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Quality of Life with Late-Stage Dementia: Exploring Opportunities to Intervene

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Abstract

Background/Objectives.—In late-stage dementia, families often prioritize quality of life (QoL) and comfort, yet little research examines factors impacting QoL. We sought to (1) describe temporal trends in QoL in late-stage dementia, and (2) explore associations between patient characteristics, care interventions, and QoL.

Design.—Secondary analysis of data from the Goals of Care clinical trial

Setting.—22 nursing homes in North Carolina

Participants.—Family decision-makers for residents with late-stage dementia

Measurements.—Family reported QoL at baseline and 9-months using the Alzheimer's Disease-Related Quality of Life Instrument (ADRQL) with five subscales scored 0–100 (higher scores indicate better quality). Families reported demographics, primary goal of care, and described their perceptions of residents' QoL. Chart reviews provided data on hospital transfers, treatment plans, and hospice enrollment. We ran mixed effects models of hypothesized variables and change in ADRQL over time.

Results.—The study sample was 241 dyads of residents with late-stage dementia and family decision-makers. Family-reported ADRQL scores reflected moderately good QoL at baseline and

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9 months (69.1 vs. 66.9; $p=0.106$). Subscales for Awareness of Self (62.8, GDS 5; 30.5, GDS 7; $p>0.01$) and Enjoyment of Activities (53.4, GDS 5; 39.4, GDS 7; $p>0.01$) were lower in later stage disease. Qualitatively, family associated better QoL for dementia with (1) activities, (2) opportunities to leave NH, (3) NH structured activities, (4) attentiveness in NH, and (5) passive interaction. ADRQL at nine months was associated with later dementia stage and referral to hospice ($p<0.01$). Age ($p=0.004$) and hospice enrollment were significantly associated with a larger decrease in ADRQL over 9-months ($p=0.019$). A primary goal of comfort was associated with a larger increase in ADRQL ($p=0.022$).

Conclusion.—Families judge QoL to be moderately good in late-stage dementia. They perceive activities, opportunities to leave the NH, and quality of interpersonal care as ways to improve dementia-specific QoL.

Keywords

nursing homes; Alzheimer's Disease; longitudinal

INTRODUCTION

Dementia is a progressive, irreversible illness that impacts all aspects of life.¹ Late-stage dementia limits one's ability to communicate with family and to participate in previously meaningful activities, adversely impacting social engagement. Progressive cognitive impairment limits decision-making about medical treatment, and further contributes to difficulties understanding and treating distressing symptoms, such as pain, dyspnea and neuropsychiatric distress.

Most patients and family caregivers prioritize comfort and quality of life as goals of care for late-stage dementia.² The Alzheimer's Disease-Related Quality of Life Instrument (ADRQL) is a validated proxy-reported instrument used to measure quality of life for nursing home residents with dementia.^{3,4} One small study has examined how ADRQL scores change over time.^{5,6} These studies indicate that families perceived better quality of life for late-stage dementia patients to be associated with higher cognitive function and well-controlled pain, while worse quality of life is associated with behavioral disturbances.

If comfort and quality of life are often primary goals of care in late-stage dementia, it is important to know what improves these outcomes. Little research describes quality of life in late-stage dementia, or factors that may improve or worsen quality of life. To explore factors that might improve quality of life in dementia, we conducted a secondary analysis of data from the Goals of Care clinical trial for a cohort of nursing home residents with late-stage dementia. The objectives of this analysis were: 1) to describe temporal trends in quality of life in late-stage dementia, and 2) to explore potential associations between patient characteristics, care interventions, and quality of life outcomes.

METHODS

We conducted an analysis of prospective data on quality of life for nursing home residents with late-stage dementia enrolled in the Goals of Care (GOC) study. The GOC study was a

cluster-randomized trial of a video-based decision aid and care planning intervention. The trial enrolled 302 dyads of nursing home residents with late-stage dementia and their family decision-makers in 22 North Carolina nursing homes. The primary analysis and detailed methods are published elsewhere.^{7,8}

To be eligible for the GOC study, nursing home residents had to be 65 and older, with dementia staged by their primary nurse as 5, 6, or 7 on the Global Deterioration Scale (GDS).⁹ Since this analysis sought to examine quality of life over time, residents were only included if they survived to 9-month follow-up. Each resident was enrolled with a family decision-maker. Family decision-makers provided written informed consent for themselves and for the resident with late-stage dementia, all of whom lacked decisional capacity. The University of North Carolina Institutional Review Board approved all study procedures.

