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Original Study

The Course of Quality of Life and Its Predictors in Nursing Home Residents With Young-Onset Dementia

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A B S T R A C T

Objective: To explore the course of quality of life (QoL) and possible resident-related predictors associated with this course in institutionalized people with young-onset dementia (YOD).
Design: An observational longitudinal study.
Setting and Participants: A total of 278 residents with YOD were recruited from 13 YOD special care units in the Netherlands.
Methods: Secondary analyses were conducted with longitudinal data from the Behavior and Evolution in Young-ONset Dementia (BEYOND)-II study. QoL was assessed with proxy ratings, using the Quality of Life in Dementia (QUALIDEM) questionnaire at 4 assessment points over 18 months. Predictors included age, gender, dementia subtype, length of stay, dementia severity, neuropsychiatric symptoms, and psychotropic drug use at baseline. Multilevel modeling was used to adjust for the correlation of measurements within residents and clustering of residents within nursing homes.
Results: The total QUALIDEM score (range: 0-111) decreased over 18 months with a small change of 0.65 (95% confidence interval −1.27, −0.04) points per 6 months. An increase in several domains of QoL regarding care relationship, positive self-image, and feeling at home was seen over time, whereas a decline was observed in the subscales positive affect, social relations, and having something to do. Residents with higher levels of QoL and more advanced dementia at baseline showed a more progressive decline in QoL over time. Sensitivity analyses indicated a more progressive decline in QoL for residents who died during the follow-up.
Conclusion and Implications: This study shows that although overall QoL in nursing home residents with YOD was relatively stable over 18 months, there were multidirectional changes in the QoL subscales that could be clinically relevant. Higher levels of QoL and more advanced stages of dementia at baseline predicted a more progressive decline in QoL over time. More longitudinal studies are needed to verify factors influencing QoL in YOD.

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Dementia is one of the most common neurodegenerative diseases leading to disabilities[1] and has important psychosocial consequences, with a large impact on quality of life (QoL).[2] Young-onset dementia (YOD) is defined as dementia with a symptom onset before the age of 65 years, which accounts for 2% to 8% of all dementia cases.[3] When the early onset of the disease is in a midlife age, people often encounter specific challenges and unmet needs resulting from a loss of sense of identity, the loss of certain abilities hindering their ability to work or cause social isolation.[4–6] All these challenges along with the progression of dementia may further compromise their QoL.

It is often challenging for younger individuals with YOD get access to age-appropriate services, in particular long-term residential care.[7] A survey from United Kingdom reported that the majority of YOD had no access to local age-appropriate long-term care.[8] At the same time, mainstream dementia services, including most nursing homes, have difficulties in meeting the needs of younger individuals, because they have been designed with a focus on the needs of older people.[7] These may very well explain the lower levels of QoL experienced by people with YOD[9,10] and increase the risk for institutionalization.[11,12] To optimize care for this specific group, more than 30 health care providers and expert organizations are affiliated with the Dutch YOD Knowledge Center delivering specialized care for persons with YOD in the Netherlands. Nursing home residents with YOD reside on special care units, which are usually part of (larger) nursing homes with 5 to 25 YOD residents per unit. A multidisciplinary team with specially trained expertise on YOD, consisting of an older care physician,[13] health care psychologist, and nursing staff, provide treatment and services regarding daytime activities, social contacts, and mobility for younger persons.[14] This network platform offers a unique opportunity for research in residential care for people with YOD.

Despite an increasing number of people diagnosed with YOD, only a few studies address the QoL in nursing home residents with YOD. A cross-sectional study of our group focusing on QoL in nursing home residents with YOD showed a mean Quality of Life in Dementia (QUALIDEM) score of 76 (total 0-111),[15] which is comparable to similar studies in residents with late-onset dementia (LOD) living in Dutch nursing homes[16] and German nursing homes.[17] Several cross-sectional studies found that QoL in people with YOD was negatively associated with depressive symptoms,[9,18–20] neuropsychiatric symptoms,[19] and psychotropic drug use,[15] which were consistent with results found in residents with LOD.[21,22] Comparatively little has been published on the course of QoL and its predictors in YOD.[2,23] Only 1 longitudinal study investigated the course and predictors associated with QoL of 88 community-dwelling persons with YOD over 2 years. This study found that the overall QoL remained stable during the study period. Male gender, a diagnosis of frontotemporal dementia, higher levels of depressive symptoms, and cognitive impairment at baseline had a significantly greater reduction in QoL at follow-up.[10]

The objective of this study is to explore the course of QoL and resident-related factors of that course in people with YOD admitted to nursing homes with YOD specialized care units. A better understanding of the course of QoL and factors influencing this course will provide valuable information to identify YOD residents at risk of declining QoL and may aid the development of interventions to improve their QoL.

