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## Quality of Life in Nursing Home Residents with Advanced Dementia

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### Abstract

**OBJECTIVES**—To examine quality of life (QOL) in nursing home (NH) residents with advanced dementia and identify correlates of QOL near the end of life.

**DESIGN**—Cross-sectional data derived from NH records, interviews with residents' surrogate decision-makers, QOL ratings by NH caregivers, and assessment of residents' cognitive function.

**SETTING**—Three NHs in Maryland.

**PARTICIPANTS**—A cohort of NH residents with dementia (n=119), who were either receiving hospice or palliative care or met hospice criteria for dementia, and their surrogates.

**MEASUREMENTS**—QOL based on the proxy-rated Alzheimer Disease Related Quality of Life (ADRQL) scale administered to NH staff and validated against a single-item surrogate-rated measure of QOL, the Severe Impairment Rating Scale to measure cognitive function, and

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#### Conflict of Interest:

The following is a disclosure statement for Peter Rabins that is required by the Johns Hopkins University: "Under an agreement between DEMeasure and Dr. Rabins, Dr. Rabins is entitled to a share of income received by DEMeasure from sales of the ADRQL questionnaire and scale used in the study described in this article. Dr. Rabins has an ownership interest in DEMeasure. The terms of this arrangement are being managed by the Johns Hopkins University in accordance with its conflict of interest policies." In addition, Dr. Rabins has provided expert testimony for Janssen Pharmaceutica and received grant support from the Jewish Community Federation of Baltimore.

The following is a disclosure statement for Betty Black that is required by the Johns Hopkins University: "Under an agreement between DEMeasure and Dr. Black, Dr. Black is entitled to a share of income received by DEMeasure from sales of the ADRQL questionnaire and scale used in the study described in this article. Dr. Black has an ownership interest in DEMeasure. The terms of this arrangement are being managed by the Johns Hopkins University in accordance with its conflict of interest policies." In addition, Dr. Black has received grant support from the Jewish Community Federation of Baltimore.

#### Author Contributions:

Zachary Corder made substantial contributions (1) to the analysis and interpretation of the data, (2) in drafting the article and revising it critically for important intellectual content, and (3) final approval of the version to be published.

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dichotomous indicators of neuropsychiatric symptoms (i.e., behavior problems, mood disorders, psychosis/delusions).

**RESULTS**—Total ADRQL scores, ranging from 12.4 to 95.1 out of 100, were normally distributed and positively correlated ( $p < .001$ ) with surrogate-rated QOL. Multiple regression analysis of ADRQL scores showed that residents with higher cognitive function ( $p < .001$ , CI = .966 – 1.650) and those receiving pain medication ( $p = .006$ , CI = 3.303 – 19.588) had higher QOL, while residents with behavior problems ( $p = .014$ , CI = -11.604 – -1.298) had lower QOL.

**CONCLUSION**—The ADRQL is a valid indicator of QOL in NH residents with advanced dementia. QOL in this population may be improved near the end of life by appropriate assessment and treatment of pain and more effective management of behavior problems.

### Keywords

quality of life; advanced dementia; end of life; nursing home residents

## INTRODUCTION

Interest in quality of life (QOL) and care at the end of life has become increasingly recognized as an important clinical and policy issue. However, little is known about health related quality of life (HRQOL) in advanced dementia patients—a population unable to assess their own QOL. HRQOL focuses on the perceived value of survival and areas of life affected most by changes in health<sup>1</sup>. The need for further research into the QOL of dementia patients nearing death is clear since HRQOL remains an important goal of health professionals and a relevant outcome measure across all disease stages<sup>2</sup>. Furthermore, reported inadequacies of end of life care for those suffering from dementia<sup>3</sup> highlight the need to examine this issue empirically. Finally, the study of HRQOL near the end of life for dementia patients raises important ethical questions regarding the possibility of an individual's cognitive function deteriorating so far as to make the construct of quality of life unmeasurable.<sup>2</sup>

