

Measuring quality of life in dementia: The case for a mixed perspective

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Introduction

- Who best to rate an Alzheimer's Disease patient's quality of life: Patient or caregiver? The case for a mixed perspective. *Alzheimer's & Dementia*. 2006; 2(3,S1): S579.
- Co-investigators: Art Zbrozek (Wyeth), Bruce Kinosian (PENN), Henry Glick (PENN)
- The data reported in these slides was made possible by a grant from Wyeth Pharmaceuticals and NIA P30-010124
- Disclosures (12 months pre/post March 2008): Jason Karlawish serves on the DSMB for Myriad Pharmaceuticals, site investigator for a Pfizer- NIA ADCS clinical trial, advisory board of Senior Bridge

Background

- Endpoints as a language of benefit
 - The need for a coherent language
drug trial ↔ diagnosis ↔ staging/severity ↔ treatment ↔ policy
researchers ↔ clinicians ↔ patients/families ↔ policy makers
 - Measures of cost effectiveness must be particularly coherent: within & between diseases
 - QALYS from HUI, EQ-5D
- The problem of incoherence of benefit in Alzheimers Disease
 - what to measure & who should measure it

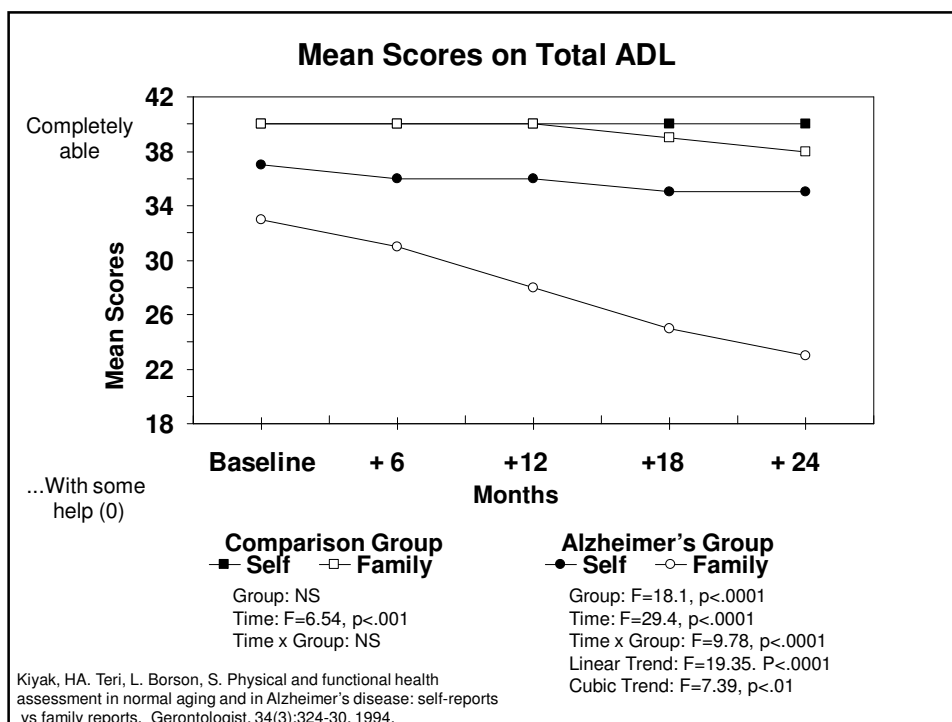
Karlawish. "The search for a coherent language: The science and politics of drug testing and approval." In *Ethics, Law and Aging Review*. New York, NY: Springer Publishing Company 8;2002:39-56.

Comparison of AD patient and CG appreciation.¹

	Patient (n=47)		Caregiver (n=47)	
	Yes	No	Yes	No
Do you have any problems you're your memory or thinking?	25 (53%)	22 (47%)	47 (100%)	0
Will your memory or thinking problems get worse?	16 (34%)	31 (65%)	42(89%)	5 (11%)
Do you have AD or dementia?	25 (53%)	22 (47%)	47 (100%)	0

¹The wording of the questions was changed for CGs. E.g. "Does your relative have problems with memory or thinking?"