Methods

Study Design

This longitudinal study used data from the Behavior and Evolution in Young-ONset Dementia (BEYOND)—II study.[24] This study was a randomized controlled trial to explore the effects of a care program to manage neuropsychiatric symptoms in institutionalized people with YOD, using a stepped-wedge design with 4 measurements (at 0, 6, 12, and 18 months). For the purpose of this study, each participant's entry data were used as his or her baseline. Detailed information about the BEYOND-II study is published elsewhere.[24]

Data Collection and Assessment Instruments

Trained researchers and research assistants collected proxy assessments through structured interviews with the nursing staff. Data on age, gender, and length of stay was retrieved from residents' medical files. QoL of residents was assessed every 6 months during 18 months: at baseline (T0) and 6 (T1), 12 (T2), and 18 months (T3).

Primary Outcome: Quality of Life

QoL was assessed with the QUALIDEM questionnaire.[25] It is a proxy assessment scale that consists of 37 items with a 4-point Likert rating scale (eg, never, rarely, sometimes, and frequently). These items are grouped into 9 subscales: (1) care relationship; (2) positive affect; (3) negative affect; (4) restless tense behaviors; (5) positive self-image; (6) social relations; (7) social isolation; (8) feeling at home; and (9) having something to do. A higher score indicates a higher level of QoL. The QUALIDEM is reported to be a reliable and validated tool to assess QoL in people with all stages of dementia.[26] In the current study, both the overall QUALIDEM score and each subscale were analyzed as dependent variables.[25]

Predictors of QoL

Dementia severity was assessed with the Global Deterioration rating Scale,[27] which is a validated scale that describes 7 different stages of dementia (range 1-7) ranging from "subjectively and objectively normal cognition" to "severe cognitive decline." Dementia subtypes, including Alzheimer's dementia (AD), frontotemporal dementia, vascular/mixed dementia, and other types of dementia were recorded from medical records.[24]

Neuropsychiatric symptoms (NPS) were assessed using the Neuropsychiatric Inventory—Nursing Home version (NPI-NH). The NPI-NH measures 12 neuropsychiatric symptoms: delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, nighttime behavior disturbances, and eating disturbances. Scores for the presence of each neuropsychiatric symptom are calculated as Frequency (range 1-4) × Severity (range 1-3), revealing a total score of 0-144. The NPI-NH has high inter-rater reliability and has been reported to be a valid rating scale for measuring a wide range of NPS in dementia.[28] We used NPI-NH 5-factor scores, including agitation/aggression, depression,

psychosis, psychomotor agitation, and apathy, based on a previous study with a large sample of Dutch nursing home residents with dementia.[29]

Psychotropic drug use (PDU) was derived from the pharmacists' electronic files and was classified according to the Anatomical Therapeutic Chemical classification system.[30] Specifically, PDU was categorized as antipsychotics (N05A), anxiolytics (N05B), hypnotics/sedatives (N05C), antidepressants (N06A), antiepileptics (N03A), antidementia drugs (N06D), and PDU (dichotomized to present or absent). Antiepileptics for residents diagnosed with epilepsy and antidementia drugs were excluded when calculating the percentage of PDU as these medications may be prescribed for epilepsy or cognitive decline rather than for NPS. Moreover, pro re nata (PRN) medication was not registered due to the uncertainty of how often these drugs were actually used.

Data Analyses

Demographic variables were described by calculating means with standard deviations (SDs) or proportions. Participants with missing values in the variables age and length of stay (n = 5) were excluded from the analysis, whereas the missing values in the primary outcome of QoL were handled by linear mixed models based on the missing at random assumption.[31] Random intercepts in these models accounted for the clustering of residents within nursing homes and correlations of repeated measures within residents. The overall course of QoL was estimated using only time as a continuous fixed effect. The threshold of clinically meaningful discrimination for changes in quality of life is estimated on half an SD,[32] and this was around 8 points change on the QUALIDEM total score from previous studies.[15,16]

To identify predictors of the course of QoL, the interaction terms with time and possible predictors[33,34] were added in the mixed model, including age, gender, length of stay, dementia subtype, dementia severity (Global Deterioration rating Scale: mild, moderate, severe), the NPI-NH total score and 5-factor score, and PDU. The effect of the intervention was adjusted for if the intervention caused a level and/or slope change (ie, the fixed effects intervention and time-in-the-intervention could not be removed from the model with a statistically significant change in the log likelihood). Supplementary Material 1 describes the full details and rationale of the analyses. Sensitivity analyses were performed on the data of those residents (n = 130) who completed all 4 measurements and participants who were lost to follow-up due to death (n = 57) to investigate the impact of drop-out and a differential course of QoL in residents who were close to dying, respectively. A 2-tailed P value $<.05$ was considered statistically significant. All analyses were performed using IBM SPSS Statistics for Windows, version 25.0 (IBM Corp, Armonk, NY).

