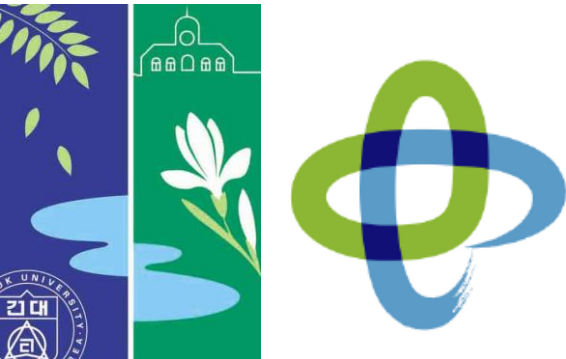


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# 삶의 질 평가도구

## Quality of Life assessment tools for dementia

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# ***Outcome measures for the clinical trials on dementia***

1. Cognitive function (as measured by psychometric tests)
2. Clinical global impression
3. Changes in global disease severity
4. Performance of activities of daily living
5. Behavioral disturbance
6. Quality of life
7. Effect on caregiver
8. Dependency (such as institutionalization)
9. Death
10. Acceptability of treatment as measured by withdrawal from trial
11. Safety as measured by the incidence of adverse effects (including side-effects) leading to withdrawal
12. Direct and indirect costs.

# Measurement of Quality of Life (QOL) in dementia

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- Increased attention to consideration of patient QOL and measuring QOL outcomes in clinical trials in pharmaceutical industry and government agencies
- Efforts to define, quantify, and systematically measure QOL in dementia → development of new measures
- Lawton's model of QOL in dementia: conceptualization of QOL
- Consider conceptualizations, psychometric data, and administration and scoring procedures

*Small et al. 1997, Whitehouse et al. 1997,  
Lawton 1994, 1997, Lawton et al. 1999*

# Lawton's model of QOL

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- Consideration of subjective and objective factors with four dimensions
  - *Psychological well-being (positive and negative affect)*
  - *Behavioral competence (cognitive and functional abilities)*
  - *Objective environment (caretakers and living situation)*
  - *Perceived QOL*
- Authors of dementia QOL scales have used different methods to implement the model

# Considerations for differences between QOL

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- Several critical dimensions that vary between QOL instruments by definitions
  - **Broad range of signs and symptoms: daily life, such as cognitive functioning, performance of ADL, and social and psychological factors**
  - **Much more narrow in focus**
- Type of dementia populations
- Severity of dementia populations

# Considerations for differences between QOL

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- Some confusion about what types of instruments
  - **ADL and depression inventories: classified as QOL measures**
  - **Operational definitions of QOL: clarify the boundaries between QOL measures and other outcome measures (NPI, and cognitive impairment)**
- Awareness of existing instruments and distinctions among measures → select the most appropriate instrument for the purposes

# Generic and health related measures as QOL

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- Not specifically tailored for dementia populations
- Not assess enjoyment of activities, feelings and mood, or response to surroundings
- Assess many symptoms of physical illness unrelated to dementia
- Not sensitive and specific measures of domains of QOL relevant to dementia patients

# Considerations for Respondent

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- Participation of patient in the assessment of QOL.
  - ***Cognitive impairment and lack of awareness***
  - ***Depends on not overall level of cognitive impairment but rather orientation, attention, and language skills***
- Deliberately designed questionnaires to accommodate dementia population
- Loss of insight and awareness factor

*Green et al. 1993, Brod et al. 1999,  
Mozley et al. 1999, Selai et al. 2001*



# Establishing the Validity of QOL Measures

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- The most challenging aspect of scale development
- Measures often used to validate QOL scores
  - **Indicators of disease severity**
  - **Depression and mood measures**
  - **Activities of daily living**
  - **Generic QOL measures**
  - **Combinations of many factors**
- A multimodal approach: the best strategy to establish construct validity of new instruments.

