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ORIGINAL ARTICLE

## Down and drowsy? Do apathetic nursing home residents experience low quality of life?

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### Abstract

This cross-sectional study investigated the relationship between apathy and quality of life (QOL) in nursing home residents ( $n = 227$ ). In all, 92 residents could be assessed with the Mini Mental State Examination (MMSE), the Geriatric Depression Scale (GDS) and the Philadelphia Geriatric Centre Morale Scale (PGCMS), and were able to answer a question about overall subjective QOL. Apathetic behaviour and consciousness disorders were measured with the Behaviour Rating Scale for Psychogeriatric Inpatients (GIP). Linear regression analysis was first applied to study the association of cognition, depression and consciousness with apathy. It was then used to study the relationship between apathy and QOL, controlling for the constructs that were associated with apathy. The relationship between apathy and QOL appeared to vary with the cognitive functioning of the residents: In residents with a low level of cognitive functioning, apathetic behaviour was associated with high QOL; in residents with a higher level of cognitive functioning, apathetic behaviour was associated with low QOL. The necessity and nature of interventions aimed at stimulating apathetic residents may depend on the level of cognitive functioning of the residents. Further research is needed to determine if and when apathy interventions are appropriate.

### Introduction

Apathy is a familiar phenomenon in nursing homes. Not only is it common in people with dementia (McPherson, Fairbanks, Tiken, Cummings & Back-Madruga, 2002), it is also found in people with physical disorders (Marin, 1991; Thomas, Clement, Hazif-Thomas & Leger, 2001). It is well known that informal caregivers and professional care-providers consider apathy in a resident to be a burden, not only for the resident but also for themselves (McPherson et al., 2002; Reichman & Negron, 2001; Thomas et al., 2001). Thomas and co-workers (2001) even found that apathy in Alzheimer patients is the complaint that is most frequently mentioned by their informal caregivers. Next to pharmacological apathy interventions, several behavioural interventions have been developed that focus on stimulating residents to engage in the life on the ward (Mahoney, Volicer & Hurley, 2000; Mickus et al., 2002; Reichman & Negron, 2001). Yet, although it is well known that

the people surrounding a resident consider apathy as a burden and interventions that focus on apathy do exist, what is still not known is whether apathy is a burden for the apathetic residents themselves, and can therefore influence their quality of life.

There is ongoing debate about the conceptualisation of apathy. The central feature of apathy is diminished goal directed behaviour (Marin, 1991; Starkstein, Petracca, Chemerinski & Kremer, 2001). Over the years, a number of specific instruments have been developed to measure apathy as a behavioural dimension (e.g., the Apathy Evaluation Scale [AES], Marin, Biedrzycki & Firinciogullari, 1991; the Dementia Apathy Interview and Rating (DAIR), Strauss & Sperry, 2002), and other instruments have included an apathy sub-scale (e.g. the Neuropsychiatric Inventory-Nursing Home version [NPI-NH], Iverson, Hopp, Dewolfe & Solomons, 2002; and the Behaviour Rating Scale for Psychogeriatric Inpatients [GIP], Verstraten, 1988). Criteria for apathy as a syndrome have also been formulated,

in which lack of motivation is considered the cause of the diminished goal directed activity (Marin, 1991; Starkstein et al., 2001), and it has been tried to distinguish apathy as a symptom from apathy as a syndrome (Marin, 1997a,b). Yet, accurate distinction is difficult. In nursing homes, where many residents suffer from multiple complex diseases, apathetic behaviour can be associated with emotional disturbance (as in depression), intellectual disturbance (as in cognitive disorder) or disturbed consciousness (as in delirium) (Marin, 1991; 1997a, b). This has implications for research on apathy and, more specifically, for care-targets (Marin, Fogel, Hawkins, Duffy & Krupp, 1995). For instance, if a resident with apathetic behaviour also suffers from depression, the question is whether both an apathy syndrome and a depression syndrome exist, or whether apathy is a symptom of the depression syndrome. Yet, at present, the distinction of apathy as a syndrome and apathy as a symptom is not made convincingly (Van der Wurff et al., 2003). Moreover, the relationships of apathy with depression, cognition and consciousness are not evident.