Given these challenges and unanswered questions, this study aims to: (1) examine the variation of HRQOL among nursing home residents with advanced dementia near the end of life, and (2) identify factors associated with HRQOL based on bivariate and multivariate analyses. In doing so, it addresses Kane's call for research on the correlates of QOL in nursing homes<sup>4</sup>. Specifically, we were interested in whether QOL, as measured by the proxy-rated Alzheimer Disease Related Quality of Life (ADRQL) scale<sup>5</sup> is associated with residents' demographic characteristics, neuropsychiatric symptoms, medical co-morbidities, severity of symptoms, status of advance directives, or aggressiveness of care. This study will also help determine whether the ADRQL is a valid measure of QOL in hospice-eligible nursing home residents and aid in the development of hypotheses for future research.

## METHODS

Care of Nursing Home Residents with Advanced Dementia (CareAD) is a prospective study that examined the experiences of nursing home (NH) residents with advanced dementia and those of their surrogate decision-makers<sup>6</sup>. CareAD was conducted at three Baltimore-area nursing homes that are operated by different types of organizations (a university, a not-for-profit organization, and a government agency). Residents were eligible for enrollment if they: (1) had a diagnosis of dementia, and (2) were receiving hospice or palliative care or met hospice criteria for dementia patients<sup>7</sup>. At the beginning of the study, all residents were screened for eligibility, as were all subsequently admitted residents. Residents not meeting enrollment criteria initially were re-screened at 2-month intervals. Participants were enrolled

from December 2000 to August 2003; data collection continued through August 2004. Data were collected at baseline, at 3-months intervals thereafter, and after the resident's death, discharge or at the end of the study. Baseline CareAD data were analyzed for this study.

Residents' surrogate decision-makers, who gave informed consent for their own participation in the study, provided proxy informed consent for the residents, and assent was obtained from all residents who were able to provide it. The CareAD study was approved by the Institutional Review Boards of the Johns Hopkins University and the University of Maryland and by the research ethics committee at each facility.

### Baseline Data Collection

Sources of the baseline data included NH medical records, resident assessments, surrogate interviews, and NH staff ratings of HRQOL. A structured medical record review was completed for each resident to obtain demographic characteristics, length of stay at the NH, and dementia diagnosis. Baseline record reviews identified all health problems, all prescribed medications (standing and "as needed"), and other interventions (e.g., tube feeding) during the prior 6 months (or since NH admission if less than 6 months). A nosology was developed to categorize residents' health problems that included medical comorbidities, neuropsychiatric symptoms, and pain as identified and recorded by NH staff in residents' charts during the review period<sup>6</sup>. Neuropsychiatric symptoms included behavior problems (e.g., agitation or aggression, refusal/resistance, aberrant motor behavior, calling out), mood disorders (e.g., depression, anxiety, withdrawal/lethargy), and psychosis or delusions. The record review identified whether residents were receiving hospice or palliative care. Since a formal hospice program was available at only one study site and all sites offered a palliative care program, these programs were combined in a single variable. The record review also identified the presence and content of any advance directives and orders to limit treatment, such as a do-not-resuscitate (DNR) order.

Residents' cognitive function was assessed using the Severe Impairment Rating Scale (SIRS)<sup>8</sup>, an 11-item instrument with possible scores of 0–22 that was designed for use with individuals who are likely to have a Mini-Mental State Examination (MMSE, range 0–30)<sup>9</sup> score of <6. Higher SIRS scores reflect higher cognitive function.

Each surrogate decision-maker was interviewed in person to obtain data on the surrogate's and resident's demographic characteristics, surrogate's relationship to the resident (i.e., spouse, child, or other), and resident's history of dementia. Using a single item (i.e., "How would you rate [*Resident's*] overall quality of life in the past two weeks?"), surrogates were asked to rate the resident's QOL as excellent, good, fair, poor, or very bad. This type of global caregiver-rated QOL measure has been used successfully in dementia research<sup>10</sup>.