Data Collection & Measures

Family decision-makers completed a baseline in-person structured interview with additional open-ended questions. Research assistants blinded to study arms completed follow-up family telephone interviews and chart reviews at 9 months.

Quality of life was measured in baseline and again in 9-month interviews using the Alzheimer's Disease-Related Quality of Life Instrument (ADRQL), which asks family members to respond "agree" or "disagree" to 47 items about quality of life with dementia, coded on a 0–100 scale, with higher values indicating better quality of life. The instrument address five subscales of quality of life: Social Interaction (12 items), Awareness of Self (8 items), Feelings and Mood (15 items), Enjoyment of Activities (5 items), and Response to Surroundings (7 items). The instrument demonstrates good internal consistency (Cronbach's alpha 0.86) and has demonstrated discriminant validity across settings and over time.¹⁰

For our second objective, we hypothesized factors that may impact quality of life based on the conceptual model by Stewart et al. including patient characteristics, family choice of primary goal of care, and care processes experienced by the resident.¹¹ We included structured interview items that assessed demographic characteristics: age, gender and race. Dementia stage (GDS) was provided by the resident's primary nurse at baseline. Family decision-maker also reported the primary goal of care for the resident by answering, "Which goal would you say is the best goal to guide (HIS/HER) care and medical treatments?" with response options of: (1) Prolonging Life, (2) Supporting Function, or (3) Improving Comfort. We used the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT-Sp) to assess the family decision-maker's well-being (Cronbach's alpha=0.8–0.88), and is also convergent with overall quality of life (high score indicates higher well-being).¹²

From structured chart review data, we calculated prognostic estimates using the Advanced Dementia Prognostic Tool (ADEPT), a calculator designed to identify late-stage dementia patients at high risk of death within six months.¹³ Chart reviews captured care processes during the 9-month follow-up period, including hospital transfers during the study period (ED visits and hospitalizations), hospice enrollment, and physical and psychological treatment plans, which was considered present if there was chart documentation of (1)

physical and (2) psychological symptom assessment and treatment if the symptoms were present.

Because a standard quantitative instrument may not capture all aspects of quality of life important to residents and families, we also invited families to speak about quality of life for the resident by responding to the multifaceted open-ended prompt, “What are personal goals for [RESIDENT]? By this question I mean what do you see as enhancing (HIS/HER) quality of life or meaning in life? What does (HE/SHE) look forward to or get pleasure from?”

Analysis

Resident and family decision-maker dyads were the unit of analysis. All analyses controlled for clustering effects at the nursing home level, and for study assignment to intervention or control. We described residents’ demographic characteristics, dementia stage, severity of illness, length of nursing home stay, baseline ADRQL score, 9-month ADRQL score, and the difference between ADRQL at 9 months and baseline in either frequency (percentage) or mean (SD), as appropriate. Likewise, we describe decision-maker education, their relationship to residents, and FACIT-Sp scores. We tested the significance of the difference in ADRQL between baseline and nine months using a t-test adjusted for clustering effects of nursing homes and assignment of intervention arm. The same analysis was repeated in each of the dementia stages (GDS 5–7) upon stratification.

To characterize quality of life further, we analyzed the content of family decision-makers’ responses to the open-ended question using constant comparative methods of qualitative description.¹⁴ Two authors reviewed all transcripts to identify themes of quality of life (NCE, KLW). Both coders reviewed all transcripts and came together to adjudicate discrepancies and reach consensus.

To examine associations between patient characteristics, care processes, and changes in ADRQL, we first examined bivariate associations between ADRQL score at baseline, 9 months, and the within-subject mean difference and each of the hypothesized factors: age, gender, race, primary goal of care and dementia stage, and care processes over 9-months follow-up: physical and psychological treatment plan, hospital transfer, or hospice enrollment. We then included these variables in a multivariate model, to investigate their adjusted associations with change in ADRQL (9-month—baseline). Statistical tests were based on t-tests from a linear mixed effects model with a random intercept to adjust for clustering effects.

