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Mapping Health Status Measures to a Utility Measure in a Study of Nursing Home Residents With Advanced Dementia

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Abstract

Background—Nursing home residents with advanced dementia commonly experience burdensome and costly interventions (eg, hospitalization) of questionable clinical benefit. To facilitate cost-effectiveness analyses of these interventions, utility-based measures are needed in order to estimate quality-adjusted outcomes.

Methods—Nursing home residents with advanced dementia in 22 facilities were followed for 18 months ($N = 319$). Validated health status measures ascertained from nurses at baseline, quarterly, and death ($N = 1702$ assessments) were mapped to the Health Utilities Index Mark 2 [range, 1 (perfect health) to 0 (death); scores below 0 indicate states worse than death]. To assess validity, utility scores were compared between residents who did and did not receive burdensome interventions (parenteral therapy, percutaneous endoscopic gastrostomy tubes, and hospital transfers), residents with and without pneumonia, and residents who did and did not die at the last assessment.

Results—Mean ($\pm$ SD) Health Utilities Index Mark 2 utility score for the cohort was 0.165 ± 0.060 (range, -0.005 to 0.215). Residents spent an average of 15.5% of their days with utilities < 0.10 . Lower utility scores were found among residents who received burdensome interventions (0.152 ± 0.067 vs. 0.171 ± 0.056 ; $P = 0.0003$); had pneumonia (0.147 ± 0.066 vs. 0.170 ± 0.057 ; $P = 0.003$); and were dying (0.163 ± 0.057 vs. 0.180 ± 0.055 ; $P = 0.006$).

Conclusions—It is feasible to map health status measures to utility-based measures for advanced dementia. This work will facilitate future cost-effectiveness analyses aimed at quantifying the cost of interventions relative to quality-based outcomes for patients with this condition.

Keywords

advanced dementia; utility-based health status measures; cost-effectiveness analysis

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Advanced dementia is the sixth leading cause of death among Americans, yet often underrecognized as a terminal illness.¹ Prior research suggests that patients dying with advanced dementia do not receive optimal end-of-life care.²⁻⁴ Most notably, these patients commonly undergo costly and burdensome interventions that are of questionable clinical benefit near the end of life (eg, tube feeding, hospitalizations).⁵ One challenge to designing health care policies that align evidence and patient preferences is the lack of rigorous research quantifying the cost effectiveness of treatment options in this condition.

Health-related quality of life (HRQOL) is an important aspect of evaluating the effectiveness of health care services. Cost-effectiveness analysis compares incremental changes in outcomes relative to costs and generally requires an estimation of quality-adjusted survival. In turn, quality adjustment requires utility-based quality of life measurements, which are not routinely collected in clinical studies. Many studies ascertain health status measures that reflect the patient's well being in multiple domains but do not assess relative preferences for a particular state.⁶ Mapping health status measures to utility-based measures is used to estimate quality-adjusted outcomes.⁷⁻⁹

Advanced dementia is characterized by profound memory deficits (cannot recognize family members), verbal ability limited to 5 words or less, inability to ambulate, and incontinence.¹⁰ Assessing health status and quality of life in these patients, who are incapable of self-report, relies on the perceptions of their caregivers. Three generic utility-based measures have been used to evaluate HRQOL in dementia: Health Utilities Index, Quality of Wellbeing Scale, and the EuroQol EQ-5D.¹¹ Although none of these instruments has been applied specifically to advanced dementia, one study reported that Health Utilities Index Mark 2 (HUI2) was able to measure health utilities in Alzheimer disease patients at varying stages of the disease.¹² Another study mapped items in the Minimum Data Set to HUI2 to create a quality-based outcome measure for nursing home (NH) residents.¹³

The recently completed Choices, Attitudes, Strategies, and Care for of Advanced Dementia at the End-of-Life (CASCADE) study used 2 validated health status measures designed specifically for end-stage dementia^{14,15} to characterize 323 nursing NH residents on a quarterly basis for up to 18 months: the Symptom Management at the End of Life in Dementia scale (SM-EOLD) and the Comfort Assessment in Dying with Dementia scale (CAD-EOLD). The objective of this report is to map these health status measures to the HUI2, a necessary step for future cost-effectiveness analyses of interventions provided to end-stage dementia patients.