Results

Participants Characteristics

A total of 280 residents were recruited from 13 YOD special care units. One resident withdrew before the start of the data collection and another resident without dementia was excluded. QUALIDEM questionnaires were available for the following number of residents: 278 at T0, 229 at T1, 172 at T2, and 130 at T3. Fifty-seven residents died during the study, and 58 residents had incomplete data because they entered the study at a later time point. Eighteen residents were lost to follow-up because they moved to another care unit and 15 due to other reasons. The mean age was 61.3 years (SD = 6.3) (Table 1). The

Table 1
Characteristics of Residents at Baseline, Residents With Full Follow-up and Those Who Had Died Before the End of the Study

Variables	Residents at Recruitment (n = 278)	Residents With Full Follow-up (n = 130)	Deceased Residents (n = 57)
Mean age at inclusion, y, mean (SD)*	61.3 (6.3)	60.2 (7.1)	62.2 (5.2)
Gender, male, n (%)	140 (50.4)	66 (50.8)	32 (56.1)
Length of stay at inclusion, mo, mean (SD)*	28.8 (32.3)	31.2 (31.5)	46.5 (38.4)
Dementia severity (GDS)			
Mild (2, 3, 4)	44 (15.8)	28 (21.5)	4 (7.0)
Moderate (5)	60 (21.6)	34 (26.2)	5 (8.8)
Severe (6, 7)	174 (62.2)	68 (52.3)	48 (84.2)
Dementia subtype			
AD	123 (44.2)	54 (41.5)	27 (47.4)
FTD	80 (28.8)	45 (34.6)	17 (29.8)
Vascular/mixed dementia	44 (15.8)	15 (11.5)	9 (15.8)
Another diagnosis†	31 (11.2)	16 (12.3)	4 (7.0)
Medication use, n (%)			
Antipsychotic drugs (N05A)	89 (32.0)	47 (36.2)	14 (24.6)
Anxiolytic drugs (N05B)	70 (25.2)	34 (26.2)	17 (29.8)
Hypnotic/sedatives (N05C)	39 (14.0)	19 (14.6)	12 (21.1)
Antidepressant drugs (N06A)	98 (35.3)	42 (32.3)	25 (43.9)
Antiepileptic drugs (N03A)	25 (9.0)	10 (7.7)	7 (12.3)
Antidementia drugs (N06D)	16 (5.8)	7 (5.4)	2 (3.5)
PDU, n (%) using at least 1 drug	177 (63.6)	81 (62.3)	33 (57.9)
Mean NPI-NH total score at baseline (0-144), mean (SD)	24.7 (20.3)	21.6 (18.1)	30.5 (25.1)
Agitation (0-48)	10.4 (10.5)	9.7 (9.4)	11.4 (12.2)
Depression (0-24)	3.0 (5.2)	2.3 (4.6)	3.9 (5.9)
Psychosis (0-24)	2.3 (4.7)	1.8 (3.5)	3.5 (5.9)
Psychomotor agitation (0-24)	5.0 (6.2)	4.3 (5.7)	5.7 (7.4)
Apathy (0-24)	4.9 (6.0)	4.6 (5.8)	7.1 (6.8)
QUALIDEM total score (0-111), mean (SD)‡	76.4 (16.4)	77.3 (14.9)	72.0 (16.2)

AD, Alzheimer's dementia; ATC, Anatomical Therapeutical Chemical classification; FTD, frontotemporal dementia; GDS, Global Deterioration rating Scale; SD, standard deviation.

*5 missing.

†Other dementia includes Lewy body dementia, Alcohol-related dementia, and Parkinson's dementia.

‡Higher (sub)scores indicate higher QoL. Numbers in parentheses represent the range of the QUALIDEM (subscale) score.