Quantitative analyses were executed using SAS 9.3 (Cary, NC) and $p < 0.05$ was considered statistically significant. Qualitative analyses were executed using ATLAS.ti (Scientific Software).

RESULTS

Nursing Home Resident & Family Decision-Maker Baseline Characteristics

The study sample consisted of 241 residents with late-stage dementia and their family decision-makers. Residents had an average age of 86.2 years and 83% were women. Three

quarters had dementia staged as GDS 6 or 7 at baseline. Family decision-makers had a mean age of 62.6 years, and a majority were female and were adult children (Table 1).

Quality of Life in Late-Stage Dementia

Family decision-makers reported an average ADRQL at baseline of 69.1 out of 100 (s.d. 15.4) and 66.9 (16.4) at 9-month follow-up, indicating moderately good quality of life ratings with little decrease on average over 9 months. The Feelings and Mood subscale generated the highest scores at each time point. While overall quality of life scores did not change after 9 months, two subscale scores did worsen significantly over this time period: Enjoyment of Activities and Awareness of Self were rated lower than the other subscales and scores decreased significantly over 9 months. These same two subscales differed significantly by dementia stage; Awareness of Self (62.8, GDS 5; 30.5, GDS 7; $p>0.01$) and Enjoyment of Activities (53.4, GDS 5; 39.4, GDS 7; $p>0.01$) subscales were significantly lower in later stage disease (Figure 1). The parent intervention did not have an impact on quality of life.

Qualitative Analysis: Family Perceptions of Personal Goals and Quality of Life

Family responses to an open-ended question on resident goals and quality of life resulted in several broad themes: (1) enjoys activities, (2) opportunities to leave NH, (3) NH structured activities, (4) attentiveness in the NH, (5) passive/non-verbal interaction, and (6) nothing. Each of the six main themes is explored in more detail, below.

First, many families reported that residents enjoyed specific activities that enhanced quality of life in the nursing home. For example, residents enjoy spending time with loved ones. One family decision-maker said, “He likes me to be there, enjoys having his children and family around for short visits.” Some residents enjoyed eating, (“At this point she gets pleasure from eating”) maintaining their own hobbies (“Reading the paper with her, and when I talk to her and do her nails”), and listening to music (“She is very musical, hums a lot. She enjoys music”).

Second, some families reported that residents liked the opportunity to leave their room or leave the nursing home. One respondent said, “I take him to cafe to eat lunch. He likes to change his environment,” and another said, “He liked it when I took him to my house for the holidays.”

Third, families highlighted organized nursing home activities. These activities included regularly-scheduling nursing home programs (“She likes being out of her room, participating in activities. Loves bingo, likes hands on activities – crafts”), enjoying animals (“She loves the African tortoise outside her window. He has a fenced in area and house. She talks to him”), and the opportunity to go outside (“She gets pleasure from outside, just being there”).

Fourth, families observed ways the attentiveness of staff in the nursing home shaped quality of life, including by helping to maintain hygiene (“For me to see that he is ‘well taken care of’ and that he has all he needs and is comfortable, his physical essentials like a bath and teeth brushing”), integrating the resident’s preferences into medical decision making (“I work hard for what she would want- not what I’d want.”) and getting respect and time from

the staff (“I don’t want staff to get frustrated and mean to them. I couldn’t do it. I hope that they would be shown respect and their needs taken care of”). One family decision-maker said, “Best thing is when the staff sits and talks with her. Mom treasures that.” Families also emphasized the patient’s comfort and being pain-free for better quality of life (“to see her live in comfort in her situation for however long she has to live”), and some had goals of maintaining or improving functional status and independence (“independence- she doesn’t like to be dependent on anyone.”).

Fifth, families reported that some residents’ quality of life benefited from passive interactions. Some residents enjoyed stimulation (“I bring her flowers sometimes. Mostly non-verbal communication but she likes that one-on-one sensory stimulation”) and physical contact (“being touched—it comforts her”) from both family and nursing home staff, sleep (“She likes to sleep”), or staying in their room (“She does not want to leave her room to do things”).