# QOL scales for dementia patient

1. Affect and Activity Indicators of QOL (AAIQOL)
2. Alzheimer Disease Related Quality of Life (ADRQL)
3. Cornell-Brown Scale for Quality of Life (CBS)
4. Dementia Care Mapping (DCM)
5. Dementia Quality of Life (DQoL)
6. Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP)
7. Quality of Life in Late-Stage Dementia (QUALID) Scale
8. Quality of Life-Alzheimer's Disease (QOL-AD)
9. Quality of Life Assessment Schedule (QOLAS)
10. Geriatric Quality of Life-Dementia (GQOL-D)

# Affect and Activity Indicators of QOL (AAIQOL)

- Assessment of patients' activity and affect: observable, quantifiable, behavioral
- Indicators of subjective, internal states of patients
- Strength: use with a broad range of patients, mild to severe stages of dementia, in both institutional and home-care settings
- Drawback: confined to just two dimensions, activity and affect

## ***Affect and Activity Indicators of QOL (AAIQOL)***

- **Fifteen activity items**
  - **From Teri and Logsdon's Pleasant Events Schedule-AD**
  - **Simple to complex, both inside and outside of the home**
  - **Proxies rate the frequency for each activity within a 1-week time frame**
  
- **Six affects items**
  - **From Lawton's Affect Rating scale**
  - **Both positive and negative affect: pleasure, anger, anxiety, depression, interest, and contentment**
  - **Frequency during the past 2 weeks on a 5-point scale, ranging from never to greater than or equal to 3 times per day**

*Teri and Rogsdon 1991, Logsdon and Teri 1997,  
Lawton et al. 1996, Albert 1999*

## ***Affect and Activity Indicators of QOL (AAIQOL)***

- Reliability and validity of AAIQOL
  - Telephone interviews were conducted with caregivers of 130 AD patients
  - One-week test-retest reliability ranged from 0.53 to 0.92 for the affect items (*Mdn* = .77)
  - Above 0.60 for 12 of 15 activity frequency items
  - No systematic differences in QOL reports were found between family and institutional caregivers.

## *Affect and Activity Indicators of QOL (AAIQOL)*

- Activity measures: significant correlation between activity and m-MMSE scores → activity decreased as dementia severity increased
- Affect measures: variable associations with dementia severity
- An overall QOL composite: high activity frequency, high positive affect, and low negative affect as indicative of higher QOL

# Alzheimer Disease Related Quality of Life (ADRQL)

- Scored by AD patients and AD experts
- Five domains with both positive and negative behaviors: social interaction, awareness of self, feelings and mood, enjoyment of activities, response to surroundings
- Mainly observable behaviors and actions, some are subjective and internal states
- Using a preference-based weighting approach
- Rare published data for psychometric characteristics
- Questionable use in both homecare and institutional settings and from mild to severe

# The Cornell-Brown Scale for Quality of Life in Dementia (CBS)

- Global assessment of QOL
- High QOL is indicated
  - **Presence of positive affect, physical and psychological satisfactions, self-esteem**
  - **Relative absence of negative affect and experiences.**
- Mild to moderate stages of dementia severity, still living at home



## *The Cornell-Brown Scale for Quality of Life in Dementia (CBS)*

- Modifying the Cornell scale for Depression in Dementia
- Assessment of positive emotions, experiences, and satisfactions
- Range from -2 (negative pole) to +2 (positive pole)
- Total scores: -38 ~ +38
- More negative the score, poorer the QOL rating
- Strength: incorporates patient and caregiver perspectives into one rating → rated by a clinician
- Semi-structured and the time-frame covers the previous month

## **The Cornell-Brown Scale for Quality of Life in Dementia (CBS)**

- Preliminary reliability and validity studies with 50 dementia patients and informants
  - Adequate inter-rater reliability (intraclass  $r = .90$ ) and internal consistency (Cronbach's alpha = 0.81)
  - Criterion validity: positive correlation between CBS scores and visual analogue positive mood ratings by pts (Spearman  $\rho = 0.63$ )
  - Negatively correlated with CDR ( $\rho = -0.35$ )
  - Reliability and validity findings were similar for the more mildly and more severely impaired halves

# Dementia Care Mapping (DCM)

- Structured, observational assessment of dementia patient experiences by proxy
- Used in residential care settings
- Appropriate for moderate to severely impaired patients
- Score the patient well-being and activities
  - **Well-versus ill-being of patients is rated on a 6-point ordinal scale based on signs from patients and on the behavior of staff towards the patient**
  - **24 activity rating categories and indicators of social withdrawal**

*Beavis et al. 2002, Fossey et al. 2002,  
Brooker et al. 1998*

## *Dementia Care Mapping (DCM)*

- Intensive assessment method: typically requires observers to rate indicators of patients' QOL every five minutes over a 6-hour time frame
- One-hour assessment: significantly correlated ( $p < 0.05$ ) with the full-length assessment for activities ( $r = 0.68$ ) and well-ill being ( $r = 0.50$ )
- Shorter observation may be more practical
- DCM8: 8<sup>th</sup> edition of DCM (2004~2005)