Table 2
Linear Mixed Model: Analysis of the Course of QoL (Measured With QUALIDEM) for the Total Sample

QUALIDEM Subscales*	T0 (n = 278)	T1 (n = 229)	T2 (n = 172)	T3 (n = 130)	Regression Coefficient† (95% CI)	*P*
A: Care relationship (0-21)	14.72 (4.82)	15.24 (4.53)	14.92 (4.47)	15.81 (3.93)	0.20 (0.01, 0.39)	**.04**
B: Positive affect (0-18)	13.40 (4.66)	13.47 (4.52)	12.90 (4.79)	11.93 (5.26)	−0.61 (−0.82, −0.40)	**<.001**
C: Negative affect (0-9)	6.46 (2.67)	6.52 (2.54)	6.69 (2.51)	6.92 (2.48)	0.05 (−0.05, 0.15)	.32
D: Restless tense behavior (0-9)	4.99 (3.00)	5.47 (3.06)	5.25 (3.03)	5.54 (2.92)	−0.09 (−0.04, 0.23)	.18
E: Positive self-image (0-9)	7.98 (1.94)	8.11 (1.95)	8.20 (1.83)	8.58 (1.17)	0.11 (0.03, 0.19)	**.01**
F: Social relations (0-18)	9.84 (4.44)	10.24 (4.69)	9.83 (4.17)	9.00 (4.46)	−0.43 (−0.59, −0.26)	**<.001**
G: Social isolation (0-9)	6.63 (2.31)	6.78 (2.13)	6.65 (2.22)	6.75 (2.43)	−0.02 (−0.12, 0.09)	.74
H: Feeling at home (0-12)	9.89 (2.78)	10.31 (2.40)	10.46 (2.24)	10.82 (1.98)	0.28 (0.18, 0.39)	**<.001**
I: Having something to do (0-6)	2.53 (2.14)	2.45 (2.23)	2.15 (2.04)	1.98 (2.10)	−0.30 (−0.39, −0.22)	**<.001**
Total QUALIDEM score (0-111)	76.44 (16.41)	78.59 (15.93)	77.03 (15.33)	77.33 (14.90)	−0.65 (−1.27, −0.04)	**.04**

The data are based on a linear mixed model using a *t* statistic. The model for the course of QoL = intercept + time. Boldface indicates significance.
*Higher (sub)scores indicate higher QoL. Numbers in parentheses represent the range of the QUALIDEM (subscale) score.
†Regression coefficient represents the change in the QUALIDEM (subscale) score per 6 months.

male-to-female ratio was comparatively equal, and the majority of residents (62.2%) had severe dementia. AD was the most common cause of dementia, followed by frontotemporal dementia and vascular or mixed dementia. Approximately 63.6% used at least 1 psychotropic drug. Residents had a mean QoL total score of 76.4 (SD = 16.4). Compared with the total sample, participants with full follow-up had fewer people with severe dementia whereas deceased participants had more severe dementia, higher levels of NPS, and lower QoL at baseline.

The Course of QoL

Linear mixed models revealed a statistically significant decline in QoL (range 0-111) of 0.65 [95% confidence interval (CI) −1.27, −0.04] points per 6 months (Table 2). Significant declines were also observed in the subscales positive affect, social relations, and having something to do. The largest relative change was found in the subscale having something to do, showing a change of 0.30 (95% CI −0.39, −0.22) points every 6 months, given the range of this particular subscale, ranging from zero to 6. However, an increase was found in the subscales care relationship, positive self-image, and feeling at home. The largest relative positive change was found in the subscale feeling at home with an increase of 0.28 (95% CI 0.18, 0.39) points per 6 months.

Predictors of the Course of QoL

Results showed that the level of QoL and dementia severity at baseline most often predicted the course of QoL as well as the course of several different domains of QoL (Table 3). Residents with higher levels of QoL at baseline showed a more progressive decline in QoL over time (regression coefficient −0.20, 95% CI −0.24, −0.15), whereas a less progressive decline was found in people showing mild dementia at baseline compared to those with severe dementia (2.63, 95% CI 1.03, 4.23). Different predictors were found for the separate domains of QoL. Compared with severe dementia, the three subscales positive affect, social relations, and having something to do showed a less progressive QoL decline in the case of mild dementia. Being a male was positively associated with the course of negative affect and positive self-image but negatively associated with social relations and having something to do. Furthermore, dementia diagnosis was associated with the course of positive affect, social relations and having something to do, with a more rapid decline observed in AD. Moreover, younger age at baseline was associated with a more rapidly progressive course in social relations and social isolation. PDU was not identified as a predictor of QoL course in YOD.