Resident's HRQOL was measured by administering the Alzheimer Disease Related Quality of Life (ADRQL) scale<sup>5</sup> to a NH professional caregiver who was most familiar with the resident. The ADRQL is a disease-specific, proxy-rated measure of behaviors relevant to the HRQOL of people with Alzheimer disease (AD) or other types of dementia. Prior studies show that it correlates with dementia severity<sup>11</sup> and detects change in HRQOL over time<sup>12</sup>. The 40-item ADRQL used in this study has been shown to have good internal consistency, score distribution, completeness of data, validity and responsiveness, and scores are largely unrelated to caregiver characteristics<sup>13</sup>. The ADRQL includes five sub-scales: (1) Social Interaction – how the person relates to others in some observable way through physical gestures, talking or facial expression, (2) Awareness of Self – awareness of the person's own special personal identity and major relationships, (3) Feelings and Mood – signs that can be seen or heard by others of how a person often feels, (4) Enjoyment of Activities – participation and enjoyment in daily life (e.g., leisure and recreational activities), and (5)

Response to Surroundings – how a person responds to their environment in some observable way (see Appendix for abbreviated items). For each item, respondents are asked to “agree” or “disagree” with whether the statement describes the resident in the last two weeks. Each sub-scale and the total ADRQL have a possible score range of 0–100, with higher scores representing higher QOL.

### Data Analysis

To identify correlates of residents’ QOL as measured by the ADRQL, we examined 23 variables categorized as follows: \_demographic characteristics (gender, age, race, education), neuropsychiatric symptoms (behavior problems, mood disorders, psychosis/delusions), medical co-morbidities (pressure ulcers, pulmonary disorders, musculoskeletal problems, total number of health problems, staff-identified pain), severity of symptoms (years since onset of dementia symptoms, years since NH admission, SIRS score, use of pain medication), status of advance directives (any advance directive, treatment instructions provided in advance directive), aggressiveness of care (DNR order, hospice/palliative care status, use of feeding tube), surrogate-rated QOL, and study sites. Univariate analyses were conducted to describe the sample, and bivariate analyses (i.e., t-tests, ANOVAs, Pearson correlations, Pearson chi-squares) were used to examine relationships between variables. Variables found to be significantly associated with total ADRQL scores at  $p < .05$  in bivariate analyses were examined further using multiple linear regression analysis. Since we did not have prior research findings on QOL of NH residents with advanced dementia to suggest a theoretical mechanism of association, we used an exploratory model building approach with variables that we believed might correlate with QOL near the end of life. The regression analysis began with the forced entry of study sites to account first for the dependency of data within each facility, followed by a forward stepwise procedure based on the probability of F-to-enter at .05 and F-to-remove at .10. Bootstrapping was used to test the final regression model and construct p-values and confidence intervals. With a total sample size of 113 (since some independent variables had missing data), a regression analysis that includes 9 predictor variables could detect a medium effect size of .15 with an alpha of .05 and 80% power. Analyses were completed using SPSS, Version 17.0 (SPSS, Inc.; Chicago, IL) and Stata 9 (StataCorp LP; College Station, TX).

## RESULTS

Out of 289 eligible residents, 126 (43.6%) were enrolled, and one resident’s surrogate withdrew consent shortly after enrollment, leaving 125 participants at the three sites (61, 42, and 22 residents, respectively). The most common reasons for non-enrollment were that residents died before enrollment (23.2%) and surrogates denied permission to enroll residents (17.6%)<sup>6</sup>. Overall, those enrolled were more likely to be female ( $p = .036$ ), white ( $p = .003$ ) and to have a female surrogate ( $p = .021$ ) than non-enrolled eligible residents<sup>6</sup>. Baseline ADRQL data were complete for 119 residents whose characteristics are summarized in Table 1. The majority of residents were female (54.6%) and white (83.2%); their mean age was 81.6 ( $\pm 6.8$ ); and they had completed an average of 11.4 ( $\pm 3.4$ ) years of education. Neuropsychiatric symptoms and medical co-morbidities were common in this sample; the majority (79%) had a DNR order; and one-third were receiving hospice or palliative care. Almost two-thirds (64.7%) of participants were identified by NH staff as having pain during the review period, the vast majority (94.8%) of whom were receiving pain medication during that time. Most surrogates were residents’ spouses (26.1%) or adult children (49.6%), with the remainder (24.4%) being other relatives, friends, or guardians.