## ***Dementia Care Mapping (DCM)***

- In analyses of data collected from residential and nursing home facilities ( $N = 177$ )
- activity and well-ill being scores were significantly correlated ( $r_s = 0.16 \sim 0.63$ ,  $Mdn = 0.53$ ), indicating internal consistency
- One- to four-week test-retest reliability: good for well-ill being scores ( $r = 0.55$ ) and moderate reliability for activities ( $r = 0.40$ ) and social withdrawal ( $r = 0.43$ )

## *Dementia Care Mapping (DCM)*

- Agreement between DCM scores and quality assurance audit measures of residential nursing care
- Concurrent validity: significant ( $p < 0.001$ ) correlation of well-ill being scores with a pencil and paper, generic measure of QOL for a subset of 19 patients ( $r = 0.73$ )
- Activities did not correlate significantly with the QOL measure ( $r = 0.29$ )
- High face validity by a staff acceptability assessment

# Dementia Quality of Life Instrument (DQoL)

- Iterative conceptual and statistical process: a literature review and consultation with expert panels composed of dementia patients, caregivers, and professional care providers
- 29-item scale, plus one global item
- 5 domains of QOL: Positive Affect (6 items), Negative Affect (11 items), Feelings of Belonging (3 items), Self-esteem (4 items), Sense of Aesthetics (5 items)
- Scores on 5 subscales but not summed

## *Dementia Quality of Life Instrument (DQoL)*

- Relies solely on patient-input
- Item-stems: simple as possible
- 5-point visual scale: multiple choice response choices to patients
- All points on the response scale: associated with verbal descriptors
- Appropriate for use in the mild to moderate stages of dementia



## ***Dementia Quality of Life Instrument (DQoL)***

- Reliability and validity in a sample of 99 patients
  - Internal consistency reliabilities for subscales: moderate to high (0.67~0.89; *Mdn* = 0.80)
  - No significant differences between mild and moderate dementia group in terms of scale reliability
  - Two-week test-retest reliability for a subset of participants ( $n = 18$ ): 0.64~0.90 (*Mdn* = 0.72)
  - Convergent validity: correlations with scores on GDS and 4 DQoL subscales ( $r = -0.48$  self-esteem,  $r = -0.61$  positive affect,  $r = -0.64$  absence of negative affect,  $r = -0.42$  feelings of belonging)
- Approximately 10 minutes to administer

# Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP)

- Related to psychological well-being
- Observer-rated: can be used in greater severity
- 11-item scales: positive and negative affective states and engagement behaviors
- 3 subscales: Frustrated/Agitated, Positive Interaction, and Discontent Expressions
- Mild to moderate stages of severity at home
- Strength: Some longitudinal data are available psychometric properties
- Drawback: relatively narrow measure, focusing only on affect and behavior.

## *Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP)*

- 🍃 Factor analysis on data from 96 caregivers of dementia outpatients
- 🍃 Strong internal consistency reliability for 3 subscales at baseline and 18-month follow-up
- 🍃 Total scale internal reliability: 0.81 at baseline, 0.82 at the follow-up
- 🍃 Validity: significant ( $p < 0.01$ ) correlations between total PWB-CIP scores and measures of depression, personality, social behavior, functional ability, problem solving, and task orientation

# The Quality of Life in Late-Stage Dementia (QUALID) Scale

- Subset of items from Albert et al.'s affect and activity measures
- 🌿 With late-stage dementia in institutional settings
- 🌿 Strength: brevity
- 🌿 Proxy-report instrument: rate 11 observable behaviors (activity and emotional states) over the preceding 7 days
- 🌿 Administered by a technician to nursing home personnel
- 🌿 Rated on a 5-point Likert scale
- 🌿 5 minutes of administration time.

## ***The Quality of Life in Late-Stage Dementia (QUALID) Scale***

- Psychometric properties in 42 residents of a dementia special care unit
  - **Internal consistency reliability: Cronbach's alpha = 0.77, Inter-item correlations were positive and 0.17 to 0.70**
  - **Test-retest reliability: 0.81**
  - **Inter-rater reliability: 0.83**
  - **Validity: correlations between QUALID scores and several other measures of dementia → moderate and significant correlations with depressive symptoms ( $r = 0.36$ ) and neuropsychiatric symptoms ( $r = 0.40$ )**

# Quality of Life-Alzheimer's Disease (QOL-AD)

- Items from various domains of QOL in older adults based on a literature review of QOL
- Face validity and comprehensiveness: from patients, caregivers, non-demented elders, dementia experts review potential items
- 13-items: physical condition, mood, memory, functional abilities, interpersonal relationships, ability to participate in meaningful activities, financial situation, and global assessments of self as a whole and QOL as a whole
- Strengths: brevity and reports from pts, caregivers, or both
- Drawback: somewhat broad because of including memory and functional abilities

# QOL-AD

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**Instructions:** Interviewer administers according to standard instructions. Circle participant responses.