Sixth, some family decision-makers expressed that nothing improved quality of life. Sample responses in this category included, “I don’t see anything he enjoys doing now,” and, simply, “Nothing.” Families also noted losses to quality of life, such as loss of the ability to do favorite activities (“She likes to sew but she can’t sew anymore”) or preparation for death (“He does not know why the good Lord keeps him alive”) (Table 2).

Patient Characteristics and Care Processes Associated with Quality of Life

In bivariate analyses (Table 3), after adjusting for clustering and randomization, across dementia stage groups quality of life was lower from 73.5 (GDS 5) to 66.7 (GDS 6) ($p<0.01$) and to 59.8 (GDS 7) ($p<0.001$) at nine months. Stage 6 GDS was associated with a larger average decrease in ADRQL over nine months (average mean difference -0.9 , GDS 5 (ref); -3.4 , GDS 6 ($p=0.006$); -0.8 , GDS 7 ($P<0.001$)). Both having a treatment plan at baseline (average mean difference -2.5 vs. -0.8 without; $p=0.024$) and hospice enrollment (average mean difference -7.1 vs. -1.5 without; $p=0.004$) were associated with more change over nine months. Lower 9-month ADRQL was also independently associated with a higher likelihood of being referred to hospice (Table 3).¹⁵

In multivariate mixed effects model (Table 4), higher age ($p=0.004$) and hospice enrollment were significantly associated with a larger magnitude of decrease in ADRQL over 9-months ($p=0.019$). Conversely, a decision at baseline of a primary goal of comfort was associated with a larger magnitude increase in ADRQL ($p=0.022$; Table 4).

DISCUSSION

Family ratings of quality of life while living with dementia were highly correlated with dementia stage and a decision to enroll in hospice. Quality of life among nursing home residents who have a prognosis of longer than nine months is dependent on dementia stage, which may change over several years. However, as dementia progresses slowly, we found that quality of life was relatively static over 9 months. One prior study suggests that pain management is associated with better quality of life for persons with late-stage dementia, and hospice may be one mechanism to improve care for physical symptoms.³ Subscales of

the ADRQL provide some additional insights. During our 9-month study period, families of residents who were not near death observed worsened social interaction, awareness of self, and enjoyment of activities. These findings correlate with our qualitative findings, in which family decision-makers reported that enhanced activities and social engagement may aid in preserving quality of life in late-stage dementia.

Approaches for improving quality of life among nursing home residents who are not near death could include those identified by the family decision-makers in this study and others: maintaining hygiene, controlling pain, integrating preferences for comfort into treatment plans, providing structured activities, outings, and opportunities for residents to engage with family, and music.¹⁶ Given the strong association between quality of life and dementia stage, hospice care may be important to consider when family perceives quality of life to become poor. Hospice referral in this study was associated with worse quality of life, indicating some referral as patients decline may already be happening; this result is substantiated by a lower likelihood of having a treatment plan in patients with higher quality of life. Additional research will be necessary to determine if hospice actually improves quality of life after its initiation, which this study did not do. Of note, the parent intervention was not associated with quality of life, which is consistent with the hypothesis that narrowly addressing goals of care is likely not robust enough to impact downstream quality of life.

As evidenced by our qualitative descriptions, quality of life in patients with dementia can encompass diverse domains (e.g., managing pain, participating in activities). Our results are consistent with Cordner's applications of the ADRQL, also in an advanced dementia population.⁵ The ADRQL subscales capture several elements of quality of life, and other measures encompass different quality of life domains, such as joy, happiness, and humor.¹⁷ Weiner et al. developed the Quality of Life in Late-Stage Dementia Scale (QUALID) that captures facial expressions (e.g., smiling, expression of discomfort), behaviors (e.g., enjoying eating, crying), and appearance (e.g., appearing sad, calm).¹⁸ Likewise, Bicket describes the importance of physical environment.¹⁹ The domains of quality of life one focuses upon can have implications for diverse types of interventions and their evidence base.^{20,21,22}

Strengths

The ADRQL is one measure that captures multiple, detailed domains of quality of life. This project presents detailed data on quality of life domains, including social interaction, awareness of self, and enjoyment of activities. The measure has been tested in multiple populations and has a strong evidence base, including, specifically, late-stage dementia.^{4,6} We capture data longitudinally across diverse nursing homes in North Carolina.

