Only residents with informed consent were included in the study. The study was approved by the Medical Ethics Committee of the region Arnhem–Nijmegen (<http://www.ccmo.nl/nl/erkende-metc-s/cmo-regio-arnhem-nijmegen>). Furthermore, the study is undertaken in accordance with the Declaration of Helsinki (<https://www.wma.net/declaration-of-helsinki>) and the applicable Dutch legislation, and in agreement with the Code of Conduct for Health Research (version 2005; <https://www.federa.org/federa-a-english>). Details and findings of the parent study have been published elsewhere [32, 33].

### Measurements

#### Sociodemographic characteristics

Data regarding sex, age, date of institutionalization, and type of care unit (DSC or SC) were available for all NH residents at their first measurement in the parent study.

#### Apathy

Apathy was assessed using the 10-item Apathy Evaluation Scale (AES-10) [34]. Item scores of this validated observational scale vary from 'not at all characteristic' (1) to 'very characteristic' (4); a higher sum score therefore reflects more apathetic symptoms (range 10–40) [35].

## Health-related quality of life

The Dutch version of the European Quality of Life five dimensions questionnaire (EQ-5D) was used to measure HRQoL [36]. In the first section of the EQ-5D, an indication of the NH resident's health state is given ranging from no problems (1), some problems (2) to severe problems (3) based on five domains. The domains are mobility, self-care, usual activity, pain/discomfort, and anxiety/depression, and they can be used to calculate utility scores. Utility scores are used to express an individual's preferred health status. A utility score of (1) refers to a preferred perfect state and a utility score of (0) represents death. The second section of the EQ-5D consists of a vertical visual analogue scale (VAS). Scores on the VAS vary from worst imaginable health (0) to perfect health (100). Information on HRQoL is provided from three different perspectives: the NH resident's own rating is the resident–resident (RR) perspective (How do you rate your general health status today?), the resident–proxy (RP) perspective represents professional caregivers who estimated QoL from the point of view of the NH resident (How do you think the resident rates his/her general health status today?), and the proxy–proxy (PP) perspective refers to the caregiver's own estimate of the NH resident's QoL (How do you rate the resident's general health status today?).

## Depressive symptoms

The Cornell Scale for Depression in Dementia (CSDD) [37], which has been validated in NH residents with and without dementia, was used to assess depressive symptoms [38, 39]. Item response categories vary from absent (0), mild (1), or severe (2), with more severe depressive symptoms being represented by a higher sum score.

## Cognitive functioning

For those NH residents who were testable, global cognitive functioning was assessed by administering the standardized Mini-Mental State Examination (MMSE) [40]. Scores range from 0 to 30 with lower scores representing greater cognitive impairment.

## Procedure

Only those NH residents with provided written informed consent were included in the parent study. Self-reported QoL (EQ-5D-RR) and the MMSE were assessed by trained interviewers (master students psychology and psychologists employed by the research team) in NH resident interviews if the NH resident was capable of being interviewed. Proxy-reported QoL (EQ-5D-RP/PP), AES-10, and CSDD were

assessed through structured interviews by the same trained interviewers with the nursing staff. Data in this study represent only a NH resident's first/baseline measurement, collected between May 2009 and April 2011. Only NH residents with available scores on AES-10, CSDD, and MMSE and at least a VAS or utility score from one of the perspectives on EQ-5D (RR, RP, PP) were included. Information on age and day of institutionalization was obtained from the NH resident's medical file.

## Statistical analysis

All statistical analyses were conducted using SPSS software version 24 (Chicago, IL). For all included NH residents, descriptive statistics were generated for age, sex, AES-10, CSDD, MMSE, and for the EQ-5D (VAS & Utility) from the RR, RP, and PP perspectives. In this study, the Dutch tariff was used to calculate utility scores for the EQ-5D [41] and, because missing scores of the individual EQ-5D domains are expected not to be random, missing scores were not imputed [42]. For a maximum of two missing items on AES-10 the lowest score (1) was imputed. For the CSDD, a missing score was registered as (0) with a maximum of 4 missing individual CSDD items [39]. If a NH resident could not be tested for reasons of cognitive impairment, the MMSE score was registered as (0).

Mixed models that accounted for clustering within NH units were built to explore the association between apathy (AES-10 standardized score as predictor variable) and HRQoL (VAS and Utility from three perspectives: RR RP and PP). Based on literature [14, 43], the models were controlled for age, sex, standardized MMSE, and standardized CSDD. Additionally, we explored whether the relationship was moderated by cognition and depression. For this, we built two models with the interaction terms: apathy x cognition and apathy x depression. Likelihood ratio tests were used to compare a model with the interaction term to a model without the interaction term.