METHODS

Study Population

The study included participants in the CASCADE study,¹⁶ a National Institutes of Health-funded prospective cohort study conducted between 2003 and 2009 that described the experience of NH residents with advanced dementia. The detailed methods of this study are provided elsewhere.^{5,16} Residents were recruited from 22 NHs with > 60 beds and within 60 miles of Boston. Eligibility criteria included (1) age over 60 years; (2) dementia (any type, determined from medical record); (3) Global Deterioration Scale score of 7 (ascertained by nurse interview);¹⁰ and (4) available, English-speaking proxies to provide informed consent. A Global Deterioration Scale score of 7 is characterized by profound memory deficits (unable to recognize family), limited verbal communication (< 5 words), incontinence, and inability to ambulate. The Institutional Review Board of Hebrew SeniorLife Institute for Aging Research, Boston, approved the study's conduct.

Health Status Measures

Data were derived from resident assessments conducted at baseline and quarterly for up to 18 months through chart reviews and nurse interviews. If a resident died, a chart review and a nurse interview were conducted within 14 days of death.

Two validated health status measures designed specifically for advanced dementia were collected from interviews with nurses providing direct care for the residents: the SM-EOLD and the CAD-EOLD (online appendix, Supplemental Digital Content 1, <http://links.lww.com/MLR/A268>).¹⁴ SM-EOLD, a 9-item symptom scale ascertained at baseline and quarterly, quantifies the frequency residents experienced symptoms over the prior 30 days: 1 = never, 2 = once a month, 3 = several days a month, 4 = once a week, 5 = several days a week, and 6 = daily. Five SM-EOLD items were used to map to the HUI2: depression, fear, anxiety, agitation, and pain. CAD-EOLD, a 14-item symptom scale ascertained by nurse interview within 14 days of the death of a resident (N = 177), rates the frequency residents experienced symptoms during the last week of life: 1 = not at all, 2 = somewhat, and 3 = a lot. Three CAD-EOLD items were used to map to the HUI2: fear, anxiety, and pain. SM-EOLD was used in all assessment periods where the resident was living at the end of the period; CAD-EOLD was used for the last assessment period if the resident died.

Mapping the Health Status to the HUI2

The HUI2 scale includes 7 domains: emotion, pain, sensation, mobility, cognition, self-care, and fertility. The description of the HUI2 scores, the associated utility value, and mapping to the resident health status data from CASCADE measures are shown in Table 1.¹⁷

In the emotion domain, the mapping used the highest score of 4 SM-EOLD items: depression, fear, anxiety, and agitation. The most severe level is used, because the HUI2 status descriptions for the emotion domain (Table 1) are based on the presence of one of the 4 components (depression, fear, anxiety, or agitation). For death assessments, the lowest value recorded on either the fear or anxiety items on the CAD-EOLD (lower score is more severe) was mapped to the HUI2 emotion domain.

The pain item on the SM-EOLD (baseline and quarterly assessments) and the CAD-EOLD (death assessment) was mapped directly to the HUI2 pain levels.

Information regarding sight, hearing, and speaking abilities of the residents was not collected in the CASCADE study. However, CASCADE's eligibility criteria limited verbal ability to 5 words or less. Each resident was assigned to HUI2 sensation level 3 (sees, hears, or speaks with limitations even with equipment). A sensitivity analysis examined the effect of assigning each resident to HUI2 level 4 (blind, deaf, or mute).

All residents were bedbound with limited or no ability to walk. Therefore, in the mobility domain all residents were assigned HUI2 level 5 for all assessments.

All residents had severe cognitive impairment and were assigned to HUI2 level 4 (unable to learn and remember) for all assessments. Similarly, all residents were dependent on others for all activities of daily living; they were assigned HUI2 level 4 in the self-care domain (requires the help of another person to eat, bath, dress, or use the toilet.)

The quality of life of NH residents with or without advanced dementia does not in any way depend on fertility; as Torrance et al¹⁷ recommend, all residents were assigned HUI2 level 1 for fertility.

Calculating the Utility Score

At each assessment, the resident's utility score was calculated based on a formula estimated by Torrance et al.¹⁷ The scores in each HUI2 domain (Table 1) are multiplied together by a factor of 1.06. A total HUI2 is calculated by subtracting 0.06. Thus, a perfectly healthy individual would have the best possible total HUI2 score of 1.00:

$$[(1.00 \times 1.00 \times 1.00 \times 1.00 \times 1.00 \times 1.00 \times 1.00) \times 1.06] - 0.06 = 1.00.$$

A score of 0.00 is anchored to death. The lowest possible score of -0.025:

$$\{[(0.53 \times 0.38 \times 0.61 \times 0.58 \times 0.65 \times 0.80 \times 0.88) \times 1.06] - 0.06 = -0.025\},$$

is interpreted as worse than death. The mean, standard deviation, and ranges for the resultant utility scores from all assessments were calculated.