Results From Sensitivity Analyses

Sensitivity analyses were undertaken with the 130 residents with complete follow-up, and the results were similar to the total sample with minor changes in the rate of the estimated coefficients (Table 4). Additionally, the 57 deceased participants had a more progressive decline in QoL with a reduction of 2.24 (−5.49, 1.00) points per 6 months, but this was not statistically significant. A much larger decline was found in the subscale positive affect with a decline of 1.56 (−2.73, −0.38) points (range 0-18) per 6 months and higher NPS of agitation, psychosis, psychomotor agitation, and apathy predicted a more rapid decline in this subscale (Table 5).

Discussion

To our knowledge, this is the first longitudinal study to explore the course and its predictors of QoL in nursing home residents with YOD. Our study showed a small decline in the overall QoL in YOD over 18 months, whereas different domains of QoL showed multidirectional changes. The level of QoL and dementia severity at baseline were found to be the most important predictors for both the total QoL score and the subscales. Moreover, residents that died during the study experienced a larger progressive decline in QoL.

Although we found an average decline of 0.65 points per 6 months in the total QoL score, this is not clinically relevant given the large range of the QUALIDEM (0-111). A similar study on community-dwelling people with YOD found no statistically significant change in the overall QoL during a 2-year follow-up, measured by family carers using the Quality of Life–Alzheimer's Disease scale (QoL-AD).[10] Another study reported a small decline in QoL (0.25 points per year) in LOD residents using the QUALIDEM.[22] Previous studies also reported that QoL remained stable or even improved in nursing home residents with dementia over time despite cognitive deterioration.[21,35,36] There are no clear or consistent relationships between changes in QoL trajectories and the natural progression of dementia over time.[37,38] Moreover, residents living in dedicated YOD special care units may receive different care and support compared with those living in the community or regular nursing homes, and the dedicated care and support may have an impact on the level of QoL. Therefore, it might be difficult to compare the results of our study with previous findings on QoL in people with YOD directly, given differences in the methodology used, the care services provided, and because the majority of previous studies involved older residents living with dementia.

Although overall QoL remained relatively stable, we found several changes in the subscales over time. The largest decline in the subscale having something to do suggests that the residents in our study experienced a lack of meaningful daytime activities. This is in line with previous research that people with YOD were at risk of unmet needs

Table 3
The Predictors of Course of QoL in Residents With YOD (N = 278)

Parameter	QUALIDEM*, Coefficient (95% CI)†									
	Total Score	Subscale A	Subscale B	Subscale C	Subscale D	Subscale E‡	Subscale F	Subscale G	Subscale H	Subscale I
Baseline QUALIDEM (sub)scale	−0.20§ (−0.24, −0.15)	−0.22§ (−0.27, −0.17)	−0.16§ (−0.21, −0.11)	−0.16§ (−0.21, −0.11)	−0.23§ (−0.29, −0.18)	−0.20§ (−0.25, −0.16)	−0.15§ (−0.19, −0.11)	−0.26§ (−0.31, −0.20)	−0.25§ (−0.29, −0.21)	−0.24§ (−0.28, −0.20)
Dementia severity										
Mild	2.63‖ (1.03, 4.23)	NS	0.91‖ (0.36, 1.47)	NS	NS	NS	0.73‖ (0.29, 1.17)	NS	NS	0.65§ (0.42, 0.88)
Moderate	NS	NS	0.63‖ (0.15, 1.12)	NS	−0.44‖ (−0.75, −0.13)	NS	NS	−0.37§ (−0.60, −0.14)	−0.29‖ (−0.52, −0.06)	0.42§ (0.21, 0.62)
Severe	Ref									
Gender										
Male	NS	NS	NS	0.33‖ (0.12, 0.54)	NS	0.17‖ (0.02, 0.33)	−0.52‖ (−0.84, −0.20)	NS	NS	−0.17‖ (−0.34, −0.01)
Female	Ref									
Dementia subtype										
VD/mixed	NS	NS	NS	−0.32‖ (−0.62, −0.03)	NS	NS	NS	NS	NS	NS
FTD	NS	NS	NS	NS	NS	NS	NS	NS	NS	0.21‖ (0.02, 0.41)
Other	NS	NS	0.70‖ (0.05, 1.34)	NS	NS	NS	0.97§ (0.48, 1.47)	NS	NS	NS
AD	Ref									
Age	NS	NS	NS	NS	NS	NS	0.04‖ (0.02, 0.06)	0.03§ (0.01, 0.04)	NS	NS
Length of stay	NS	NS	NS	0.003‖ (0.00, 0.01)	NS	NS	0.005‖ (0.00, 0.01)	NS	NS	NS
NPI-NH total	NS	NS	NS	NS	−0.06‖ (−0.11, −0.01)	NS	NS	NS	NS	NS
NPI-Apathy	NS	NS	NS	NS		NS	NS	NS	−0.04‖ (−0.09, 0.00)	NS

FTD, frontotemporal dementia; NS, not significant; Ref, reference group.
Subscale A = care relationship; subscale B = positive affect; subscale C = negative affect; subscale D = restless tense behavior; subscale E = positive self-image; subscale F = social relations; subscale G = social isolation; subscale H = feeling at home; subscale I = having something to do.