## Results

### Resident characteristics and mental status

The present study included data from 521 NH residents, half of whom resided in DSC units ( $n = 259$ , 50%). As shown in Table 1, most NH residents were women ( $n = 433$ , 66%) and the mean age was 80.2 years ( $SD = 10.7$ ). The mean apathy score on AES-10 was 25.5 ( $SD = 8.6$ ). The mean EQ-5D VAS score of Resident–Resident perspective (RR) was 64.8 ( $SD = 21.7$ ) and the mean EQ-5D utility score was 0.6 ( $SD = 0.3$ ). In the Resident–Proxy (RP) perspective, the mean VAS score was 64.8 ( $SD = 17.1$ ) and the mean utility

**Table 1** Characteristics of nursing home residents, mental status, and health-related quality of life from different perspectives

	N (%)	Min/max score	Mean	SD
<b>Characteristics</b>				
Age, years		31.3–102.4	80.1	10.7
Residents (female %)	521 (344/66)			
Dementia Special Care unit	259 (50)			
<b>Mental status</b>				
Apathy <sup>a</sup>				
AES-10	521	10.0–40.0	25.5	8.6
Depressive symptoms <sup>b</sup>				
CSDD	521	0.0–40.0	9.3	7.3
Cognitive functioning <sup>c</sup>				
MMSE	521	0.0–30.0	14.3	9.3
<b>Quality of life</b>				
EQ-5D <sup>d</sup>	265			
<b>Resident's own rating (RR)<sup>e</sup></b>				
VAS <sup>e</sup>	360		64.8	21.7
Utility <sup>f</sup>	421		0.6	0.3
<b>Resident–proxy perspective (RP)<sup>h</sup></b>				
VAS	497		64.7	17.3
Utility	486		0.5	0.3
<b>Proxy–proxy perspective (PP)<sup>i</sup></b>				
VAS	520		63.1	14.7
Utility	520		0.5	0.3

<sup>a</sup> Apathy: standardized scores on AES-10

<sup>b</sup> Depressive symptoms: standardized score on the CSDD

<sup>c</sup> Cognition: score on the MMSE. Quality of Life: Dutch version of the European Quality of Life (EQ-5D<sup>d</sup>)

<sup>e</sup> VAS score on Visual Analogue Scale

<sup>f</sup> Utility preferred health status calculated using Dutch Tariff

<sup>g</sup> RR resident–resident perspective, resident's own rating

<sup>h</sup> RP: proxy–resident perspective, proxy rating by imagining the resident perspective

<sup>i</sup> PP proxy–proxy perspective, proxy's own rating

score was 0.5 (SD = 0.3). In the Proxy–Proxy (PP) perspective, the mean VAS and utility scores were 63.1 (SD = 14.7) and 0.45 (SD = 0.26), respectively.

### Relationship between apathy and QoL (EQ-5D) from different perspectives

Mixed models showed no statistically significant association between apathy and HRQoL from the RR perspective, nor when corrected for cognition and depression [RR EQ-5D VAS: Estimated effect  $-0.05$ , 95% CI  $-0.18$  to  $0.08$ ,  $P = 0.423$ ; RR EQ-5D Utility:  $-0.08$ , 95% CI  $-0.20$  to  $0.03$ ,  $P = 0.161$  (see Table 2)]. From the RP and PP perspectives, there was a negative association of apathy with

QoL ([RP EQ-5D VAS: Estimated effect  $-0.31$ , 95% CI  $-0.48$  to  $-0.15$ ,  $P < 0.001$ ; RP EQ-5D Utility:  $-0.30$ , 95% CI  $-0.46$  to  $-0.14$ ,  $P < 0.001$ ]; [PP EQ-5D VAS:  $-0.29$ , 95% CI  $-0.44$  to  $-0.14$ ,  $P < 0.001$ ]; PP EQ-5D Utility:  $-0.30$ , 95% CI  $-0.45$  to  $-0.14$ ,  $P < 0.001$ ]), also after correction for depression and cognition. As shown in Table 2, the fit of the models was not improved by adding interaction terms. Results indicate that better cognitive functioning (higher score on MMSE) was related to lower HRQoL utility scores from the Resident–Resident perspective (RR EQ-5D-Utility: estimated effect  $-0.25$ , 95% CI  $-0.39$  to  $-0.10$ ,  $P = 0.001$ ) (Table 2).

