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## Quality of life of family carers of persons with young-onset compared to late-onset dementia

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### ABSTRACT

**Objectives:** To compare quality of life (QOL) of family carers of persons with young- (YOD) to late-onset dementia (LOD).

**Methods:** This was a cross-sectional comparison of 88 carers of persons with YOD and 100 carers of persons with LOD. The Quality of Life – Alzheimer’s Disease questionnaire (QOL–AD) was used to measure QOL of both carers and persons with dementia. Depressive symptoms were measured by the Geriatric Depression Scale (GDS) for carers and the Cornell Scale for Depression in Dementia for persons with dementia. Care burden was measured by the Relatives’ Stress Scale. Activities of Daily Living (ADL) of the persons with dementia were assessed using the total score from the Lawton & Brody Instrumental-ADL scale and the Physical Self-Maintenance Scale. Multiple linear regression models with interactions between covariates and group (YOD versus LOD) were estimated.

**Results:** The QOL–AD scores of YOD-carers were significantly poorer compared to LOD-carers (mean difference 2.5 (95% CI 0.7; 4.3),  $p = 0.006$ ). Poorer QOL of carers was associated with more depressive symptoms (mean QOL–AD change  $-0.5$  ( $-0.6$ ;  $-0.3$ ),  $p < 0.001$ ), but with no difference between the two groups. In contrast to LOD, QOL of carers of people with YOD was also significantly associated with symptom duration ( $p = 0.002$ ), depressive symptoms of the persons with dementia ( $p = 0.030$ ), ADL ( $p = 0.001$ ), and carer burden ( $p = 0.002$ ).

**Conclusion:** YOD-carers reported significantly poorer QOL compared to LOD-carers. QOL was significantly associated with depressive symptoms in carers of both groups.

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Quality of life; young-onset dementia; late-onset dementia; family; carer

## Introduction

Extensive dementia research shows that family carers of people with dementia may experience negative health outcomes from providing informal care for people with dementia (Baumgarten et al., 1992; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Pinquart & Sorensen, 2003; Schulz, Visintainer, & Williamson, 1990; Vitaliano, Zhang, & Scanlan, 2003). High rates of carer burden and depression are associated with poorer quality of life (QOL) (Farina et al., 2017; Millenaar, de Vugt, et al., 2016; Rosness, Mjørud, & Engedal, 2011), and QOL of carers of people with young-onset dementia (YOD), defined by symptom debut before 65 years of age, seems to be poorer compared to carers of people with late-onset dementia (LOD) (Millenaar et al., 2016). This is likely associated with the life-stage specific circumstances characteristic of families with YOD due to extensive obligations related to work, partnership and family, and social activities (Millenaar, Bakker, et al., 2016; Millenaar et al., 2016; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010). Having a spouse or parent with YOD affects the roles, relationships and dynamics within the families, often precipitating family conflicts

(Luscombe, Brodaty, & Freeth, 1998). It is not uncommon for spouses to work reduced hours or retire from work to provide home care, adding additional strain to the family economy (Ducharme et al., 2014; Gibson, Anderson, & Acocks, 2014; Luscombe et al., 1998). Distressed carers are less capable of maintaining their normal everyday life and providing good quality care for their loved ones. Additionally, carer distress due to neuropsychiatric symptoms of people with YOD have been shown to predict institutionalization (Bakker et al., 2013a). Thus, interventions aimed at enhancing QOL of the family carers may not only benefit the health and wellbeing of the carer, and the dyadic care relationship and family environment, but also reduce the significant societal and health economic costs of young-onset dementia (Kandiah et al., 2016).

Identifying characteristics important to carer QOL in YOD is a prerequisite for targeted interventions, and a recent review article identified carer QOL as a key domain for future research (Dow et al., 2018). In the present study, we therefore wanted to compare QOL and factors associated with it in family carers in YOD and LOD.