*Higher (sub)scores indicate higher QoL.

†Regression coefficient represents the interaction with the predictor and time indicating the change in the slope of QUALIDEM (subscale) score over time.

‡The fixed effects intervention and time-in-the-intervention were added in the mixed model of subscale E to correct the intervention effect.

§$P < .01$.

‖$P < .05$.

Table 4
The Predictors of Course of QoL in Residents With YOD With Full Follow-up (N = 130)

Parameter	QUALIDEM*, Coefficient (95% CI)†									
	Total Score	Subscale A	Subscale B	Subscale C	Subscale D	Subscale E‡	Subscale F	Subscale G	Subscale H	Subscale I
Time§	−0.92‖ (−1.56, −0.28)	0.19 (0.02, 0.40)	−0.64** (−0.87, −0.42)	0.01 (−0.09, 0.12)	−0.05 (−0.10, 0.21)	0.10‖ (0.02, 0.17)	−0.51** (−0.69, −0.34)	−0.03 (−0.15, 0.08)	−0.27** (0.15, 0.38)	−0.34** (−0.44, −0.25)
Baseline QUALIDEM (sub)scale	−0.16** (−0.21, −0.11)	−0.20** (−0.25, −0.14)	−0.12** (−0.19, −0.06)	−0.13** (−0.19, −0.07)	−0.22** (−0.29, −0.15)	−0.15** (−0.20, −0.09)	−0.13** (−0.17, −0.08)	−0.23** (−0.29, −0.16)	−0.21** (−0.26, −0.17)	−0.22** (−0.27, −0.17)
Dementia severity										
Mild	2.29‖ (0.52, 4.06)	NS	0.93‖ (0.30, 1.56)	NS	NS	NS	0.63‖ (0.14, 1.12)	NS	NS	0.62** (0.35, 0.89)
Moderate	NS	NS	0.65‖ (0.09, 1.21)	NS	−0.38‖ (−0.75, −0.01)	NS	NS	−0.37** (−0.65, −0.09)	NS	0.42** (0.17, 0.66)
Severe	Ref									
Gender										
Male	NS	NS	NS	0.34‖ (0.09, 0.60)	NS	NS	−0.52‖ (−0.89, −0.15)	0.26‖ (0.01, 0.50)	NS	NS
Female	Ref									
Dementia subtype										
VD/mixed	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
FTD	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS
Other	NS	NS	0.74‖ (0.08, 1.40)	NS	NS	NS	0.89** (0.39, 1.38)	NS	NS	NS
AD	Ref									
Age	NS	NS	NS	NS	NS	NS	0.03‖ (0.00, 0.06)	0.03** (0.01, 0.04)	NS	NS
Length of stay	NS	NS	NS	NS	NS	NS	0.006‖ (0.00, 0.01)	NS	NS	NS

FTD, frontotemporal dementia; NS, not significant; Ref, reference group.

*Higher (sub)scores indicate higher QoL.

†Regression coefficient represents the interaction with the predictor and time indicating the change in the slope of QUALIDEM (subscale) score over time.

‡The fixed effects intervention and time-in-the-intervention were added in the mixed model of Subscale E to correct the intervention effect.

§Mixed models only with intercept and time.

‖$P < .05$.

**$P < .01$.

Table 5
The Predictors of Course of QoL in Deceased Residents With YOD (n = 57)