The mean total ADRQL score was 63.3 ( $\pm 17.3$ ), with normally distributed total scores having a range of 12.4 – 95.1 (see Figure in on-line Appendix). Scores ranged from 0 to 100 on each sub-scale, except for Feelings and Mood (range=7.7–100). Few residents had scores

of zero on the Social Interaction (n=2), Response to Surroundings (n=3), and Awareness of Self (n=5) sub-scales. Residents were most likely to score zero on Enjoyment of Activities (n=20). The high mean score for Response to Surroundings reflects a more skewed distribution, suggesting that this sub-scale may be of limited value in assessing this aspect of QOL near the end of life.

Most surrogates (68.7%) rated residents' QOL as excellent, good or fair. Total ADRQL scores were positively correlated with surrogate-rated QOL ( $F=7.231$ ,  $df=114$ ,  $p<.001$ ), suggesting the validity of the ADRQL in advanced dementia. While surrogate-rated QOL was not associated with surrogates' relationships to residents ( $X^2=9.179$ ,  $df=8$ ,  $p=.327$ ), it was correlated with SIRS scores ( $F=4.518$ ,  $df=114$ ,  $p=.002$ ), indicating that better surrogate-rated QOL was associated with higher cognitive function.

Other correlates of total ADRQL scores are shown in Table 2. Resident characteristics associated significantly with higher ADRQL scores included: female gender, older age, less education, absence of behavior problems, presence of staff-identified pain, use of pain medication, higher SIRS scores (cognitive function), and not receiving hospice or palliative care. Mean ADRQL scores also differed across study sites, with Site 3 residents having significantly higher scores than Site 1 residents. In addition, residents with behavior problems were less likely to receive pain medication (Fisher's Exact Test,  $p=.044$ ).

In the multiple regression analysis, study sites were significantly related to total ADRQL scores in the first 2 steps but not thereafter. Three other variables entered and remained in the final model ( $R^2=.415$ ), including SIRS scores ( $p<.001$ ,  $CI=.966-1.650$ ), use of pain medication ( $p=.006$ ,  $CI=3.303-19.588$ ), and behavior problems ( $p=.014$ ,  $CI=-11.604-1.298$ ). Residents with higher cognitive function and those being treated for pain had higher QOL, while individuals with behavior problems had lower QOL. An interaction variable for behavior problems and pain medication use was tested and found not significant.

## DISCUSSION

This study is among the first to describe the HRQOL of people with advanced dementia near the end of life. Findings of note are that total ADRQL scores were normally distributed and there was a wide range of scores within each sub-scale despite the hospice eligibility of this sample. These findings strongly counter the view that advanced dementia renders the concept of quality of life unmeasurable or meaningless in this population. Strengthening this conclusion is the parallel finding of Koopmans and colleagues<sup>14</sup> who also reported that the overall QOL of a sample of 39 NH residents in the final phase of dementia was moderate based on the QUALIDEM, another dementia-specific measure of HRQOL. The finding that scores were normally distributed demonstrates that total ADRQL does not have a floor effect and further supports the contention that improvement in QOL may be possible in late stage dementia.

Measuring the QOL of NH residents with dementia who cannot be interviewed is a major challenge<sup>4</sup>. While self-ratings are clearly preferable, Kane<sup>4</sup> suggests that a proxy approach is necessary for residents who cannot communicate their perspective yet can still interact with their environment. The ADRQL is one such approach that relies on a proxy to rate the resident's HRQOL based on the individual's observable behaviors. Since self-rated QOL was impossible in this sample, we included an additional surrogate-rated global measure of QOL that correlated positively with staff-rated ADRQL scores, providing support for its validity in this population.