Limitations

While we have the dementia stage at baseline, this secondary analysis was not able to fully assess changes within patients at multiple timepoints during the study period, or for longer than nine months. Quality of life is difficult to capture in people with late-stage dementia for two reasons: first, the degree of cognitive impairment requires proxy report by family decision-makers; second, there is difficulty in determining appropriate indicators for good

quality of life. We used one well-supported proxy-reported measure for assessing quality of life in this population, though different proxies (e.g., spouses, adult children) may systematically report differently from one another. Although the ADRQL subscales capture several detailed elements of quality of life, the instrument is proprietary and takes more time to administer, which limits its broader uptake. In absence of a patient's ability to report, the available proxy-reports are equally valid, though may indeed lead to different evaluations. This study only captured ADRQL at baseline and 9-month follow-up, therefore we excluded those who died during the study period. Decedents may have had accelerated worsening of quality of life leading up to death differently from those who survived.

Future studies could capture longitudinal progression longer than nine months. Studies of specific interventions raised in our qualitative analysis can test causal relationships. This study does not describe quality of life for home-dwelling people with late-stage dementia. We only include individuals who have a family decision-maker; results may be systematically different for those without a family advocate.

Conclusion

Changes in quality of life in late-stage dementia are largely impacted by dementia stage and comfort-based care among 9-month survivors in this study. Nursing home research can test and implement interventions derived from the perceptions of family decision-makers identified in this study, including comfort-based approaches to dementia care—particularly as the disease progresses—to improve quality of life for their residents.

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Figure 1. ADRQL overall and subscales at 9-months follow-up stratified by dementia stage (GDS). Awareness of Self and Enjoyment of Activities subscales vary significantly across stages at $p < 0.05$.

Table 1.

Characteristics of residents, residents' care processes, and family members.

	N=241 n (%)
Resident	
Age, mean(sd)	86.2 (7.0)
Female gender	200 (83%)
Race	
African American	29 (12%)
Caucasian	206 (86%)
Other	5 (2%)
Dementia stage*	
5 – moderate	63 (26%)
6 - moderately severe	123 (51%)
7 – severe	55 (23%)
Severity of illness: ADEPT, ** mean(sd)	8.6 (2.6)
Nursing home stay (days), mean(sd)	726 (780)
Care Process Characteristics	
Goals of Care Trial, intervention arm	124 (51%)
Presence of both physical & psychological treatment plans at baseline	182 (76%)
Hospital transfer during 9-month follow-up	
0	177 (73%)
1	48 (20%)
2+	16 (7%)
Hospice enrollment during 9-month follow-up	28 (12%)
Primary goal of care at baseline	
Prolonging Life	10 (4%)
Supporting Function	54 (22%)
Improving Comfort	163 (68%)
Multiple/Other	14 (6%)
Family Decision-Maker	N=241 n (%)
Age, mean(sd)	62.6 (10.7)
Female Gender	156 (65%)
Race	
African American	28 (12%)
Caucasian	210 (87%)
Other	2 (1%)
Relationship	
Spouse	33 (14%)

Son/in-law	66 (27%)
Daughter/in-law	124 (51%)
Other	18 (7%)
Education Level	
Less than high school	3 (1%)
High school graduate	35 (15%)
Some college/vocational school	57 (24%)
College graduate	80 (33%)
Advanced degree	66 (27%)
Spiritual Well-Being: FACIT-Sp, *** mean(sd)	37.1 (8.0)

* Global Deterioration Scale (GDS)

** Advanced Dementia Prognostic Tool (ADEPT), a prognostic calculator designed to identify late-stage dementia patients at high risk of death within six months

*** Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT-Sp)

Table 2.

Qualitative associations between activities, personal goals, and enhanced quality of life, reported by family decision-makers.