Various studies have focussed on the relationship between apathy and disturbances of emotion, intellect or consciousness. In the literature on depression, the co-existence of apathy and depression is described in various ways: apathy as a symptom of depression, apathy accompanied by depression, and apathy caused by depression (Baldwin & O'Brien, 2002; Starkstein et al., 2001; Wood et al., 2000). In other studies, no relationship was found between apathy and depression (Levy et al., 1998; McPherson et al., 2002; Nagatomo, Nomaguchi & Matsumoto, 1992). As already mentioned, apathy is often found in residents with cognitive problems (Nagatomo et al., 1992; Starkstein et al., 2001). In recent years it has been established that these problems are mainly related to frontal-lobe dysfunction (McPherson et al., 2002; Reichman & Negron, 2001). Although dementia is a frequently mentioned cause of apathy, the relationship between apathy and dementia is complex. The use of cholinesterase inhibitors in the treatment of dementia has been found to reduce apathy (Reichman & Negron, 2001). It has even been suggested that neuropsychiatric features such as apathy contribute to the severity of cognitive and functional deficits and may impact the rate of progression of the dementia (Doody, Massman, Mahurin & Law, 1995, Reichman & Negron, 2001). With regard to its relationship with consciousness, apathy is reported to be a common symptom of hypoactive delirious status (Marin, 1996).

Given the above-mentioned considerations, in this study, apathy is operationalised as apathetic behaviour and is measured as a continuous variable. The possible relationships with depression, cognition and consciousness are taken into consideration.

Evidently, an important determinant of the usefulness of apathy interventions is the presence of a

negative relationship between apathy and quality of life (QOL), but little is known about this relationship. Volicer and co-workers (1999) consider apathy as a component of (negative) psychological well-being, but this assumption has not yet been confirmed. Only one empirical study was identified, which reports that no relationship was found between apathy and QOL (Yamashita, Iijima & Kobayashi, 1999). A second important determinant of the usefulness and also the content of apathy interventions is the cause of the apathetic behaviour, which may also influence the relationship with QOL. If it is found that the variance in the apathetic behaviour is not independent of depressive, cognitive or consciousness disorders, these associations may influence the relationship between apathy and QOL.

The above described considerations resulted in the following research questions: (1) To what extent are depressive, cognitive and/or consciousness disorders related to apathetic behaviour?; and (2) To what extent is apathetic behaviour a threat to quality of life?

## Methods

### *Participants and procedure*

Participants were selected from nine nursing homes in the Netherlands. The nursing homes were members of the University Nursing Home Network of the VU University Medical Centre. The Medical Ethics Committee of the VU University Medical Centre had approved the research proposal, and written informed consent was obtained from the participants or their legal representatives. Data on a maximum sample of 30 residents in long stay units were collected over a period of three months per nursing home.

The data collection had a total duration of two years. The principal investigator (DLG, a trained psychologist) administered the self-report scales and the cognitive test (see later). The observational assessments were made by the nursing staff (licensed practical nurses) employed by the nursing homes, who were blinded for the outcome of the other ratings. The completeness of the interview data depended on the cognitive and physical abilities of the residents, and their willingness to answer questions. An assessment ceased if a resident was unwilling or unable to answer the questions that were asked. To ensure the validity of cross-sectional comparisons, the self-report and the observational assessments of each resident were both carried out within the same four-week period.

### *Instruments*

Depression was operationalised as self-reported depressive complaints, and measured according

to the Geriatric Depression Scale (GDS, Brink et al., 1982). The GDS is widely used to screen for depression in the elderly. It consists of 30 dichotomous questions that focus on the emotional and cognitive components of depression, but does not contain any questions about physical symptoms. The scores range from 0 (no depressive complaints) to 30 (many depressive complaints).

Cognition was measured according to the Mini Mental State Examination (MMSE, Folstein, Folstein & McHugh, 1975). This instrument is often used to screen for cognitive disorders, and focuses on orientation, memory and attention, naming objects, performing written and verbal tasks, writing a sentence, and drawing a complex figure. The scores range from 0 (severely impaired) to 30 (intact).