Another approach for measuring QOL in NH residents is the use of selected items from the Minimum Data Set (MDS)<sup>15</sup>. An advantage of the recent MDS 3.016 is the inclusion of data from residents who are capable of being interviewed. While the MDS 3.0 is a broad-based assessment instrument, some of its components are reflected in the ADRQL, such as mood, behavior and preferences for activities. Domains included in the ADRQL as a dementia-specific measure of QOL that differ from the MDS 3.0 are Awareness of Self, Response to Surroundings and, to some extent, Social Interaction. The ADRQL is intended for use with other established measures of cognitive and functional status—domains that are not incorporated in the ADRQL but are included in the MDS 3.0.

Three factors correlated with total ADRQL scores in our multivariate analysis. First, higher cognitive function was associated with higher HRQOL, a finding that has been reported by some studies of QOL in dementia<sup>17,18,19</sup> but not by others<sup>20,21,22</sup>. Other investigators report that the relationship depends on who rates the person's QOL (i.e., self v. family or caregiver v. staff ratings)<sup>20</sup>. The strong correlations between cognitive function and both staff-rated QOL (ADRQL) and surrogate-rated QOL support the validity of the finding in this sample. However, a better test would be to examine the relationship between changes in cognitive function and QOL over time, an analysis we will pursue in the future.

Second, residents who received pain medication had significantly higher QOL. While studies have linked pain to lower HRQOL<sup>23,24</sup>, pain management has been identified as a means by which HRQOL may be improved<sup>25</sup>. Residents with staff-identified pain were more likely to receive pain medication, which we believe explains why residents with staff-identified pain had *higher* QOL scores. For people with advanced dementia who are unable to provide self-reports, pain assessment must rely on proxy reports using observational strategies<sup>26</sup>. Our study shows that both staff-identified pain and use of pain medications are strong correlates of ADRQL scores, suggesting the importance of pain assessment and pain management to QOL. When pain is assessed appropriately and treated effectively, pain behaviors can be reduced<sup>27</sup>. If pain were relieved, improvements in QOL might be reflected in any of the ADRQL domains, particularly those of Feelings and Mood, Enjoyment of Activities, and Social Interaction.

Finally, our data show that residents with behavior problems had significantly lower HRQOL than those without such problems. Significant relationships between behavioral disorders and poor QOL in persons with dementia has been widely reported<sup>20,28</sup>. Two-thirds of our sample had behavior problems during the baseline period, the most prevalent of which was agitation or aggression (50%)<sup>29</sup>. While our bivariate finding suggests that some behavior problems might be due to untreated pain, the interaction variable for these two factors was not associated significantly with QOL. The challenge is to identify and provide appropriate therapies that effectively treat behavior problems in advanced dementia.

Limitations of the CareAD study include: (1) a substantial number of eligible residents died before enrollment (23%) and surrogates declined to give permission for 18% of eligible resident to participate; (2) participants were more likely to be white and female than were non-participants, and (3) the study was conducted at only three NHs in a single geographic area. These factors may limit the generalizability of the data. While most dementia-related deaths occur in NHs<sup>30</sup>, correlates of QOL in dementia patients cared for at home near the end of life may differ from our findings.

This study demonstrates that the ADRQL is a valid measure of QOL in advanced dementia, and score distributions in this sample suggest that improvements in QOL may be possible. Recognizing that dementia patients near the end of life do indeed experience measurable HRQOL is an important step in the investigation of ways in which health care providers

might improve QOL for these patients. Our findings point explicitly to aspects of care that warrant greater attention by clinicians with the goal of maximizing QOL as death nears. Pain assessment and effective pain management are critical in this vulnerable population in which self-reporting of discomfort is usually impossible but where pain behaviors are observable. Behavior problems unrelated to pain must be addressed with pharmacological and non-pharmacological therapies to improve QOL and prevent behavior-related injuries that may be incurred by patients and staff.