## Discussion

To our knowledge, this study is one of the first to explore the association between apathy and HRQoL from the NH resident's own perspective and from two proxy perspectives using a large sample of NH residents of DSC units and SC units, the most common types of units for elderly residents in the Netherlands. We found that apathy was negatively associated with HRQoL in NH residents when estimated using proxy-based reports provided by professional caregivers; the same association was not found when HRQoL was estimated from the NH resident's own self-reported perspective. When accounting for cognitive functioning and depressive symptoms, a significant negative relationship remained between apathy and HRQoL from the proxy perspective, and no moderating effect of either depression or cognition was found.

Our finding that apathy in NH residents is associated with lower proxy-based HRQoL is in line with results from recent studies of Hongisto [44] and Appelhof [15], who also found that apathy was associated with lower general proxy-based QoL in NH residents with dementia. Our findings are in line with findings of studies in other parts of the Netherlands and previous findings on neuropsychiatric symptoms and QoL in NHs [16, 43, 45]. Also, a recent study on possible differences in QoL and Quality of care (QoC) in Europe [46] shows that, despite great variation in QoL and QoC scores among European countries and settings, there are no overall differences regarding QoL for persons with dementia living at home and those in nursing homes. Selbaek et al. [5] found that the weighted mean prevalence of apathy was 36% (range 17–82) in NH residents with dementia. In previous research of our research group based on the same dataset [13], we confirmed that the apathy scores of our sample fall within this range; regarding apathy as a categorical construct, we found the prevalence of apathy to be 50% in NHs. Therefore, we believe our sample is a representative for Dutch NHs and NHs in general.

In this study, we found no significant association between apathy and self-reported HRQoL. This is in line with

**Table 2** Apathy as predictor of health-related Quality of Life from resident and proxy perspective

	Resident–Resident (RR) <sup>f</sup> perspective QoL VAS <i>n</i> = 360; Utility <i>n</i> = 421			Resident–Proxy (RP) <sup>g</sup> perspective QoL VAS <i>n</i> = 497; Utility <i>n</i> = 486			Proxy–Proxy (PP) <sup>h</sup> perspective QoL VAS <i>n</i> = 520; Utility <i>n</i> = 520		
	Estimated effect (95%CI)	df	<i>P</i>	Estimated effect (95%CI)	df	<i>P</i>	Estimated effect (95%CI)	df	<i>P</i>
Quality of Life (EQ-5D VAS) <sup>d</sup>									
Model 1 <sup>i</sup>									
Apathy <sup>a</sup>	−0.05 (−0.18 to 0.08)	353.60	0.423	−0.31 (−0.48 to −0.15)	230.56	<0.001	−0.29 (−0.44 to −0.14)	232.24	<0.001
Depression <sup>b</sup>	−0.04 (−0.14 to 0.07)	353.99	0.503	−0.02 (−0.14 to 0.10)	223.31	0.746	0.00 (−0.11 to 0.12)	231.98	0.971
Cognition <sup>c</sup>	−0.15 (−0.31 to 0.01)	290.10	0.070	−0.19 (−0.44 to 0.07)	228.29	0.146	−0.11 (−0.34 to 0.12)	205.59	0.358
Model 2 <sup>j</sup>									
Apathy × Depression	−0.04 (−0.14 to 0.06)	344.04	0.434	0.00 (−0.09 to 0.09)	477.50	0.968	0.00 (−0.12 to 0.11)	226.85	0.948
Model 3 <sup>k</sup>									
Apathy × Cognition	0.10 (−0.04 to 0.24)	351.13	0.180	0.03 (−0.06 to 0.13)	478.91	0.494	0.00 (−0.21 to 0.21)	231.80	0.987
Quality of Life (EQ-5D Utility) <sup>e</sup>									
Model 1									
Apathy	−0.08 (−0.20 to 0.03)	414.49	0.161	−0.30 (−0.46 to −0.14)	228.73	<0.001	−0.30 (−0.45 to −0.14)	232.08	<0.001
Depression	−0.09 (−0.18 to 0.01)	414.80	0.094	−0.05 (−0.17 to 0.06)	224.72	0.358	−0.08 (−0.19 to 0.04)	227.85	0.197
Cognition	−0.25 (−0.39 to −0.10)	363.76	0.001	−0.24 (−0.47 to 0.00)	218.65	0.053	−0.04 (−0.28 to 0.19)	228.04	0.720
Model 2									
Apathy × depression	−0.04 (−0.13 to 0.06)	402.99	0.444	0.03 (−0.08 to 0.15)	219.24	0.565	0.03 (−0.08 to 0.14)	222.84	0.625
Model 3									
Apathy × cognition	0.03 (−0.10 to 0.15)	406.35	0.683	0.02 (−0.19 to 0.23)	227.27	0.847	0.02 (−0.19 to 0.23)	227.27	0.847