Validity of the mapped HUI2 scores was assessed using 3 comparisons of means: residents who received at least 1 burdensome intervention versus those who had received none, residents who had pneumonia versus those who did not, and residents who died after their last assessment period versus those who did not. Burdensome treatments, as previously described in the CASCADE study,⁵ included parenteral hydration, intravenous antibiotics, percutaneous endoscopic gastrostomy tubes, and hospital transfers. We hypothesized that residents who had burdensome interventions, pneumonia, and who died would have lower HUI2 scores. Mean utilities were compared using Generalized Estimating Equation models that allowed for clustering at the resident level.

RESULTS

Study Population

There were 323 NH residents with advanced dementia in the CASCADE study. Four residents were excluded from this report due to incomplete follow-up. The remaining 319 residents contributed a total of 1702 assessments (baseline, $n = 319$; quarterly, $n = 1206$; and death, $n = 177$). Their mean age was 85.4 years; 86.2% were female, 89.3% were white, and 177 residents (55.5%) died.

Utility Scores

The mean (SD) utility score based on all assessment periods was 0.165 ± 0.060 , ranging from -0.005 to 0.215. On average, 0.3% of a resident's time was at a utility level < 0 , 15.2% was between 0 and 0.10, 42.6% was between 0.10 and 0.20, and the remaining 41.9% was between 0.20 and the maximum 0.215 (Fig. 1). Significantly lower mean utility scores were found among residents who received burdensome interventions (0.152 ± 0.067 vs. 0.171 ± 0.056 ; $P = 0.0003$), had pneumonia (0.147 ± 0.066 vs. 0.170 ± 0.057 ; p value = 0.003), and were dying (0.163 ± 0.057 vs. 0.180 ± 0.055 ; $P = 0.006$), compared with residents without those characteristics (Fig. 2).

DISCUSSION

Using the rich CASCADE dataset, this study demonstrates the feasibility of mapping health status measures collected from NH residents with advanced dementia to a widely accepted utility-based measure, the HUI2. Although all residents had very advanced disability, the derived HUI2 scores were sensitive to variability in the residents' clinical course (eg, burdensome interventions, pneumonia, and dying state). This finding supports the validity of

our approach, and it also suggests that even at the very advanced stages of dementia, HRQOL is a measurable and potentially an important aspect of evaluating the effectiveness of health care services.

In our cohort, the HUI2 scores ranged from -0.005 to 0.215 with a mean of 0.165 . As expected, these utility estimates indicate the very low values attributed to the health states of advanced dementia. Ten years spent in a health state with a utility of 0.10 is equivalent to 1 year in perfect health (utility of 1.0). Residents with advanced dementia in this study spent 15.5% of the observation time at a utility level of < 0.10 . Although, no prior research directly examined HRQOL in advanced dementia, 1 study that mapped the Minimum Data Set to HUI2 scores, reported a mean HUI2 of 0.36 (range, 0.32 – 0.40) among a general NH population.¹³ In another cross-sectional study, the HUI2 was administered to caregivers for patients at various dementia stages classified by the Clinical Dementia Rating scale.¹² The mean HUI2 scores reported for patients at the 2 most severe levels were 0.27 and 0.14 , respectively.

There are several challenges to measuring HRQOL in advanced dementia. First, it is impossible to directly measure HRQOL from the patient perspective. Nonetheless, proxy report based on nurse observations as measured in the validated SM-EOLD and CAD-EOLD, although imperfect, is a reasonable approach. Second, the advanced stage of disability makes variability more difficult to discern. In fact, HUI2 variability in this study was limited to the emotion and pain domains, although that was adequate to detect differences based on burdensome interventions, pneumonia, and a dying state. Third, the HUI2 is a generic utility-based measure and may not be ideal for capturing variation in HRQOL in advanced dementia. It is particularly challenging to assign a generic utility-based score to patients that cannot directly express their health status. HRQOL measures designed specifically for this condition exist,^{6,18–20} although none is preference based and have limited applicability to cost-effectiveness analysis. Finally, there were limitations in the CASCADE data with respect to mapping, such as the lack of direct measurement of sensation. Future studies that collect health status measures (ie, SM-EOLD and CAD-EOLD) and utility-based measures (ie, HUI2) can be used to further validate the mapping approach used in this study.