## Materials and methods

### The YOD-Participants

The family carers and persons with YOD were recruited from a Nordic multicenter cohort study of community-dwelling people described in detail in a previous study (Hvidsten et al., 2018). Fifty dyads of persons with Alzheimer's dementia (AD) and thirty-eight dyads of persons with frontotemporal dementia (FTD) were recruited. Alzheimer's dementia was diagnosed according to the International Classification of Diseases-10th revision (ICD-10) criteria (World Health Organization, 1992), and frontotemporal dementia according to the Neary et al. criteria (Neary et al., 1998), the International consensus criteria for behavioral variant-FTD (Rascovsky et al., 2011) or the Mesulam criteria for the language variant (Mesulam, 2003). For the persons with YOD, the age at inclusion was below 70 years of age. The carers were required to have face-to-face contact with the persons with dementia at least once weekly and to give informed consent. The definition of "family" was broad, including all significant others providing informal, unpaid care.

### The LOD-participants

A random sample of one hundred dyads of community-dwelling persons with LOD was included from a previous Norwegian randomized controlled study on the effect of psychosocial intervention on depression in persons with dementia and their carers (Bruvik, Ulstein, Ranhoff, & Engedal, 2012), whose baseline data were collected in 2009–2011. In this study the inclusion criteria required having a diagnosis of dementia according to the ICD-10 criteria (diagnosis was not specified), a score of at least 15 points on the Mini Mental State Examination and informed consent to participation. For the persons with LOD, the age at inclusion was 70 years and above. Carers had to have face-to-face contact with the persons with dementia at least once weekly.

### Data collection

#### Family carers

For the carers of persons with YOD the sociodemographic data, including the relationship with the persons with dementia, and the clinical characteristics were recorded in semi-structured interviews at the memory clinics or in their homes, whichever was most convenient. These interviews were conducted by an ambulant team of trained project nurses covering all the Norwegian memory clinics, or by local project nurses at the recruiting memory clinics in Denmark and Iceland. For the carers of persons with LOD the registrations were made by trained nurses and occupational therapists in the participating municipalities where the study participants were recruited.

#### Persons with dementia

Socio-demographic and clinical data of the persons with dementia were collected in semi-structured interviews conducted in parallel sessions with the interviews of their carers.

## Assessments

### Family carers

The Quality of Life – Alzheimer's Disease (QOL-AD) was used to assess QOL of the family carers. The questionnaire covers 13 items; physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money, and life as a whole. The items are rated on a four-point scale from poor to excellent, with a total score ranging from 13 to 52, higher score indicating better QOL.

The Relatives' Stress Scale (RSS) was used to assess carer burden (Greene, Smith, Gardiner, & Timbury, 1982), consisting of 15 statements scored on a five-point scale from 0 = not at all to 4 = considerably. The total score ranges from zero to 60 with higher scores indicating greater burden. According to a previous Norwegian study, cut-off scores above 23 and 30, respectively, are associated with medium and high risk of psychiatric morbidity (Ulstein, Wyller, & Engedal, 2007). For evaluating depressive symptoms the Geriatric Depression Scale (GDS) (Yesavage et al., 1982) was used, which has been applied in younger populations in previous studies (Rosness et al., 2011). This questionnaire consists of 30 questions with YES/NO responses scored either as zero or 1, with a cut-off score of ten indicating mild depression and scores above 20 indicating severe depression (Brink et al., 1982).

### Persons with dementia

The proxy version of the QOL-AD questionnaire was used to assess QOL of the persons with dementia, where the carers responded on their behalf (i.e. "how do you think he/she would rate his/her own life as a whole"). The Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) was assessed to rate overall cognitive function and depressive symptoms were rated with the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, Abrams, Young, & Shamoian, 1988). Activities of Daily Living (ADL) were measured by adding the sum scores from the Lawton & Brody Instrumental-ADL (I-ADL) (Lawton & Brody, 1969) and the Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969), with total sum scores ranging from 24 (normal functioning) to 61 (total dependency for all functional abilities).

### Statistical analyses

Distribution of continuous variables was assessed by inspecting histograms. Characteristics of dyads were presented as frequencies and percentages for categorical variables and means and standard deviations (SD) for continuous variables. Characteristics of persons with dementia and their carers were compared between those with YOD and LOD by Independent Samples t-tests and Fisher's Exact test.