Karlawish et al. The ability of persons with Alzheimers Disease to make a decision about taking an AD treatment. *Neurology* 2005;64:1514-19.



	Not depressed (GDS≤5)	Depressed (GDS>5)
QOL rating	n (%) GDS mean ± s.d. (range)	n (%) GDS mean ± s.d. (range)
Poor	0	1 (4%) 7
Fair	9 (6%) 4.2 ± 0.7 (3-5)	11 (39%) 8.5 ± 2.2 (6-13)
Good	51 (34%) 2.1 ± 1.6 (0-5)	12 (43%) 7.5 ± 2.0 (6-12)
Very good	62 (42%) 1.4 ± 1.3 (0-5)	2 (7%) 7.5 ± 2.1 (6-9)
Excellent	27 (18%) 0.7 ± 0.7 (0-2)	2 (7%) 7.0 ± 1.4 (6-8)
Total	149 (100%)	28 (100%)

James. Am J Geriatric Psychiatry. XXXXX

Problems in CEA in AD

- Persons with AD have impairments in awareness of cognitive/functional disabilities
 - Caregiver reports may address this shortcoming
- But why should caregivers report patient experiences of pain, mood, mobility and sensation?

Instruments for CEA

- Health preference measures such as Health Utilities Index (HUI) are essential in assessing overall value of an intervention
- Health Utilities Index Mark II (HUI2)
 - Seven domains
 - Sensation
 - Mobility
 - Emotion
 - Cognition
 - Self-care
 - Pain
 - Fertility (omitted)

HUI2

Sensation

1. Able to see, hear, and speak normally for age.
2. Requires equipment to see or hear or speak.
3. Sees, hears, or speaks with limitations even with equipment.
4. Blind, deaf, or mute

Mobility

1. Able to walk, bend, lift, jump and run normally for age.
2. Walks, bends, lifts jumps or runs with some limitations but does not require help.
3. Requires mechanical equipment (such as canes, crutches, braces, or wheelchair) to walk or get around independently
4. Requires the help of another person to walk or get around and requires mechanical equipment as well.
5. Unable to control or use arms and legs.

Emotion

1. Generally happy and free from worry.
2. Occasionally fretful, angry, irritable, anxious, depressed, or suffering from night terrors
3. Often fretful, angry, irritable, anxious, depressed or suffering from night terrors.
4. Almost always fretful, angry, irritable, anxious, depressed.
5. Extremely fretful, angry, irritable, or depressed usually requiring hospitalization or psychiatric institutional care.

HUI2 continued

Cognition

1. Learns and remembers normally for age.
2. Learns and remembers more slowly than normal for age.
3. Learns and remembers very slowly and usually requires special assistance in learning situations.
4. Unable to learn and remember.

Self-Care

1. Eats, bathes, dresses and uses the toilet normally for age.
2. Eats, bathes, dresses or uses the toilet independently but with difficulty.
3. Requires mechanical equipment to eat, bathe, dress or use the toilet independently.
4. Requires the help of another person to eat, bathe, dress or use the toilet.

Pain

1. Free of pain and discomfort
2. Occasional pain. Discomfort relieved by non-prescription drugs or self-control activity without disruption of normal activities.
3. Frequent pain. Discomfort relieved by oral medicines with occasional disruption of normal activities.
4. Frequent pain. Frequent disruption of normal activities. Discomfort requires prescription narcotics for relief.
5. Severe pain. Pain not relieved by drugs and constantly disrupts normal activities

Purpose

- Derive HUI scores using an algorithm that mixes patient/caregiver reports on the subscales
 - Patient self-rating
 - pain, mood, mobility, sensation.
 - Caregiver rating
 - cognition, usual care
- H: A HUI-mixed perspective (HUI-MP) will have better validity than any one perspective