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1. Physical health	Poor	Fair	Good	Excellent
2. Energy	Poor	Fair	Good	Excellent
3. Mood	Poor	Fair	Good	Excellent
4. Living situation	Poor	Fair	Good	Excellent
5. Memory	Poor	Fair	Good	Excellent
6. Family	Poor	Fair	Good	Excellent
7. Marriage	Poor	Fair	Good	Excellent
8. Friends	Poor	Fair	Good	Excellent
9. Self as a whole	Poor	Fair	Good	Excellent
10. Ability to do chores around the house	Poor	Fair	Good	Excellent
11. Ability to do things for fun	Poor	Fair	Good	Excellent
12. Money	Poor	Fair	Good	Excellent
13. Life as a whole	Poor	Fair	Good	Excellent

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Comments:

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## *Quality of Life-Alzheimer's Disease (QOL-AD)*

- Patients are interviewed and caregivers respond to the QOL-AD items on a questionnaire separately
- Response options are 4-point (1 = poor, 4 = excellent), 13 to 52, with higher scores indicating greater QOL
- Composite scores that combine reports from patients and caregivers are weighted to favor patient self-report, multiplied by 2
- Average administration time: 10 minutes to patients, less than 10 minutes to caregivers



## **Quality of Life-Alzheimer's Disease (QOL-AD)**

- Psychometric properties in 77 AD outpatients and caregivers and F/U study with 177 patients
  - **Internal consistency reliability (Cronbach's alpha): 0.84 ~ 0.88 for both**
  - **Patient-caregiver agreement for the total score:  $r = 0.40$ ,  $p < 0.01$  in initial study, lower in second study**
  - **Individual item agreement ranged from 0.04 (ability to do chores) ~ 0.45 (energy) with  $Mdn = 0.24$ .**
  - **Test-retest reliability: 0.76 for patients, 0.92 for caregivers**
  - **Moderate levels of cognitive impairment: not affect internal consistency reliability and patient-caregiver agreement**

## ***Quality of Life-Alzheimer's Disease (QOL-AD)***

- **Psychometric properties – continued**
  - **Validity from first study: low to moderate correlations between QOL scores and the MMSE and reports of instrumental ADL, depression, and engagement in pleasant events**
  - **Validity from second study: correlations between QOL-AD scores and several measures of domains (behavioral competence, psychological status, physical function, and interpersonal environment) and stronger associations between caregiver-reported QOL and measures of these other domains**

# Korean version of QOL-AD

## -어르신 본인용-

검사자는(첨부된) 지침에 따라 질문을 하고, 어르신의 응답에 따라 합당한 곳에 표시 (O) 합니다.

1. 신체 건강	나쁘다	그저그렇다	좋다	매우좋다
2. 원기 / 기운	나쁘다	그저그렇다	좋다	매우좋다
3. 기분	나쁘다	그저그렇다	좋다	매우좋다
4. 생활 환경	나쁘다	그저그렇다	좋다	매우좋다
5. 기억력	나쁘다	그저그렇다	좋다	매우좋다
6. 가족 관계	나쁘다	그저그렇다	좋다	매우좋다
7. 결혼 생활	나쁘다	그저그렇다	좋다	매우좋다
8. 친구 관계	나쁘다	그저그렇다	좋다	매우좋다
9. 전체적인 자기 자신	나쁘다	그저그렇다	좋다	매우좋다
10. 일상적인 집안일을 처리하는 능력	나쁘다	그저그렇다	좋다	매우좋다
11. 재미 삼아 무슨 일을 할 수 있는 능력	나쁘다	그저그렇다	좋다	매우좋다
12. 금전 상태	나쁘다	그저그렇다	좋다	매우좋다
13. 전체적인 생활	나쁘다	그저그렇다	좋다	매우좋다

: 보호자용 설문도 동일

# Quality of Life Assessment Schedule (QOLAS)

- 5 domains: Physical, Psychological, Social/family, Usual activities, Cognitive functioning
- Patients choose two issues from each 5 domains → rate for 10 issues on a 6-point scale (0 = no problem; 5 = worst), 0 to 50 with higher scores reflecting poorer QOL
- Strength: only dementia QOL tools tailored to individual patients and both qualitative and quantitative measurement approaches
- 🌿 Drawback: psychometric properties from data in a small sample of patients