Further research is needed to identify other potentially modifiable correlates of QOL since our final model accounted for only 41.5% of the variance in ADQRL scores. Potential factors not examined in this study include NH characteristics and policies that may affect residents' QOL<sup>4</sup>. Additional work is needed on measuring QOL and examining change in QOL in late-stage dementia and whether, for example, a shorter version of the ADRQL might be a better, more efficient indicator of QOL in this population. This study also highlights the importance of using QOL as an outcome measure for interventions that seek to improve end-of-life care in dementia. It is critical to identify aspects of QOL that are amenable to meaningful change even in dementia patients' final days.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## APPENDIX

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### Alzheimer Disease Related Quality of Life (ADRQL) - Subscales and Abbreviated Items\*

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#### A. Social Interaction

- 1 Smiles around people
- 2 Pays no attention to others
- 3 Stays around people
- 4 Seeks contact
- 5 Talks with people
- 6 Touches/allows touching
- 7 Comforted or reassured by others
- 8 Gets pleasure from pets/children
- 9 Is cheerful
- 10 Shows delight
- 11 Shows humor
- 12 Enjoys other's activities

#### B. Awareness of Self

- 1 Activities related to previous work
- 2 Aware of place in family
- 3 Makes choices in routine activities
- 4 Shows interest in events, places from past
- 5 No response to his/her name
- 6 No beliefs or attitudes expressed
- 7 Talks on telephone
- 8 Enjoyment from possessions

#### C. Feelings and Mood

- 1 Wrings hands
- 2 Hits, kicks objects
- 3 Yells, curses
- 4 Locks self in
- 5 Is easily angered
- 6 Cries
- 7 Is restless and wound-up
- 8 Resists help
- 9 Appears content
- 10 Upset when approached
- 11 Pushes, grabs, hits
- 12 Upset when in home

#### D. Enjoyment of Activities

- 1 Enjoys activities alone
- 2 No participation in former activities
- 3 No pleasure from activities
- 4 Does nothing

#### E. Response to Surroundings

- 1 Says feels unsafe
  - 2 Upset outside home
  - 3 Talks about leaving
  - 4 Says wants to die
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\* ADRQL – A proxy-rated measure of dementia-specific health related quality of life; 40-item version; possible range of scores is 0–100; higher scores reflect higher quality of life.

**Table 1**

## Residents' Baseline Characteristics (n=119)

Characteristics	n (%)	Mean ( $\pm$ SD)
<u>Demographics</u>		
Gender (female)	65 (54.6)	
Race (white)	99 (83.2)	
Age (years)		81.6 (6.8)
Education (years)*		11.4 (3.4)
<u>Neuropsychiatric Symptoms</u>		
Behavior problems	79 (66.4)	
Mood disorders	77 (64.7)	
Psychosis or delusions	32 (26.9)	
<u>Medical Co-morbidities</u>		
Pressure ulcers	73 (61.3)	
Pulmonary disorders	20 (16.8)	
Musculoskeletal problems	72 (60.5)	
Pain identified by staff	77 (64.7)	
Total number of health problems		22.0 (7.4)
<u>Severity of Symptoms</u>		
SIRS Score (cognitive function) <sup>†</sup>		10.3 (6.7)
Years with dementia symptoms*		8.6 (5.7)
Years since nursing home admission		2.0 (3.0)
Use of Pain medications	98 (82.4)	
<u>Advance Directives</u>		
Any advance directive	80 (67.2)	
Treatment instructions in directive	63 (52.9)	
<u>Aggressiveness of Care</u>		
Do-not-resuscitate order	94 (79.0)	
On hospice or palliative care	39 (32.8)	
Using feeding tube	9 (7.6)	
<u>Quality of Life Indicators</u>		
ADRQL Total Score <sup>‡</sup>		63.3 (17.3)
Social Interaction sub-score		68.8 (29.6)
Awareness of Self sub-score		31.0 (22.5)
Feelings and Mood sub-score		76.1 (23.9)
Enjoyment of Activities sub-score		46.4 (31.8)
Response to Surroundings sub-score		92.1 (18.8)
<u>Surrogate-rated quality of life*</u>		
Excellent	10 (8.7)	
Good	31 (27.0)	
Fair	38 (33.0)	