<sup>a</sup> Apathy standardized scores on AES-10

<sup>b</sup> Depressive symptoms standardized score on the CSDD

<sup>c</sup> Cognition score on the MMSE

<sup>d</sup> VAS score on Visual Analogue Scale of EQ-5D for health-related Quality of Life

<sup>e</sup> Utility preferred health status calculated using Dutch Tariff on EQ-5D

<sup>f</sup> RR resident–resident perspective, resident's own rating

<sup>g</sup> RP proxy–resident perspective, proxy's rating by estimating the resident's perspective

<sup>h</sup> PP proxy–proxy perspective, proxy's own rating

<sup>i</sup> Model 1 Mixed models for RR, RP, and PP perspective (VAS and Utility) with correction for depression and cognition. The main effects are reported for the models without the interaction terms because the models with the interaction terms did not improve the model fit

<sup>j</sup> Model 2 Mixed models for RR, RP, and PP perspective (VAS and Utility) with interaction term Apathy × Depression

<sup>k</sup> Model 3 Mixed models for RR, RP, and PP perspective (VAS and Utility) with interaction term Apathy × Cognition. The estimated effects for the interaction terms are reported for the models 2 + 3 with those interaction terms. All models corrected for clustering, age, sex, standardized MMSE, standardized Cornell

previous findings that NPS in general in dementia do not influence self-reported QoL [44]. Memory problems (due to hippocampus degeneration) and problems in self-awareness and executive functioning (due to decreased functioning of fronto-subcortical circuits) might influence a person's

judgement on his/her own QoL. One can speculate that as their ability to reflect retrospectively may be impaired, NH residents with severe cognitive problems might judge QoL only in light of the emotional status and thoughts of the person in the present moment, which, in the context,

is often a positive interaction with an interviewer. This might account for the differences we found in the association between apathy and QoL from the resident perspective and the proxy perspective. Self-report can be regarded as the most important perspective when assessing perceived QoL, also when it would ‘only’ refer to a specific moment as described above. However, a response reflecting a longer period in time will often be important. When a NH resident loses the ability to clearly report about his/her experience due to decline of cognition, awareness, and communication abilities, reliance on proxy judgment by informal and formal caregivers increases. Our study shows the implications of this reliance, as we found different results based on different perspectives. Therefore, we recommend to use different perspectives, of which we have shown in earlier research [31] that the proxy–resident perspective is more similar to the resident–resident perspective than the proxy–proxy perspective is, indicating that nursing staff may be able to put themselves in the residents’ shoes to some extent.

Besides, we found that for the resident perspective, better cognition was associated with lower HRQoL. This is in line with previous findings of Gerritsen [18] and Yeager [19] that the relationship between proxy-rated apathy and general self-reported QoL is influenced by cognition, which may suggest that NH residents with better cognition have insight into their deficits, which perhaps results in experiencing lower QoL.

Although previous research shows that apathy is not reported as a very disturbing neuropsychiatric symptom by professional caregivers [47, 48], our results suggest that professional caregivers may nevertheless consider apathy to negatively influence HRQoL. A possible explanation might be that caregivers compare and reflect on presumed differences between previous and current health status in light of a NH resident’s decreased independence, social disengagement, and other (behavioral) changes due to apathy. In contrast to the current status, the status before apathy as measured with the AES-10 (with questions regarding—among others—things like taking initiative, interest in new things, motivation, engaging life with intensity), might therefore be considered the preferred health status. Although the disability paradox [49] could be an explanation for a tendency in proxies to underestimate the NH residents’ QoL as compared to the NH residents’ own perceptions of their QoL, in a recent study, Leontjevas [31] found that professional caregivers did not tend to report systematically poorer HRQoL in NH residents but instead attenuated scores toward the middle.

The current study has strengths and limitations. The large representative sample of NH residents in DSC and SC is one of the strengths of this study. Also, HRQoL was considered from the resident perspective as well as from two proxy perspectives. Our findings are based on a

specific apathy scale (AES-10) validated in both NH residents with and without dementia, in contrast to a single-item apathy subscale of NPI often used in other studies. A potential limitation of this study is that its results were based on a relatively narrow QoL approach: the health-related dimensions of EQ-5D and its VAS regarding the subjective evaluation of one’s health status. The EQ5D was selected for the parent study because it was regarded as the only instrument available to explore HRQoL from three perspectives in the long-stay nursing home population with and without cognitive impairments. However, other possible aspects, such as environmental aspects and social interaction, have not been accounted for in this study [50, 51] and their relationship with apathy needs further exploration in future research. Yet, differences in proxy-based ratings versus self-reported measurements have been seen in other instruments with a broader conceptualization of QoL [14, 52].