Consciousness disorders and apathetic behaviour were measured according to two sub-scales of the Behaviour Rating Scale for Psychogeriatric Inpatients (GIP). The GIP is a Dutch observational measure for behavioural disorders. It is especially suitable for use in nursing home residents with dementia, but it can also be used in physically frail residents (Verstraten, 1988). Nurses who had received specific instructions made the assessments, which were based on a two-week observation period. Scores on the first sub-scale, the GIP-consciousness disorders, range from 0 to 21, with high scores representing lower consciousness. Consciousness concerns the level at which the resident is awake, and the items assess whether the resident is drowsy, absent-minded, or in a state of dreaminess or sleepiness. The GIP-apatetic behaviour sub-scale assesses how often the resident reacts when spoken to, how the resident reacts to music and unusual events, and whether the resident reads newspapers or magazines, watches television, or listens to the radio. The scores range from 0 to 18 with high scores representing much apathetic behaviour.

As there is no consensus of opinion with regard to what QOL exactly is, two different self-report measurement instruments were used. First, a general question on overall subjective QOL was asked: 'Overall, what is the quality of your life at the moment?'. Although this operationalisation might be considered to be too simple for such a complex concept, the advantage is that the answer, and thus the score, is not dependent on the researcher's approach to QOL, but reflects the resident's own approach. The subjective QOL question is part of the Brod scale to measure QOL in patients with dementia (Brod, Stewart, Sands & Walton, 1999), but 'at the moment' has been added, because in the pilot of this study, it was found that without this time-frame the residents tended to evaluate the whole of their past life. The response categories are 1 = bad, 2 = moderate, 3 = good, 4 = very good, and 5 = excellent. The Brod scale has been found reliable in a study of patients with dementia who had an MMSE-score higher than 9 (Brod et al., 1999). The second measure of

QOL was the Philadelphia Geriatric Centre Morale Scale (PGCMS; Lawton, 1975). The PGCMS measures life-satisfaction and is in line with the approach to QOL of the researchers, i.e., that overall QOL is equal to subjective or psychological well-being (Gerritsen, Steverink, Ooms & Ribbe, 2004). For several years the PGCMS has been an outcome measure in QOL research (e.g., Faulk, 1988; Yamashita et al., 1999). It consists of 17 dichotomous items measuring life satisfaction, and the scores are summed, with a high score indicating high QOL. The scale has been found to be reliable, valid and sensitive (Van Campen & Kerkstra, 1998).

### Analyses

The first research question, concerning the extent to which depressive (GDS), cognitive (MMSE) and consciousness disorders (GIP-consciousness disorders) are related to apathetic behaviour (GIP-apatetic behaviour), was studied by applying linear regression analysis. Subsequently, again using linear regression, the relationship between apathetic behaviour (GIP-apatetic behaviour) and overall QOL (subjective QOL question and PGCMS) was analysed, controlling for the variables that were found to be associated with apathetic behaviour. Confounding and interaction were studied. If an additional variable produced a change of more than 10% in the Beta-coefficient of the first independent variable, it was considered to be a confounder. If the interaction term of two independent variables made a significant contribution to the regression model ( $p < 0.05$ ), interaction was considered to exist.

## Results

### Participants

Of the 300 residents who were invited to participate, 237 gave informed consent. Data were obtained for 227 residents, 92 of whom were able to complete the subjective QOL question, the PGCMS, the GDS and the MMSE. Data on 23 of the other residents ( $n = 135$ ) were incomplete for reasons other than insufficient cognitive abilities (unwilling to be interviewed, walking away during the interview, insufficient command of the Dutch language). A total of 92 residents were included in the analyses. Their average age was 79.4 years (range 52–98) and 79% were female. Their basic demographic characteristics appear to be much the same as those of the residents in other nursing homes in the Netherlands (Prismant & Arcares, 2002). At the time of the study, the mean age of the Dutch nursing home population was 80.6, and 72.3% were women. The cognitive functioning of the 92 residents (mean MMSE score 18.4) was higher than that of the excluded 135. Only half of these 135 ( $n = 74$ ) could complete an MMSE, and had a mean score of 10.1. Table I shows the



Table I. Descriptions of the instruments used ( $N_{\text{participants}} = 92$ ).