In this era of health care reform and fiscal constraint, it is increasingly important to measure the cost effectiveness of different approaches to care, including among patients near the end of life. This report provides an important step toward developing the methodology needed to evaluate the cost effectiveness of treatment options for the growing number of Americans suffering with advanced dementia.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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References

1. Heron, M.; Tejada-Vera, B. [Accessed April 27, 2011] Deaths: leading causes for 2005 [CDC National Vital Statistics Reports web site]. Dec 23, 2009 Available at: http://www.cdc.gov/nchs/data/nvsr/nvsr58/nvsr58_08.pdf
2. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med*. 2004; 19:1057–1063. [PubMed: 15482560]

3. Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med.* 2004; 164:321–326. [PubMed: 14769629]
4. Di Giulio P, Toscani F, Villani D, et al. Dying with advanced dementia in long-term care geriatric institutions: a retrospective study. *J Palliat Med.* 2008; 11:1023–1028. [PubMed: 18788965]
5. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med.* 2009; 361:1529–1538. [PubMed: 19828530]
6. Ettema TP, Dröes R-M, de Lange J, et al. A review of quality of life instruments used in dementia. *Qual Life Res.* 2005; 14:675–686. [PubMed: 16022061]
7. Mortimer D, Segal L. Comparing the incomparable? A systematic review of competing techniques for converting descriptive measures of health status into QALY-weights. *Med Decis Making.* 2008; 28:66–89. [PubMed: 18263562]
8. Nichol MB, Sengupta N, Globe DR. Evaluating quality-adjusted life years: estimation of the health utility index (HUI2) from the SF-36. *Med Decis Making.* 2001; 21:105–112. [PubMed: 11310943]
9. Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. *J Health Econ.* 2002; 21:271–292. [PubMed: 11939242]
10. Reisberg B, Ferris SH, de Leon MJ, et al. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry.* 1982; 139:1136–1139. [PubMed: 7114305]
11. Selai C. Assessing quality of life in dementia. *Med Care.* 2001; 39:753–755. [PubMed: 11468494]
12. Neumann PJ, Kuntz KM, Leon J, et al. Health utilities in Alzheimer's disease: a cross-sectional study of patients and caregivers. *Med Care.* 1999; 37:27–32. [PubMed: 10413389]
13. Wodchis WP, Maxwell CJ, Venturini A, et al. Study of observed and self-reported HRQL in older frail adults found group-level congruence and individual-level differences. *J Clin Epidemiol.* 2007; 60:502–511. [PubMed: 17419961]
14. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of end-of-life care in dementia. *Alzheimer Dis Assoc Disord.* 2001; 15:194–200. [PubMed: 11723370]
15. Kiely DK, Volicer L, Teno J, et al. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord.* 2006; 20:176–181. [PubMed: 16917188]
16. Mitchell SL, Kiely DK, Jones RN, et al. Advanced dementia research in the nursing home: the CASCADE study. *Alzheimer Dis Assoc Disord.* 2006; 20:166–175. [PubMed: 16917187]
17. Torrance GW, Feeny DH, Furlong WJ, et al. Multiattribute utility function for a comprehensive health status classification system. Health Utilities Index Mark 2. *Med Care.* 1996; 34:702–722. [PubMed: 8676608]
18. Ready RE, Ott BR. Quality of Life measures for dementia. *Health Qual Life Outcomes.* 2003; 1:11–19. [PubMed: 12740036]
19. Corder Z, Blass DM, Rabins PV, et al. Quality of life in nursing home residents with advanced dementia. *J Am Geriatr Soc.* 2010; 58:2394–2400. [PubMed: 21054329]
20. Weiner MF, Martin-Cook K, Svetlik DA, et al. The quality of life in late-stage dementia (QUALID) scale. *J Am Med Dir Assoc.* 2000; 1:114–116. [PubMed: 12818023]

FIGURE 1.

Average proportion of time observed at various levels of utility. The average proportions shown are based on averages of individual residents weighted by the number of observed days for each resident. For all residents ($N = 319$), 0.3% of the time was spent at levels of utility < 0 , 15.2% at levels between 0.0 and 0.1, 42.6% at levels between 0.1 and 0.2, and 41.9% between 0.2 and 0.215.

FIGURE 2.

Utility scores for nursing home residents with advanced dementia. The panels show distributions of Health Utilities Index 2 (HUI2) scores (possible range, -0.025 to 1.000 ; higher score indicates better quality) based on data collected at each quarterly follow-up and death assessment ($N = 1383$ assessments). Panel A: the mean utility score for assessments where residents had received at least 1 burdensome intervention ($N = 282$) was 0.152 ± 0.067 (SD) compared with 0.171 ± 0.056 (SD) for assessments when the resident did not receive a burdensome intervention ($N = 1101$); the difference between the group means, after adjusting for correlation within residents, was 0.016 ($P = 0.0003$). Panel B: the mean utility score for assessments where residents had at least 1 occurrence of pneumonia ($N = 195$) was 0.147 ± 0.066 (SD) compared with 0.170 ± 0.057 (SD) for assessments when the resident did not have pneumonia ($N = 1188$); the difference between the group means, after adjusting for correlation within residents was 0.014 ($P = 0.003$). Panel C: the mean utility score for the last assessment where residents died ($N = 177$) was 0.163 ± 0.057 (SD)

compared with 0.180 ± 0.055 (SD) for the last assessment for residents who did not die ($N = 142$); the difference between the group means was 0.017 ($P = 0.006$).