Theme	ADRQL Score	GDS Stage	Quote	Implications for Nursing Home Dementia Care
Enjoys Activities				
Spend time with loved ones	71.7	6	Likes me to be there. Enjoys having his children and family around for short visits.	Provide an environment welcoming to loved ones
Food & eating	58.7	6	At this point she gets pleasure from eating.	Provide opportunities for residents to experience food eating, perhaps as a structured NH activity
Hobbies (reading/being read to, gardening, watching television/sports, going for walks, participating in spiritual/religious activities, feel needed, getting hair/nails done, crafting)	73.1	6	Don't know if they have a flower activity that they could work with flowers at the height of their wheelchairs.	Elicit favorite activities of residents and facilitate hobbies as is reasonable
	70.4	5	Loves to walk but can't go out on his own.	
	81.7	6	This place provides wonderful activities- music and church services. And he will probably go to church until he dies.	
	67.8	6	Keeping his mind occupied in activities, stimulation. He wants to feel needed. Give him a job, set the table, cups, napkins, hanging clothes in the laundry room.	
	93.0	6	Activities, nails, girl stuff. I'd want more activities for her.	
Music	50.8	7	She is very musical, hums a lot. She enjoys music.	Provide opportunities for residents to experience music, perhaps as a structured NH activity
Opportunity to leave NH				
Outings with family	33.1	6	I take him to cafe to eat lunch. He likes to change his environment.	Allow supervised trips away from the NH with loved ones
Go to a family member's home	64.0	7	He liked it when I took him to my house for the holidays.	
In the Nursing Home				
NH structured activities				
Programs (e.g., movie night, crafts)	62.6	5	She likes being out of her room, participating in activities. Loves bingo, likes hands on activities – crafts.	Create a calendar of events or activities for residents
Animals	82.1	6	She likes the lady that brings the dog around. She loves the African tortoise outside her window. He has a fenced in area and house. She talks to him.	Consider providing access to animals or pets in the NH (e.g., fish tank, bird feeders outside windows, pet visits from residents' loved ones)
Going outside	82.0	6	She gets pleasure from, warm enough, go outside, just being there.	Provide a space (e.g., yard, garden area) for residents

Theme	ADRQL Score	GDS Stage	Quote	Implications for Nursing Home Dementia Care
				to safely go outside as is feasible
Attentiveness in the NH				
Maintain hygiene	70.2	5	For me to see that he is 'well taken care of' and that he has all he needs and is comfortable, his physical essentials like a bath and teeth brushing.	Provide care consistent with best-practices; acknowledge residents' limitations in self-care and support them
Integrate preferences into medical decision making	87.0	6	I work hard for [...] what she would want- not what I'd want. She wrote a living will.	Discuss the residents' values and preferences with their family decision-makers and conduct advance care planning or complete Medical Orders for the Scope of Treatment (MOST) form (POLST in some states)
Get respect from staff	80.7	5	I don't want staff to get frustrated and mean to them. I couldn't do it. I hope that they would be shown respect and their needs taken care of.	Train staff in best practices for interacting with and engaging residents with late-stage dementia
Spend time with staff	83.1	5	Best thing is when the staff sits and talks with her. Mom treasures that.	Engage with residents when delivering care; treat residents with respect
Spend time around other people	69.6	6	Being with other people in any kind of setting. Especially if there's something to watch, something going on. Even if she's not involved she enjoys things happening with other people.	Provide opportunities for residents to leave their rooms, sit in common rooms, or engage with other residents as is feasible
Promote comfort or remain pain-free	81.7	7	to see her live in comfort in her situation for however long she has to live.	Follow guidelines for pain and symptom management in NH residents with dementia
Maintain functional status or independence	72.9	5	independence- she doesn't like to be dependent on anyone- continue to walk on her own, toileting, etc.	Provide physical/ occupation therapy or otherwise support the functional status of residents as is feasible
Passive/Non-Verbal Interaction				
Stimulation	73.5	6	I bring her flowers sometimes. Mostly non-verbal communication but she likes that one-on-one sensory stimulation.	Provide sounds/music, relaxing smells, or colorful visual stimuli
Physical contact	75.2	7	Being touched—it comforts her.	Provide gentle physical contact for residents who are comforted by such behaviors
Sleep	68.7	6	She likes to sleep.	Allow peaceful, quiet, comfortable rooms for residents to sleep as is reasonable
Stay in room	92.2	6	She does not want to leave her room to do things.	Make rooms comfortable environments; do not require participatory activities or schedules
Nothing				

Theme	ADRQL Score	GDS Stage	Quote	Implications for Nursing Home Dementia Care
Nothing	52.6	7	She really has no cognitive function. She does not get pleasure from anything. She is existing in her own little world.	
Hobbies previously enjoyed	70.9	6	She likes to sew but she can't sew anymore.	
Ready to die	97.1	5	He does not know why the good Lord keeps him alive.	