Parameter	QUALIDEM*, Coefficient (95% CI)†									
	Total Score	Subscale A	Subscale B	Subscale C	Subscale D	Subscale E‡	Subscale F	Subscale G	Subscale H	Subscale I
Time§	−2.24 (−5.49, 1.00)	−0.10 (−1.10, 0.89)	−1.56‖ (−2.73, −0.38)	0.52‖ (0.02, 1.03)	0.13 (−0.48, 0.74)	−0.12 (−0.54, 0.29)	−0.44 (−1.20, 0.32)	0.01 (−0.45, 0.48)	−0.12 (−0.64, 0.40)	−0.63‖ (−1.04, −0.23)
Baseline QUALIDEM (sub)scale	−0.40** (−0.67, −0.12)	NS	−0.40‖ (−0.65, −0.15)	−0.51** (−0.82, −0.21)	−0.70** (−0.89, −0.51)	−0.62** (−0.85, −0.39)	−0.35‖ (−0.62, −0.08)	−0.63** (−0.87, −0.39)	−0.48** (−0.74, −0.20)	−0.63** (−0.95, −0.31)
Dementia severity										
Mild	10.02‖ (1.02, 19.02)	NS	4.29‖ (0.89, 7.7)	NS	−1.41‖ (−2.72, −0.86)	NS	NS	NS	NS	2.28‖ (0.75, 3.81)
Moderate	NS	NS	0.65‖ (0.09, 1.21)	NS	NS	NS	NS	NS	NS	NS
Severe	Ref									
Gender										
Male	NS	−2.3‖ (−4.3, −0.31)	NS	NS	−1.73‖ (−2.61, −0.86)	NS	NS	NS	NS	0.91‖ (0.25, 1.57)
Female	Ref									
Dementia subtype										
VD/mixed	NS	NS	NS	NS	1.35‖ (0.19, 2.51)	NS	NS	NS	NS	NS
FTD	NS	NS	NS	NS	1.94‖ (0.80, 3.09)	NS	−1.93‖ (−3.84, −0.02)	NS	NS	−1.24‖ (−2.14, −0.34)
Other	NS	NS	0.74‖ (0.08, 1.40)	NS	NS	NS	NS	NS	NS	NS
AD	Ref									
Age	1.42‖ (0.68, 2.15)	NS	0.42‖ (0.14, 0.70)	0.18‖ (0.05, 0.31)	0.26** (0.15, 0.36)	NS	0.25‖ (0.06, 0.44)	NS	NS	NS
Length of stay	0.16‖ (0.06, 0.26)	NS	0.06‖ (0.02, 0.10)	NS	0.02‖ (0.01, 0.04)	NS	0.006‖ (0.00, 0.01)	0.02‖ (0.00, 0.04)	NS	NS
NPI-NH total	NS	NS	0.65‖ (0.15, 1.15)	NS	NS	NS	NS	NS	NS	NS
Agitation	NS	NS	−0.58‖ (−0.99, −0.16)	NS	NS	NS	NS	NS	NS	NS
Psychosis	NS	NS	−0.73‖ (−1.32, −0.14)	NS	NS	NS	NS	NS	NS	−0.24‖ (−0.41, −0.07)
Psychomotor agitation	NS	NS	−0.71‖ (−1.25, −0.16)	NS	NS	NS	NS	NS	NS	NS
Apathy	NS	NS	−0.70‖ (−1.18, −0.22)	NS	NS	NS	NS	NS	NS	NS

FTD, frontotemporal dementia; Ref, reference group.

*Higher (sub)scores indicate higher QoL.

†Regression coefficient represents the interaction with the predictor and time indicating the change in the slope of QUALIDEM (subscale) score over time.

‡The fixed effects intervention and time-in-the-intervention were added in the mixed model of Subscale E to correct the intervention effect.

§Mixed models only with intercept and time.

‖$P < .05$.

**$P < .01$.

regarding performing meaningful daytime activities.[6,20] Engaging in age-specific work for community-dwelling YOD residents has been shown to improve their self-esteem and well-being.[39] Although residents living in the YOD special care units are provided with therapeutic environments and facilities appropriate for younger people, such as computer and sports equipment,[14] support programs that are person centered and delivered in small groups are desired for meaningful engagement.[40] It is therefore crucial to provide purposeful activities, tailored to individualized needs of residents at younger ages to enrich their daily life and with that likely preserve QoL.[41] At the same time in our study, we found the largest increase in the subscale feeling at home, which may indicate that YOD residents to some extent are successful in adapting to the physical and social environment of the nursing home. Also, the improvements in the subscales care relationship and positive self-image may have a positive impact on their improved sense of feeling at home.[42]

As in research on old residents with dementia living in nursing homes,[43] higher baseline levels of QoL predicted a more progressive decline in QoL for YOD residents. Hvidsten et al[10] also found that YOD residents with better QoL and poorer QoL at baseline may experience different trajectories of change over time. Also, in line with studies exploring predictors of QoL in LOD residents,[44,45] more advanced dementia at baseline predicted a more progressive decline in proxy-rated QoL over time. Evidence also shows that proxy reports of QoL tend to be lower than self-reports in people with YOD,[20] particularly for those with advanced dementia.[46] Additionally, a more progressive decline in QoL, notably the subscale positive affect, was found in participants approaching death, especially for those with higher levels of NPS. End-stage dementia is a difficult time emotionally and physically for both residents and care staff. Results highlight the necessity and importance of timely palliative care to support the emotional well-being and better management of NPS for residents at the end of life stage.[47,48]