A linear regression analysis was employed to assess the characteristics associated with differences in QOL-AD scores between persons with YOD and LOD. Eleven characteristics of the persons with dementia (sex, symptom duration, scores on the CSDD, ADL, MMSE, and QOL-AD) and the carers (sex, age, relationship type with the persons with dementia dichotomized into "spousal" and "other", and scores on the GDS and RSS) were selected based on

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**Table 1.** Descriptive statistics of the young-onset ( $n = 88$ ) and late-onset dementia ( $n = 100$ ) dyads, means and standard deviations unless otherwise specified. QOL-AD = Quality of Life – Alzheimer's Disease, ADL = Activities of Daily Living. P-value denotes between-group comparison of baseline data using independent samples t-test, \* Fisher's Exact test. †Likelihood ratio.

Characteristics	LOD	YOD	P-value
<i>Person with dementia</i>			
Dementia diagnosis, n			
Alzheimer's	NS	50	
Frontotemporal	NS	38	
Age	80.1 (5.8)	63.0 (4.8)	< 0.001
Male, n (%)	40 (40)	48 (55)	0.057*
Mini Mental Status Examination	20.9 (3.5)	21.9 (6.1)	0.202
Symptom duration, years	4.4 (3.0)	4.8 (2.7)	0.364
Cornell Scale for Depression In Dementia	7.9 (3.5)	7.0 (5.6)	0.260
Activities of Daily Living	31.4 (8.6)	21.3 (7.8)	< 0.001
QOL-AD	32.7 (5.1)	36.3 (6.6)	< 0.001
<i>Family member</i>			
Number, dyads	100	88	
Age	64 (13.0)	57 (11.7)	< 0.001
Male, n (%)	31 (31)	36 (41)	0.172*
Relationship, n (%)			
Spousal	52 (52)	61 (70)	0.001†
Adult children	43 (43)	16 (18)	
Other	5 (5)	10 (12)	
Geriatric Depression Scale	6.1 (5.7)	6.7 (5.8)	0.485
Relative Stress Scale	24.2 (11.5)	18.7 (12.4)	0.002
QOL-AD	41.2 (4.8)	38.4 (6.5)	0.001

previous research on predictors of QOL, features of the study population, and assessment of correlations among covariates, where highly correlated covariates were excluded (e.g. CSDD was selected instead of Neuropsychiatric Inventory due to correlation of 0.7).

First, linear regression model with only variable YOD versus LOD was estimated. Then unadjusted models containing variable for YOD versus LOD, entering one characteristic at a time and interaction between these two, were estimated. Finally, adjusted model including variable for YOD versus LOD, all considered characteristics and interactions between those and YOD versus LOD variable was estimated. Akaike's Information Criterion, where smaller value means better model, was applied for model reduction. To simplify the interpretation of the interaction terms in unadjusted and adjusted models, the results were presented as mean QOL-AD with 95% confidence interval (CI) within YOD and LOD groups for each category of categorical characteristics. Mean within- and between-group differences were presented together with 95% CI and p-values. Continuous characteristics were presented as mean change in QOL-AD with corresponding 95% CI for one-unit change in characteristic within each group. Mean differences between groups with 95% CI and p-values were presented as well. Selected interactions were illustrated graphically.

The analyses were performed using the SPSS v 25 and SAS v 9.4. The results with p-values below 0.05 were considered statistically significant.

## Results

The descriptive statistics of the YOD and LOD-groups are shown in Table 1. The distribution of spouses, adult children and others (e.g. siblings, friends) were significantly different between the two groups ( $p = 0.001$ ), with 18% more spousal relationships and a smaller proportion of adult children in the YOD-group compared the LOD-group. The family carers of persons with YOD reported significantly poorer QOL-AD scores compared to the carers of the LOD-group ( $p = 0.001$ ) but lower scores on carer burden ( $p = 0.002$ ), Table 1. In contrast, carers of persons with YOD reported significantly

better proxy QOL-AD scores for the persons with dementia compared to carers of persons with LOD ( $p < 0.001$ ).

There were no significant differences in MMSE scores or symptom duration between people with YOD and LOD, however, persons with YOD had significantly less functional impairments ( $p = < 0.001$ ). The regression analysis showed that higher scores on the MMSE were associated with higher carers' QOL in YOD as opposed to carers in LOD, but there was no significant difference between the two groups regarding this association. There were weak correlations ( $r = 0.3$ ) between the QOL-AD scores of the persons with dementia and their family carers within both YOD-and LOD-groups, and significantly different mean QOL-AD scores of the persons with dementia and their carers ( $p = 0.027$  in the YOD-group and  $< 0.001$  in the LOD-group). The QOL-AD scores of carers in the YOD-group was significantly poorer compared to the LOD-group (mean difference 2.5 (95% CI 0.7; 4.3)  $p = 0.006$ ).