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TABLE 1
Mapping Health Status in Nursing Home Residents With Advanced Dementia to HUI2 Domains

HUI2 Domains	Utility*	Health Status Mapping		
Emotion		SM-EOLD ⁷ Emotion Items (Depression, Fear, Anxiety, or Agitation) [§]	CAD-EOLD ⁷ Emotion Items (Fear or Anxiety) [§]	
Generally happy and free from worry	1.00	1	Never	3
Occasionally fretful, angry, irritable, anxious, depressed, or suffering "night terrors"	0.93	2/3	1–3 d/mo	—
Often fretful, angry, irritable, anxious, depressed, or suffering "night terrors"	0.81	4	Once/wk	2
Almost always fretful, angry, irritable, anxious, depressed	0.70	5	Several days/wk	—
Extremely fretful, angry, irritable, anxious, or depressed	0.53	6	Daily	1
Pain		SM-EOLD ⁷ Pain Item	CAD-EOLD ⁷ Pain Item	
Free of pain and discomfort	1.00	1	Never	3
Occasional pain	0.97	2/3	1–3 d/mo	—
Frequent pain, discomfort relieved by oral medicines with occasional disruption of normal activities	0.85	4	Once/wk	2
Frequent pain, frequent disruption of normal activities. Discomfort requires prescription narcotics for relief	0.64	5	Several days/wk	—
Severe pain, pain not relieved by drugs, and constantly disrupts normal activities	0.38	6	Daily	1
Sensation				
Able to see, hear, and speak normally for age	1.00			All residents assigned to level 3 [¶]
Requires equipment to see or hear or speak	0.95			
Sees, hears, or speaks with limitations even with equipment	0.86			
Blind, deaf, or mute	0.61			
Mobility				
Able to walk, bend, lift, jump, and run normally for age	1.00			All residents assigned to level 5
Walks, bends, lifts, jumps, or runs with some limitations but does not require help	0.97			
Requires mechanical equipment (such as canes or wheelchair) to walk or get around independently	0.84			
Requires the help of another person to walk or get around and requires mechanical equipment as well	0.73			
Unable to control or use arms and legs	0.58			
Cognition				

HUI2 Domains	Utility*	Health Status Mapping
Learns and remembers normally for age	1.00	All residents assigned to level 4
Learns and remembers more slowly than peers	0.95	
Learns and remembers very slowly	0.88	
Unable to learn and remember	0.65	
Self-care		
Eats, bathes, dresses, and uses the toilet normally for age	1.00	All residents assigned to level 4
Eats, bathes, dresses, or uses the toilet independently with difficulty	0.97	
Requires mechanical equipment to eat, bathe, dress, or use the toilet independently	0.91	
Requires the help of another person to eat, bathe, dress, or use the toilet	0.80	
Fertility		
Able to have children with a fertile spouse	1.00	All residents assigned to level 1#
Difficulty in having children with a fertile spouse	0.97	
Unable to have children with a fertile spouse	0.88	

*Torrance et al.¹⁷

[†]Symptom Management at the End-of-Life in Dementia (SM-EOLD) scale was used in all assessment periods where the resident was living at the end of the period.

[‡]Comfort Assessment in Dying with Dementia (CAD-EOLD) scale was used in the after-death assessment, and provided the quality-of-life estimate for the period between the previous assessment and death.

[§]The highest score on any of the emotional items from the SM-EOLD (depression, fear, anxiety, or agitation) and lowest score from the CAD-EOLD items (fear or anxiety) was mapped to the highest HUI2 level.

^{||}The highest score on the pain item from the SM-EOLD and CAD-EOLD was mapped to the highest HUI2 level.

[¶]A sensitivity analysis was conducted assigning all residents to Health Utilities Index level 4 in sensation domain. Overall mean utility scores were reduced by 0.07, but the results of the 3 validity tests were unchanged.

[#]Fertility is not a factor for this population; therefore, quality of life is not reduced due to an inability to have children. A score of 1 is assigned for all residents.

HUI2 indicates Health Utilities Index Mark 2.