Table 3.

Association of patient characteristics and care with subsequent quality of life, adjusted for clustering at the nursing home level and study arm.

Variable	ADRQL at Baseline Mean (SD)	ADRQL at 9 months mean (SD)	Average Mean Difference Mean (SD)	p-value for mean difference within each variable
Resident age *	0.28 (0.14)	0.01 (0.16)	-0.26 (0.12)	0.949
Resident gender				
Female	69.1 (15.5)	66.7 (16.6)	-2.2 (12.7)	0.863
Male	69.6 (14.8)	67.7 (15.2)	-2.0 (11.5)	
Resident race				
African American	71.8 (13.4)	68.1 (12.2)	-3.7 (10.9)	0.069
Caucasian	68.7 (15.7)	66.4 (16.8)	-2.1 (12.7)	
Other	79.2 (7.5)	91.2 (5.5)	12.0 (13.0)	
Baseline decision for comfort as the primary goal of care				
No	73.6 (14.6)	68.2 (16.7)	-5.2 (12.8)	0.527
Yes	67.0 (15.3)	66.3 (16.2)	-0.7 (12.1)	
ADEPT Score *	-0.69 (0.37)	-0.55 (0.42)	0.06 (0.32)	0.186
Dementia stage				
5	74.3 (14.8)	73.5 (14.5)	-0.9 (13.3)	Ref
6	70.3 (14.6)	66.7 (16.4)	-3.4 (13.2)	0.006
7	60.6 (14.4)	59.8 (15.4)	-0.8 (9.7)	<0.001
Goals of Care intervention arm **				
Control	69.1 (15.5)	65.9 (16.8)	-3.1 (12.7)	0.502
Intervention	69.2 (15.3)	67.8 (15.9)	-1.2 (12.3)	
Physical and psychological treatment plan at baseline				
No	71.7 (16.2)	70.4 (16.0)	-0.8 (9.3)	0.024
Yes	68.3 (15.1)	65.8 (16.4)	-2.5 (13.3)	
Had hospital transfer during 9-month follow-up				
0	69.7 (15.4)	67.0 (16.6)	-2.6 (12.3)	Ref
1	66.7 (14.7)	64.6 (15.8)	-1.7 (13.0)	0.377
2+	70.5 (17.5)	72.0 (14.9)	1.5 (12.2)	0.233
Enrolled in hospice during 9-month follow-up				
No	69.7 (15.0)	68.0 (16.4)	-1.5 (12.0)	0.004
Yes	64.9 (17.7)	58.3 (13.5)	-7.1 (14.9)	

* We report the effect on ADRQL of a one-unit increase in each continuous variables.

** The effect of intervention arm is only adjusted for clustering at the nursing home level.

Table 4.

Factors impacting quality of life measured by 9-month ADRQL: multivariate mixed effects model.

Variable	Coefficient (s.e.)	<i>p</i> -value
Resident age	−0.4 (0.1)	0.004
Resident female gender	3.4 (2.4)	0.165
Resident race		
White	Ref	
African American	−2.2 (2.6)	0.399
Other	10.4 (8.7)	0.235
Baseline decision for comfort as the primary goal of care	4.2 (1.8)	0.022
ADEPT severity of illness score	0.6 (0.4)	0.143
Dementia stage (GDS) at baseline		
5	Ref	
6	−2.5 (1.9)	0.197
7	−1.8 (2.4)	0.453
Goals of Care arm: intervention (vs. control)	1.2 (1.7)	0.460
Physical and psychological treatment plan at baseline	−2.0 (1.9)	0.287
Hospital transfer during 9-month follow-up	0.9 (1.9)	0.630
Enrolled in hospice during 9-month follow-up	−6.0 (2.5)	0.019