Also, although we controlled for depression and cognition and investigated whether they moderated the relationship between apathy and HRQoL, we did not account for dementia subtype, medication use, and other NPS, such as agitation or psychosis [16, 17], because these were not registered or fully accounted for in the parent study. Also, we could not account for possible environmental differences due to unit type or characteristics of persons living in SC units and DSC units and it might have been better to use data from residents in the same condition. However, impairments in fronto-subcortical brain circuits that are involved in apathy are known to be present in residents living in DSC units [2] as well as in residents of SC units [4, 53]. Also within DSC there are people with different levels of dementia and cognitive impairment due to neurological diseases like Parkinson’s disease or strokes, and within SC units there are residents with and without cognitive impairments. Therefore, we investigated the effect of cognition as a dimensional variable, rather than using SC and DSC as categorical variable for cognitive functioning or medical conditions.

Also, we only used data from those NH residents who were testable for the resident perspective. If an MMSE was missing for reasons of cognitive impairment, we assigned a minimal MMSE score of (0) to those NH residents, but missing HRQoL scores were not imputed. Several other causes were related to missing residents’ own rating scores such as absence, sickness, temporary admission to hospital, or lack of cooperation during a measurement. This led to a smaller subsample of patients with available self-reports. It is a challenge to estimate QoL in NH residents with advanced dementia who are not able to communicate their perspective [54]. Therefore, for those NH residents unable to rate HRQoL due to incomprehension, the association between apathy and self-reported QoL is still unclear. However, from the proxy perspective, cognition did not moderate the

association, so there is little reason to assume it would be moderated in the resident perspective.

The findings from the proxy perspective provide further confirmation that apathy is a relevant target of care. Yet, although research indicates that therapeutic activities reduce apathy in NH residents with dementia [55–57], apathy is often not treated. Most interventions in NHs are directed toward disruptive behavioral symptoms. Apathy causes the least distress in nursing staff [48] and is regarded as the least difficult symptom to manage [47], which might explain why apathy is rarely identified as a problem that needs specific treatment. To our knowledge this has, however, never been truly investigated. Therefore, further insight is necessary into the attitudes, beliefs, and behavior of multidisciplinary NH professionals regarding apathy and its treatment.

## Conclusion

Results indicate that apathy is negatively associated with HRQoL of NH residents as reported by professional caregivers (proxies) and that this association is not influenced by depression or cognitive functioning of the NH residents. Reducing apathy appears important in order to optimize HRQoL in NH residents. Given a non-significant association between apathy and HRQoL in self-reports, and given that caregivers, on the other hand, usually do not consider apathy a goal of treatment, further research is necessary to explore attitudes and beliefs among NH residents and caregivers toward apathy and its consequences.

**Author contributions** All authors meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals. JN, RL and DG: concept and design analysis, interpretation of data, statistical analyses, preparation of manuscript. RTCMK and MS: study concept and design of the parent study, preparation of manuscript.

**Funding** This study was funded by Archipel Landrijt, Knowledge Centre for Specialized Care, Eindhoven, the Netherlands; Radboud University Medical Centre, Department of Primary and Community Care, Radboud Alzheimer Centre, Nijmegen, the Netherlands; and the Nijmegen University Network of NHs (UKON), the Netherlands. The parent study was funded by the Netherlands Organization for Health Research and Development (ZonMw). The funding agencies had no role in the study design; in the collection, analysis, or interpretation of the data; in the writing of the manuscript; nor in the decision to submit the manuscript for publication.

## Compliance with ethical standards

**Conflict of interest** The authors declare that they do not have conflicts of interest.

**Ethical approval** The study was approved by the Medical Ethics Committee of the region Arnhem–Nijmegen (<http://www.ccmo.nl/nl/erken-de-metc-s/cmo-regio-arnhem-nijmegen>). Furthermore, the study was

undertaken in accordance with the Declaration of Helsinki (<https://www.wma.net/declaration-of-helsinki>) and the applicable Dutch legislation, and in agreement with the Code of Conduct for Health Research (version 2005; <https://www.federa.org/federa-english>).

**Informed consent** Informed consent obtained from all individual participants (or their legal representative) is included in the study.

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