Table 2 shows the results from the linear regression model with the QOL-AD scores of the carers as the dependent variable. In unadjusted and adjusted models, higher carer scores on the GDS were significantly associated with lower QOL-AD scores ( $p < 0.001$ ), with no difference between groups, see Figure 1(A and B). Higher carer QOL-AD scores were significantly associated with higher QOL-AD scores of the persons with dementia in both groups in unadjusted model, but only in the LOD-group ( $p = 0.023$ ) in the adjusted model, with no overall difference between groups. In both models, there were significant interactions between YOD- and LOD-groups and scores on the CSDD, symptom duration for the persons with dementia, and for scores on the RSS. In adjusted model, increasing scores on the CSDD was significantly associated with lower QOL-AD scores in the YOD-group while showing a slight non-significant increase in the LOD-group, and there was overall significant difference between the groups ( $p = 0.021$ ), see Figure 1(C and D). A similar overall difference was shown for symptom duration ( $p = 0.004$ ). In the YOD-group lower QOL-AD scores were associated with higher scores on the RSS, with significant overall differences between groups ( $p = 0.011$ ). However,

**Table 2.** Variables associated with QOL-AD score in carers of people with young- (YOD) and late-onset dementia (LOD = reference group), results of linear regression analysis. YOD = cares of people with young-Onset Dementia. LOD = cares of people with late-Onset Dementia. YOD/LOD is the effect of YOD compared to LOD on QOL-AD. CSDD = Cornell Scale for Depression in Dementia. ADL = Activities of Daily Living sum score. MMSE = Mini Mental State Examination. GDS = Geriatric Depression Scale. RSS = Relatives' Stress Scale.