Construct	Instrument	Mean score	Min/Max score	Median	(SD)
Depressive complaints	GDS	11.3	0–26	11	7.0
Cognition	MMSE	18.4	6–30	19	6.6
Consciousness disorders	GIP-C	4.2	0–15	4	3.5
Apathetic behaviour	GIP-A	5.9	0–13	6	3.3
QOL: Subjective quality of life	Question on subjective QOL	1.6	0–4	2	0.9
QOL: Life satisfaction	PGCMS	9.2	1–17	9	4.7

Table II. Regression of depressive complaints, cognition and consciousness disorders with apathetic behaviour ( $n = 92$ ).

Dependent variable: Apathetic behaviour (GIP-A)					
Model	Variables	Beta	$p$ -value	95% CI*	Adjusted $R^2$
1	(constant)				
	Depressive complaints	0.103	0.329	–0.082, 0.243	0.000
2	(constant)				
	Depressive complaints	0.162	0.114	–0.031, 0.283	0.095
	Cognition	0.329	0.002	0.106, 0.441	
3	(constant)				
	Depressive complaints	0.124	0.183	–0.047, 0.241	0.252
	Cognition	0.222	0.022	0.027, 0.342	
	Consciousness disorders	0.415	0.000	0.251, 0.659	

\*CI, confidence interval.

mean scores with ranges, and median and standard deviations for the various scales.

*To what extent are depressive, cognitive and/or consciousness disorders related to apathetic behaviour?*

In stepwise linear regression analysis, it appeared that depressive complaints were not related to apathetic behaviour, whereas cognitive and consciousness disorders were (see Table II). The beta-coefficient of depressive complaints was not significant in any of the three models (0.103 in model 1; 0.162 in model 2; 0.124 in model 3). The beta-coefficients of cognitive and consciousness disorders showed that they were significant predictors of apathetic behaviour, and together explained 25% of the variance (model 3).

*To what extent is apathetic behaviour a threat to quality of life?*

Two regression analyses, one with the subjective QOL question as the dependent variable, and one with life-satisfaction (PGCMS) as the dependent variable, were conducted. In both analyses, apathetic behaviour was the independent variable, and cognitive and consciousness disorders were covariates. Depressive complaints were not included in these analyses, because they did not appear to be related to apathetic behaviour. With subjective QOL as the dependent variable, Table III shows that, initially, apathetic behaviour was not a predictor of subjective

QOL ( $p = 0.777$ , model 1). It then appeared that ‘consciousness disorders’ were a subtle confounder of that relationship (model 2), as were cognitive disorders (model 3), so both variables were retained in the model. The interaction term of apathetic behaviour and consciousness disorders was not significant at the 0.05 level ( $p = 0.078$ ), so it was removed (not shown in Table III). Model 4 shows that the interaction term of apathetic behaviour and cognitive disorders was significant ( $p = 0.004$ ). The  $p$ -value of the beta-coefficient of apathetic behaviour also changed dramatically (from 0.763 to 0.008), which suggests that apathy may, indeed, be a predictor of subjective QOL.

With life-satisfaction as the dependent variable, Table III shows the same pattern, although in this regression model the interaction term of apathetic behaviour and cognitive disorders was not significant at the 0.05 level ( $p = 0.095$ ). The  $p$ -value of the beta-coefficient of apathetic behaviour also changed considerably in the regression with life-satisfaction when the interaction term of apathetic behaviour and cognitive disorders was entered (from 0.940 to 0.145). The interaction term of apathetic behaviour and consciousness disorders was not significant in the regression with life-satisfaction ( $p = 0.139$ ).

Figure 1 illustrates the relationship between apathetic behaviour and QOL by sub-dividing the residents, on the basis of their MMSE score, into a ‘high-cognition’ group with MMSE scores of 18 or higher ( $n = 40$ ), and a ‘low-cognition’ group with MMSE scores of less than 18 ( $n = 52$ ). It shows that

Table III. Regression of apathetic behaviour, cognition and consciousness disorders with subjective quality of life and with life-satisfaction ( $n=92$ ).