In this study, we were able to add relevant insights into the course of QoL and predictors of that course in nursing home residents with YOD. We had the opportunity to follow a relatively large group of people for a long period of time, and this extends the findings of previous cross-sectional studies.[9,15,20] However, some limitations have to be addressed. First, in this study, data were analyzed as a longitudinal study based on the BEYOND-II project, which was primarily designed for the evaluation of an intervention on NPS. However, we think we have addressed this issue because each resident had their baseline data recorded and the effect of the ongoing intervention on QoL was corrected in the model. Second, calculating and interpreting an overall QUALIDEM score should be done with caution as this might lead to loss of information considering multidirectional changes of subscales. However, these multidirectional changes were meaningful to clinical practice and may have demonstrated QUALIDEM's sensitivity to change in subscales in longitudinal studies. Third, we have not included social and environmental factors related to QoL and this may have potentially influenced our findings. The study power was also limited given the number of predictors and sample size included in this study. Moreover, there was a risk of inflated type I error rate due to multiple testing. However, our study is exploratory in nature and these exploratory findings will aid in further research of longitudinal studies on the course and factors of QoL in nursing home residents with YOD. Finally, we only included Dutch nursing homes with YOD special care units, and this could limit the generalizability of our findings to nursing homes without such specialized units.

Conclusion and Implications

This study shows that QoL in nursing home residents with YOD can be stable over time, whereas multidirectional changes in the QoL subscales could be clinically relevant. Specifically, the relatively largest decline in the subscale having something to do requires extra attention. Future research should enable care professionals to provide interventions tailored to individualized and specific care needs of residents with YOD, such as age-specific and purposeful activities, aiming to improve QoL in this particular group. QoL in people with advanced dementia and in those at the end of life should receive more attention in future research. More longitudinal studies are needed to verify factors influencing QoL in YOD and contribute to a better understanding of the relationship between QoL and the progression of disease in the context of nursing homes. Especially, social factors such as the availability of social support and visits from family or friends, as well as environmental factors related to the care concept in the nursing home deserve attention in future research. Furthermore, a comparison between residents with YOD living in YOD special care units and their counterparts living in regular care units may offer valuable insights into the specialized residential care to improve QoL for people with YOD.

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Supplementary Material 1

Statistical Analyses

To allow for the maximum use of available data from both intervention and control group, we first explored the potential impact of the ongoing intervention (multicomponent care program)[1] on QoL to decide whether data from both groups could be merged. This was conducted by comparing model 1 (with the fixed effects intervention and time-in-the-intervention) and model 2 (without the fixed effects intervention and time-in-the-intervention). Likelihood ratio tests showed no significant differences between the 2 models for almost all Quality of Life in Dementia (QUALIDEM) outcomes, which means that exposure of the residents to the intervention was unlikely to have significantly affected the QoL, except for the subscale E: positive self-image (Supplementary Table 1). Therefore, results from model 2 were reported, in which data of all residents were merged. The fixed effects intervention and time-in-the-intervention were added in the model of subscale E to correct the intervention effect.

Supplementary Table 1
Likelihood Ratio Test for the Entire Cohort (N = 278) to Determine the Influence of the Intervention on the Course of QoL

QUALIDEM	−2 Log Likelihood Model 1	−2 Log Likelihood Model 2	χ^2 (df = 2)*	*P*
Subscale A: Care relationship	3855.602	3855.973	0.371	.83
Subscale B: Positive affect	4064.262	4067.319	3.057	.22
Subscale C: Negative affect	2893.111	2897.572	4.461	.11
Subscale D: Restless tense behavior	3318.896	3320.398	1.502	.47
Subscale E: Positive self-image	2440.359	2447.132	6.773	**.03**
Subscale F: Social relations	3684.304	3689.024	4.720	.09
Subscale G: Social isolation	2843.447	2843.639	0.192	.91
Subscale H: Feeling at home	2822.973	2823.148	0.175	.92
Subscale I: Having something to do	2570.742	2571.654	0.912	.63
Total QUALIDEM score	5789.334	5789.728	0.394	.82

QUALIDEM, Quality of Life in Dementia.
Comparison between model 1 with intervention and model 2 without intervention.
Values marked with bold indicate statistically significant with $P < .05$.
*χ^2 represents the difference in −2 log likelihood ratio between model 1and model 2.