Characteristics	Unadjusted models				Adjusted AIC-reduced model			
	YOD Mean (95% CI)	LOD Mean (95% CI)	YOD vs. LOD		YOD Mean (95% CI)	LOD Mean (95% CI)	YOD vs. LOD	
			Mean (95% CI)	p-value			Mean (95% CI)	p-value
Sex, person with dementia								
Female	39.1 (37.2; 41.1)	41.8 (40.4; 43.2)	-2.7 (-5.1; -0.2)	<b>0.032</b>	41.3 (30.1; 52.5)	40.9 (28.8; 53.1)	0.4 (-13.8; 14.6)	0.956
Male	38.4 (36.5; 40.3)	40.4 (38.6; 42.2)	-2.0 (-4.6; 0.6)	0.132	41.4 (30.0; 52.9)	41.0 (28.8; 53.3)		
Female vs. Male	0.7 (-2.0; 3.4)	1.4 (-0.9; 3.6)	-0.6 (-4.2; 2.9)	0.725	-0.1 (-2.0; 1.8)			
p-value	0.613	0.251			0.908			
Symptom duration								
1-unit increase	-0.8 (-1.3; -0.4)	-0.2 (-0.6; 0.2)	-0.6 (-1.2; -0.1)	<b>0.036</b>	-0.7 (-1.1; -0.3)	0.1 (-0.2; 0.4)	-0.8 (-1.3; -0.3)	<b>0.004</b>
p-value	<b>0.001</b>	0.306			<b>0.002</b>	0.440		
CSDD								
1-unit increase	-0.6 (-0.8; -0.4)	-0.1 (-0.3; 0.1)	-0.5 (-0.8; -0.2)	<b>0.001</b>	-0.3 (-0.5; -0.03)	0.1 (-0.1; 0.3)	-0.4 (-0.7; -0.1)	<b>0.021</b>
p-value	< <b>0.001</b>	0.349			<b>0.030</b>	0.268		
ADL 1-unit increase p-value	-0.2 (-0.3; 0.00)	-0.04 (-0.2; 0.1)	-0.1 (-0.3; 0.1)	0.264	0.3 (0.1; 0.5)	0.0 (-0.1; 0.1)	0.3 (0.1; 0.5)	<b>0.006</b>
1-unit increase	0.056 (-0.04; 0.4)	0.507 (-0.2; 0.4)	0.1 (-0.3; 0.5)	0.640	<b>0.001</b> (0.03; 0.5)	0.978 (-0.3; 0.3)	0.3 (-0.1; 0.6)	0.134
MMSE	0.2 (-0.04; 0.4)	0.1 (-0.2; 0.4)	0.1 (-0.3; 0.5)	0.640	0.3 (0.03; 0.5)	0.0 (-0.3; 0.3)	0.3 (-0.1; 0.6)	0.134
p-value	0.106	0.562			<b>0.023</b>	0.971		
QOL-AD, person with dementia								
1-unit increase	0.3 (0.1; 0.5)	0.3 (0.1; 0.5)	0.0 (-0.3; 0.3)	0.994	0.1 (-0.1; 0.2)	0.3 (0.0; 0.5)	-0.2 (-0.5; 0.1)	0.152
p-value	<b>0.003</b>	<b>0.006</b>			0.564	<b>0.023</b>		
Carer sex								
Female	38.8 (37.0; 40.5)	40.9 (39.5; 42.2)	-2.1 (-4.3; 0.1)	0.063	40.9 (29.8; 52.0)	40.5 (28.3; 52.7)	0.4 (-13.8; 14.6)	0.956
Male	38.8 (36.7; 40.9)	42.1 (40.1; 44.1)	-3.4 (-6.2; -0.5)	<b>0.023</b>	41.4 (30.0; 52.9)	41.0 (28.8; 53.3)		
Female vs. Male	-0.0 (-2.8; 2.8)	-1.3 (-3.7; 1.1)	1.3 (-2.4; 4.9)	0.506	-0.5 (-2.3; 1.3)			
p-value	0.988	0.303			0.561			
Carer age								
1-unit increase	-0.0 (-0.1; 0.1)	-0.05 (-0.1; 0.04)	0.03 (-0.1; 0.2)	0.658	-0.1 (-0.2; 0.01)		0.4 (-13.8; 14.6)	0.956
p-value	0.762	0.246			0.076			
Relationship type								
Other	39.1 (36.7; 41.5)	42.0 (40.4; 43.6)	-2.9 (-5.8; 0.0)	0.05	40.3 (29.2; 51.3)	39.9 (28.4; 51.4)	0.4 (-13.8; 14.6)	0.956
Spousal	38.6 (37.0; 40.3)	40.6 (39.0; 42.1)	-2.0 (-4.2; 0.3)	0.09	41.4 (30.0; 52.9)	41.0 (28.8; 53.3)		
Other vs. Spousal p-value	0.5 (-2.5; 3.4)	1.4 (-0.8; 3.6)	-0.9 (-4.6; 2.8)	0.626	-1.2 (-3.6; 1.3)	0.356		
GDS								
1-unit increase	-0.7 (-0.8; -0.5)	-0.5 (-0.6; -0.3)	-0.2 (-0.4; 0.1)	0.193	-0.5 (-0.6; -0.3)		0.4 (-13.8; 14.6)	0.956
p-value	< <b>0.001</b>	< <b>0.001</b>			< <b>0.001</b>			
RSS								
1-unit increase	-0.3 (-0.4; -0.2)	-0.1 (-0.2; -0.1)	-0.2 (-0.3; -0.1)	<b>0.004</b>	-0.2 (-0.3; -0.1)	0.0 (-0.1; 0.1)	-0.2 (-0.3; -0.04)	<b>0.011</b>
p-value	< <b>0.001</b>	<b>0.002</b>			<b>0.002</b>	0.921		

only the adjusted model showed a significant interaction between YOD- and LOD-group in ADL, see Figure 1(E and F), where higher ADL score (i.e. poorer functional status) was associated with significantly higher QOL-AD scores in YOD ( $p = 0.001$ ) while no association was found in the LOD-group, see Figure 1(F).

The multiple AIC-reduced model explained 49% of the total variance in QOL-AD.