Model	Variables	Subjective quality of life (question)				Life-satisfaction (PGCMS)			
		Beta	<i>p</i> -value	95% CI*	Adj. $R^2$	Beta	<i>p</i> -value	95% CI*	Adj. $R^2$
1	(constant)								
	Apathetic behaviour	0.030	0.777	-0.221, 0.294	-0.010	-0.022	0.835	-0.353, 0.286	-0.011
2	(constant)								
	Apathetic behaviour	0.048	0.691	-0.235, 0.353		0.032	0.793	-0.315, 0.411	
	Consciousness disorders	-0.038	0.752	-0.373, 0.271	-0.020	-0.113	0.348	-0.586, 0.209	-0.012
3	(constant)								
	Apathetic behaviour	-0.035	0.763	-0.330, 0.243		-0.009	0.940	-0.383, 0.355	
	Consciousness disorders	-0.082	0.476	-0.419, 0.197		-0.135	0.264	-0.622, 0.173	
	Cognition	0.348	0.001	0.140, 0.572	0.080	0.170	0.127	-0.063, 0.494	0.003
4	(constant)								
	Apathetic behaviour	-0.568	0.008	-1.216, -0.184		-0.334	0.145	-1.197, 0.179	
	Consciousness disorders	-0.102	0.358	-0.433, 0.158		-0.147	0.220	-0.639, 0.149	
	Cognition	-0.185	0.370	-0.608, 0.229		-0.155	0.486	-0.754, 0.362	
	Apathetic behaviour * cognition	0.915	0.004	0.006, 0.029	0.156	0.557	0.095	-0.002, 0.029	0.024

\*CI, confidence interval.

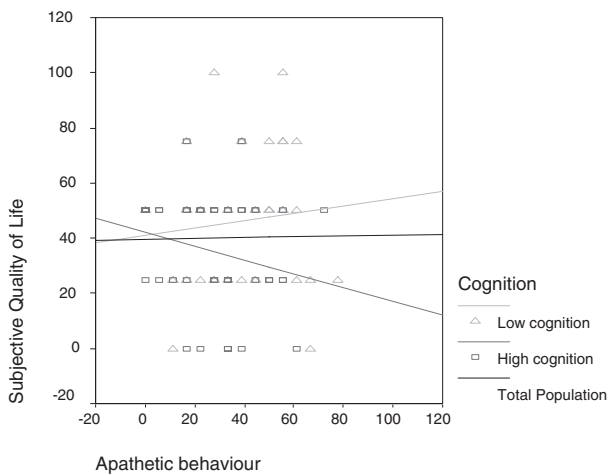


Figure 1. Illustration of the relationship between apathetic behaviour and subjective quality of life.

in the high-cognition group there was a negative relationship between apathetic behaviour and subjective QOL, suggesting that in residents with intact to moderately impaired cognition, apathetic behaviour is associated with low QOL. In contrast, in people with severe cognitive disorders there appeared to be a positive relationship between apathetic behaviour and subjective QOL.

## Discussion

The finding that depression was not significantly associated with apathy (whereas cognition and consciousness were), is in line with the findings of Levy et al. (1998), McPherson et al. (2002), and Nagatomo et al. (1992). Subsequently, it became clear that the relationship between apathy and QOL was not significantly influenced by consciousness but was influenced by cognition. Initially, no relationship was found between apathy and QOL, but after controlling for consciousness and cognition,

there was a strong indication that apathy may influence QOL. However, the relationship depends on the resident's level of cognitive functioning. In residents with relatively good cognition, apathetic behaviour was found to be associated with lower QOL, but in those with severe cognitive impairment apathetic behaviour was associated with high QOL.

The negative association of apathy and QOL that was found in residents with relatively good cognition confirms the use of the available apathy interventions. However, the positive association that was found in residents with severe cognitive disorders is intriguing. It has already been mentioned that the apathy of people with dementia is a heavy burden on their carers. The absence of a negative relationship in these residents might therefore suggest that it is not their own QOL, but the QOL of the people in their environment that is affected by their apathetic behaviour. It should be investigated whether the burden on the carers justifies intervention in the behaviour of the resident, or whether the intervention should focus on the carers themselves (see also Marin, 1996). Yet, a positive relationship was found between apathy and QOL in residents with severely impaired cognition, which even suggests a protective effect of apathy. In her adaptation-coping model, Dröes demonstrates that apathy in residents with dementia can be a coping behaviour for the adaptive tasks of 'coping with their own invalidity' and 'maintaining an emotional balance'. Disengagement and withdrawal from stimulating activities can be considered as problem-oriented coping, which can contribute to the feeling of control and balance. Apathy can also be an emotion-oriented coping mechanism to curtail feelings of insufficiency and shame caused by problematic functioning (Dröes, 1991; Finnema, 2000). The positive relationship that was found between apathy and QOL in residents with severe cognitive disorders suggests that for them apathy may be an adequate coping mechanism.