Characteristics	n (%)	Mean ( $\pm$ SD)
Poor	22 (19.1)	
Very bad	14 (12.2)	
<u>Study Sites</u>		
Site 1	40 (33.6)	
Site 2	57 (47.9)	
Site 3	22 (18.5)	

\* Missing data – education (n=6), years with dementia symptoms (n=1), surrogate-rated quality of life (n=4).

<sup>†</sup>SIRS – Severe Impairment Rating Scale, possible range of scores is 0–22, higher scores reflect higher cognitive function.

<sup>‡</sup>ADRQL – Alzheimer Disease Related Quality of Life scale, possible range of total ADRQL scores and each sub-scale is 0–100, higher scores reflect better quality of life.

**Table 2****Bivariate Correlates of Total ADRQL Scores\***

<b>Residents' Characteristics</b>	<b>ADRQL Scores Means (<math>\pm</math>SD)</b>	<b>Statistic</b>	<b>P-Value</b>
<u>Demographics</u>			
Gender (female vs male)	66.7 (14.8) vs 59.2 (19.2)	t = -2.36	.020
Race (white vs black)	62.2 (17.0) vs 68.8 (17.8)	t = -1.58	.117
Age (years)		R = 0.28	.002
Education (years)		R = -0.21	.029
<u>Neuropsychiatric Symptoms</u>			
Behavior problems (yes vs no)	60.5 (17.2) vs 68.7 (16.2)	t = 2.50	.014
Mood disorders (yes vs no)	61.2 (17.0) vs 67.1 (17.3)	t = 1.80	.074
Psychosis or delusions (yes vs no)	60.8 (19.9) vs 64.2 (16.2)	t = 0.96	.340
<u>Medical Co-morbidities</u>			
Pressure ulcers (yes vs no)	63.7 (18.0) vs 62.6 (16.3)	t = -0.36	.723
Pulmonary disorders (yes vs no)	67.3 (15.7) vs 62.4 (17.5)	t = -1.15	.252
Musculoskeletal problems (yes vs no)	65.4 (17.2) vs 59.9 (17.1)	t = -1.72	.089
Pain identified by staff (yes vs no)	66.8 (16.8) vs 56.8 (16.3)	t = -3.14	.002
Total number of health problems		R = 0.09	.354
<u>Severity of Symptoms</u>			
SIRS Score (cognitive function) <sup>†</sup>		R = 0.53	<.001
Years with dementia symptoms		R = -0.08	.387
Years since nursing home admission		R = 0.04	.639
Use of Pain medications (yes vs no)	66.1 (15.6) vs 49.9 (18.9)	t = -4.16	<.001
<u>Advance Directives</u>			
Any advance directive (yes vs no)	63.7 (15.8) vs 62.4 (20.2)	t = -0.33	.743
Treatment instructions (yes vs no)	62.9 (16.1) vs 63.7 (18.6)	t = 0.28	.783
<u>Aggressiveness of Care</u>			
Do-not-resuscitate order (yes vs no)	63.7 (17.0) vs 61.7 (18.6)	t = -0.52	.605
Hospice/palliative care (yes vs no)	58.4 (16.2) vs 65.5 (17.4)	t = 2.13	.035
Using feeding tube (yes vs no)	58.7 (19.9) vs 63.6 (17.1)	t = 0.82	.412
<u>Study Sites</u>			
Site 1	57.9 (18.4)	F= 4.06	.020
Site 2	64.3 (14.5)		
Site 3	70.4 (19.4)		

\* ADRQL – Alzheimer Disease Related Quality of Life scale, possible range of scores is 0–100, higher scores reflect better quality of life.

<sup>†</sup>SIRS – Severe Impairment Rating Scale, possible range of scores is 0–22, higher scores reflect higher cognitive function.