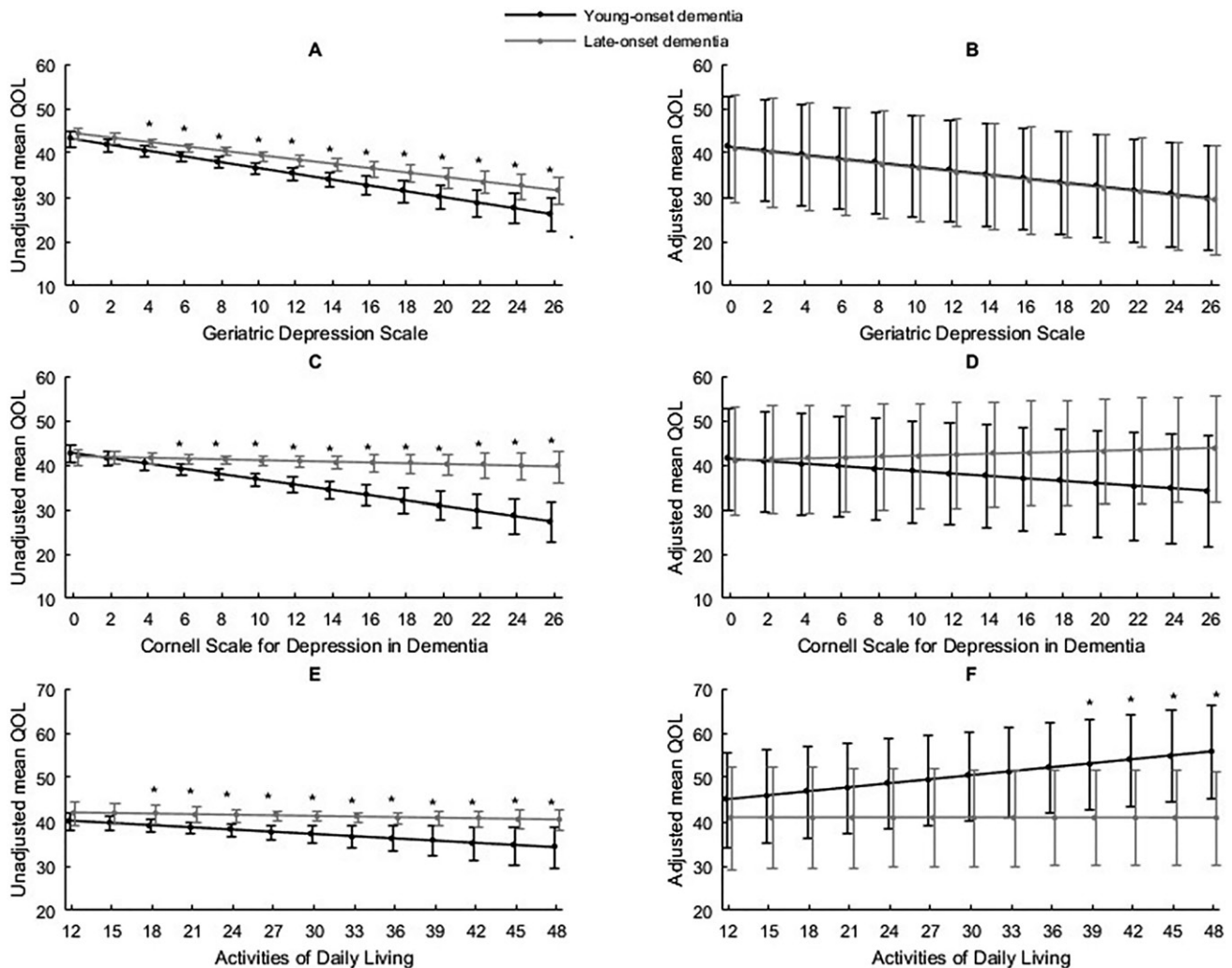
## Discussion

Key findings were poorer QOL in YOD-carers compared to LOD-carers, the common factor of depressive symptoms of

carers in both groups, and the impact of carer burden on QOL in YOD. This study contributes valuable insight into two carer groups whose QOL have hardly been compared before (Millenaar et al., 2016).