Another possible explanation of the complex relationship between apathy and QOL regards decreased frontal-lobe function. In addition to the knowledge that it may cause apathetic behaviour, evidence has also been found that it may influence emotional functioning (Paradisio, Chemerinski, Yazici, Tartaro & Robinson, 1999; Tekin & Cummings, 2002). This implies that the positive relationship that was found might be related to decreased frontal-lobe function. A suggestion for further research is, therefore, that the relationship between various cognitive functions, apathy and QOL should be studied more specifically.

In the only study that investigated the relationship between apathy and QOL (Yamashita et al., 1999), no relationship was found, but cognition was not included as a control variable. This finding is therefore in accordance with the absence of a relationship that was initially found in the present study, before cognition was included in the analyses. No empirical evidence of consciousness disorders as a cause of apathy was identified. This makes further research into the relationship between apathy and consciousness disorders necessary, also in view of the finding in the present study that the interaction term of apathy and consciousness disorders in relation to subjective QOL only just failed to reach significance. In this respect, however, it should be noted that if this interaction term had been retained in the linear regression model, adding the interaction term of apathetic behaviour and cognitive disorders to the equation would have resulted in a change in the *p*-value of the interaction term of apathetic behaviour and consciousness disorders from 0.078 to 0.495.

#### *Methodological considerations*

Some methodological considerations give rise to suggestions for further research. The difficult task of measuring QOL is even more controversial in cognitively impaired residents. The reliability and validity of the answers given by the residents with cognitive disorders may be questionable, although recent research has asserted that patients with moderately severe dementia still can report on their QOL, even when they have poor insight into, and awareness of their dementia (Brod et al., 1999; Logsdon, Gibbons, McCurry & Teri, 2002; Kane, 2003; Mozley et al., 1999). To establish which residents are able to self-report validly, several measurement instruments, including the Brod scale of which a segment was used in this study, incorporate means to ensure that the residents understand the questions (Brod et al., 1999; Kane, 2003). Moreover, by operationalising and measuring QOL in two different ways, an attempt was made to guarantee validity. The fact that a similar pattern was found with both methods (Table III) is an important

indication that there is, indeed, a relationship between apathy and QOL, and that it is influenced by cognition. The finding that the relationship was less convincing with regard to life-satisfaction may be related to the fact that several questions in the PGCMS concern an evaluation of the past, whereas the subjective QOL-question focused specifically on QOL at the present time. The use of other instruments to measure QOL would provide more information on the relationship with apathy. However, an additional problem may be that only residents who could answer all the questions were included in the analyses. This was less than half of the study sample (92 out of 227), so that only a selection of the nursing home population was used. Further research, including all the residents in a nursing home, based on both self-report and observational instruments to measure each concept, will provide more insight, and is therefore recommended.

In conclusion, there appears to be an intriguing relationship between apathy and QOL. The results of this study suggest that apathetic behaviour in residents with limited cognitive disorders is an important target for intervention, but that interventions might not be effective for residents with severe cognitive disorders. The possible consequences of apathy, such as the negative influence of apathy on the rehabilitation process (Anderson, Krogstad & Finset, 1999), and its suggested impact on the rate of progression of dementia (Doody et al., 1995; Reichman & Negron, 2001), may be reasons to justify apathy interventions. Apathy that is drug-induced or socio-environmentally induced (Marin, 1996) is also a target for intervention. Nevertheless, in view of the positive relationship that was found between apathy and QOL in residents with a low level of cognition, careful consideration is necessary before interventions are applied. The results of the present study suggest that apathy in nursing home residents may, at least partially, be caused by cognitive disorders, and possibly also by consciousness disorders. Therefore, given the fact that they have consequences with regard to the interpretation of apathy, the co-occurrence of these disorders should always be taken into account. Further study of the relationship between apathy and QOL and of the causes of apathy is recommended, investigating not only possible explanations, but also taking into account the methodological considerations described above.

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