Methods

- In home interviews
- Persons with very mild to moderate AD
 - MMSE 12 to 30
- Caregiver
 - (1) a decision maker for or w/ PT, (2) at least one time a week contact with the patient, and (3) either assisted the PT w/ADLs, was a knowledgeable informant with HCPs, or both
- Penn ADC, TJU memory clinic, VA geriatrics

Subject characteristics (N=110)

	Patients	Knowledgeable Informant
Male	61 (55%)	32 (29%)
Race		
White	80 (88%)	89 (81%)
Black	21 (19%)	21 (19%)
Asian	1 (1%)	0 (0%)
Age	76.9 ± 7.8 (52-91)	65.5 ± 12.6 (29-91)
Education	14.4 ± 3.7 (5-21)	15.5 ± 2.9 (11-21)
Spousal Relationship	74 (67%)	74 (67%)

Data reporting caregiver and patient assessments of preference-based quality of life are in press at *Alzheimers and Dementia*.

HUI Results: Emotion

Emotion (N=110)	Pt Rating	KI Rating
Generally Happy	80 (73%)	41 (37%)
Occasionally Fretful	28 (25%)	49 (45%)
Often Fretful	2 (2%)	13 (12%)
Almost Always Fretful	0 (0%)	7 (6%)

HUI Results: Cognition

Cognition (N = 110)	Pt Rating	KI Rating
Normal for age	65 (60%)	3 (3%)
More slowly for age	39 (16%)	44 (40%)
Very slowly	4 (4%)	48 (44%)
Unable to learn	1 (1%)	15 (14%)

HUI Results: Care

Care (N = 110)	Pt Rating	KI Rating
Normal for age	103 (94%)	83 (75%)
With difficulty	6 (5%)	24 (22%)
Requires help	0 (0%)	3 (3%)
Requires Equipment	1 (1%)	0 (0%)

Results- Mixed Perspective

Patient Self	KI Direct	Mixed Perspective
0.83±0.15 (0.18–1.00)	0.72±0.18 (0.17–1.00)	0.78±0.16 (0.17–0.97)
N=109	N=110	N=110

Lack of disability?

- 32 (29%) of patients rated themselves without disability (HUI=1.00)
- 1 (1%) of knowledgeable informants rated the patient without disability
- Mixed perspective produced no score of 1.0

Construct Validity of HUI-MP

	HUI-mixed Perspective	Pt Rating	KI Direct Rating
3 MSE	0.23*	0.00	0.15
IADL- pt. self rating	-0.37*	-0.35*	-0.34*
IADL – KI view	-0.40*	-0.15	-0.44*
GDS- pt. self rating	-0.42*	-0.55*	-0.26*
PCS- pt. self rating	0.40*	0.56*	0.32*
PCS- KI view	0.25*	0.24*	0.32*
MCS- pt self rating	0.21*	0.31*	0.02
MCS- KI view	0.35*	0.35*	0.46*

* $p \leq 0.05$

Construct Validity

- Associates well with
 - Criteria measures of AD severity
 - MMSE
 - KI-rated IADLs
 - Patient experience
 - GDS, MCS
 - PCS

Mixed Perspective

- Univariate correlations agree with KI and PT perspectives
 - mixed perspective versus patient $r=0.74$, $p<0.0001$
 - mixed perspective versus patient KI $r=0.76$, $p<0.0001$

Conclusions

- Combining patient ratings (pain, mood, mobility, sensation) with characteristics usually assessed by KIs (cognition and usual care) shows reasonable convergent/divergent validity
 - Only mixed perspective correlates with measures of cognition, function, and mood
- Scores reflect at least some disability
 - But IADL disability is not captured in the HUI
- Message is the method – mixed perspective – more so than the HUI

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