YOD-carers reported significantly poorer QOL compared to LOD-carers, although the latter cared for persons with greater functional impairments and experienced more burden. This could possibly be explained by a higher proportion of people with FTD in YOD, as behavioral changes have been shown to be particularly stressful for the carers (de Vugt et al., 2006; Riedijk et al., 2006), although a Norwegian study did not find poorer QOL in YOD-carers of people with AD compared to non-AD (mean QOL-AD 38.5

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**Figure 1.** The unadjusted (figure A, C and E) and adjusted slopes (figure B, D and F) showing the interaction between the young- (YOD, black line) and late-onset dementia (LOD, grey line) groups for the association between QOL-AD and Geriatric Depression Scale scores (GDS), Cornell Scale for Depression in Dementia, and Activities of Daily Living in the linear regression model. Significant differences are marked by asterisks.

(SD 5.3) versus 35.8 (5.9),  $p=0.18$ ) (Rosness et al., 2011). Unfortunately, we were not able to adjust our analyses for significant difference in distribution of diagnoses. However, we adjusted for important characteristics, such as age, sex, symptom duration (as a proxy for dementia severity), cognitive symptoms and depressive symptoms, ADL, QOL of the person with dementia, and relationship type with the carer, which could mediate the effect of diagnosis on carer QOL.

In the comparison group, LOD-carers living in the same household reported significantly poorer QOL than those living in separate households (QOL-AD scores 40 versus 42, respectively; unpublished data) (Bruvik et al., 2012). However, when adjusting for different carer composition (spousal relationship indicating co-residency) between the two groups in the present study, relationship type was non-significant to carer QOL. A Norwegian carer study by Rosness et al. (2011) did not find marital status to be associated with carer QOL, but rather associated with depressive symptoms (Rosness et al., 2011). Overall, mean QOL-AD scores above 37 in the present study indicate good QOL (Conde-Sala et al., 2016) similar to the aforementioned study (Rosness et al., 2011). The YOD-carers also reported their own QOL as better compared to their proxy reports for the persons with YOD.

A common feature of all family carers in the present study was the negative impact that their depressive symptoms had on QOL, regardless of caring for a person with YOD or LOD. This corresponds well with previous research on carer QOL in both YOD and LOD and emphasizes the importance of diagnosing and treating depressive symptoms in carers (Kaiser & Panegyres, 2007; Moniz-Cook et al., 2008). The present study found poorer QOL of YOD-carers when applying a disease-specific measurement to include important domains likely to be affected by dementia (Page et al., 2017; Ready & Ott, 2003). Previously, the Need-YD (Dutch national Needs in Young-onset Dementia) have shown significantly lower (i.e. poorer) mental and physical component scores of the generic QOL measurement RAND-36 in YOD-carers compared to LOD-carers in the presence of the same number of physical and psychological complaints (Millenaar et al., 2016). Contrary to QOL in LOD-carers, we also found QOL in YOD-carers to be negatively associated with depressive symptoms of the persons with dementia. The mental wellbeing of family carers of people with YOD should be routinely assessed in a dyadic approach to improve QOL and support carers in providing good quality care.

Despite high levels of distress in YOD-carers, inconclusive results regarding burden and depression have been

found in comparison with LOD (Arai, Matsumoto, Ikeda, & Arai, 2007; Freyne, Kidd, Coen, & Lawlor, 1999; van Vliet et al., 2010). A recent study assessing carers' perspectives on the QOL of persons with young- and late-onset Alzheimer's dementia found no significant difference in carer burden between the two groups (Kimura et al., 2018). Only one UK study published in 1999 found significantly higher burden in YOD compared to LOD (Freyne et al., 1999). Although the symptom duration in the two groups were similar in the present study, YOD-carers showed deteriorating QOL-AD scores with increasing symptom duration while scores improved in LOD-carers, suggesting accumulative strain and/or insufficient adaptability to change. Younger carers may find themselves in a situation with more commitments and less flexibility. As a result, the adaptation process may be prolonged or delayed.

The families in the YOD-group reported significantly less burden compared to the LOD-group. This could be related to differences in co-morbidity profiles between the two groups, which we unfortunately were unable to adjust for. However, the decline in QOL with increasing burden was significantly steeper in the YOD-group, suggesting greater impact when burden was present. This underscores the importance of identifying carers at high risk of negative health outcomes for early intervention.

Post hoc analyses of interactions showed that although several interactions were significant in the final model, the only significant difference between the two groups was found at higher scores (> 38 points) on ADL. This degree of functional impairments would require supervision and assistance in daily living incompatible with the family member being fully employed or necessitate the introduction of additional informal or formal support. This discrepancy between the use of formal help and increasing care needs might explain why longer symptom duration was associated with poorer QOL in carers in the YOD-group, as older people are more likely to receive and benefit from existing services in dementia care (Bakker et al., 2013b; Cations et al., 2017; Wolfs, de Vugt, Verkaik, Verkade, & Verhey, 2010). A possible explanation for the positive association between better QOL in carers with higher ADL-scores (i.e. more functional impairments) of the persons with dementia could be better access and greater acceptability towards use of formal help with progressive disease.

The adjusted AIC-reduced model explained almost half of the total variance (49%) in QOL-AD. Just as QOL is a multifaceted concept, our results show the complexity of factors which may impact on QOL, particularly in YOD.

We applied the QOL-AD questionnaire as a measure for QOL in carers as well as for the persons with dementia. This has been done in several studies of carers (Bruvik et al., 2012; Farina et al., 2017; Rosness et al., 2011), probably due to the lack of better alternatives as there are few dementia-specific QOL measurements for carers (Page et al., 2017) and generic measures tend to miss out on important disease-specific aspects (Coons, Rao, Keininger, & Hays, 2000; Moniz-Cook et al., 2008; Ready & Ott, 2003). However, this questionnaire has not been validated for use in carers. Applying the QOL-AD covered dementia-specific domains supplemented by more general considerations (such as accommodation) and overall perspectives of QOL (e.g. self and life as a whole). As co-residing spouses are

the most frequent carers in dementia, it is not unreasonable to expect reciprocity within the dyads in domains impacted by dementia. Under the assumption that although having dementia may change perspectives and priorities of domains important to QOL the specific domains involved are nevertheless universal to all people, then the questionnaire should also be applicable to carers. As the QOL-AD was developed for people with dementia, the memory item is the most disease-specific of all questionnaire items, perceivably irrelevant to carer QOL. However, a review of dementia carers and cognitive decline proposed a theoretical chronic stress model including several possibly modifiable factors (e.g. psychosocial, behavioral and physiological variables) to explain the higher risk of cognitive decline observed in dementia carers compared to non-carers (Vitaliano, Murphy, Young, Echeverria, & Borson, 2011). This could justify the inclusion of a memory item in carer QOL.

Another methodological issue was the reliance on proxy-measures for characteristics of the people with dementia and informant biases. In the present study, there was relatively low correlation between QOL of carers and the people with dementia within both YOD- and LOD-group, ( $r=0.3$  for both groups,  $p=0.027$  and  $< 0.001$ , respectively). In unadjusted analysis there was a significant association between QOL within the dyads ( $p=0.003$  in YOD and  $0.006$  in LOD), but when adjusted for cognition and carer reported questionnaires including ADL, QOL was only significantly associated with QOL in LOD-dyads ( $p=0.023$ ). Overall, there was a slight increase in carer QOL with increasing QOL of the person with dementia, but no significant difference between the two groups. This would suggest that carers in both groups were able to differentiate their own QOL from that of the persons with dementia, also when considering the proxy reported assessments that they provided, indicating minor proxy biases.

### Strengths and limitations

A major strength is the comparison of an under-assessed and increasingly utilized outcome measure in dementia research (QOL) in carers in two different dementia groups, representing populations with different characteristics. This contributes important knowledge necessary for preventive measures and targeted clinical intervention. An important limitation is the non-disclosure of diagnosis distribution in the LOD-group and insufficient statistical power to stratify the analyses on diagnosis in the YOD-group. A higher proportion of carers of people with FTD may have contributed to poorer QOL-AD scores in the YOD-group compared to LOD-group. The methodology may also have been limited by use of an assessment tool (the QOL-AD) not validated for carer QOL.

### Conclusion

Nordic carers of people with YOD manage to maintain good QOL in their dedication to provide good quality care, but they experience poorer QOL compared to LOD-carers. Depressive symptoms had negative impact on QOL in both groups. Although the factors associated with QOL are complex and intertwined, adequate treatment of depressive

745 symptoms and a dyadic approach to intervention is recom-  
746 mended in enhancing QOL in YOD as in LOD.

## 747 Disclosure statement

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