## **Quality of Life Assessment Schedule (QOLAS)**

- Psychometric properties from 22 dementia patient-carer dyads
  - **Internal consistency reliability: coefficient alpha 0.78 for patients and caregivers**
  - **Construct validity: significantly ( $p < 0.05$ ) higher patient reported QOL for a subgroup of patients with less disability in ADLs**
  - **Agreement between patient-reported QOL and generic measure of QOL ranged from poor to good (kappa = 0.09~0.67, *Mdn* = 0.45), for caregiver from poor to very good (kappa = 0.09~0.82, *Mdn* = 0.47)**

# Geriatric Quality of Life-Dementia (GQOL-D)

- WHOQOL의 하부척도를 문항 개념 및 내용을 근간
- 52개의 item pool로부터 최소한의 문항으로 '치매 노인용 삶의 질 척도'를 구성
- 임상가가 측정, 5-7분 소요
- 15 Items: 13문항 (신체적 건강, 심리적 건강, 사회적 관계, 환경 등), 2문항 (전반적인 건강 및 삶의 만족도를 측정하는 문항 등)
- 4점 척도('1=만족하지 않는다, 2=보통이다, 3=만족한다, 4=아주 만족한다'), 총점: 15-60점

## Geriatric Quality of Life-Dementia (GQOL-D)

### ■ Psychometric properties

- Internal consistency: Cronbach's  $\alpha=0.87$
- Test-retest reliability: 0.86, ‘쓸 수 있는 돈이나 재정 상태’ , ‘긍정적인 감정’ , ‘거동 능력’ , ‘일상 활동’ 등의 문항에서 높은 검사-재검사 상관관계
- 척도 내 ‘전반적인 생활’ 문항과 총점의 상관:  $r=0.69$  ( $p < .001$ )
- ‘전반적인 생활’ 문항과 모든 문항의 상관:  $r=0.28$  (수면),  $r=0.51$  (전반적인 건강),  $p < 0.001$
- 요인 분석: 2개의 구성 요인을 채택 → 첫 번째 요인(주로 환경과 관련된 문항), 두 번째 요인(신체적 건강 및 기억력과 관련된 문항이 대부분)

## **Characteristics of dementia quality of life scales - 1**

<b>Tools</b>	<b>Pts</b>	<b>Proxy</b>	<b>Data</b>	<b>Population</b>	<b>Subscales</b>	<b>Standard vs. Individualized</b>	<b>Items</b>
<b>AAIQOL</b>	No	Yes	Yes <i>N</i> = 130	Mild to severe Institutional home-care settings	Positive Affect Negative Affect Activity	Standard	21
<b>ADRQL</b>	No	Yes	No	Not specified	Social Interaction Awareness of Self Feelings & Mood Enjoyment of Activities Response to Surroundings	Standard	48
<b>CBS</b>	Yes	Yes	Yes <i>N</i> = 50	Mild-moderate Home-care setting	None	Standard	19
<b>DCM</b>	No	Yes	Yes <i>N</i> = 19-177	Moderate-severe Institutional-care setting	Well-ill Being Social Withdrawal Activity	Standard	NS
<b>DQoL</b>	Yes	No	Yes <i>N</i> = 99	Mild to moderate Home-care setting	Self-esteem Positive Affect Negative Affect Aesthetics Feelings of Belonging	Standard	30



## **Characteristics of dementia quality of life scales - 2**

<b>Toolse</b>	<b>Pts</b>	<b>Proxy</b>	<b>Data</b>	<b>Population</b>	<b>Subscales</b>	<b>Standard vs. Individualized</b>	<b>Items</b>
<b>PWB-CIP</b>	No	Yes	Yes N = 96	Mild-moderate Home-care setting	Positive Interaction Frustrated/agitated Discontent	Standard	11
<b>QUALID</b>	No	Yes	Yes N = 42	Severe dementia, Institutional setting	None	Standard	11
<b>QOL-AD</b>	Yes	Yes	Yes N = 177	Mild-severe Home-care setting	None	Standard	13
<b>QOLAS</b>	Yes	Yes	Yes N = 22	Mild-moderate Home-care setting	Physical Psychological Social/family Usual Activities Cognitive	Both	10
<b>GQOL-D</b>	Yes	No	Yes N=42	Not specified	None	Standard	15

## ***Studies from dementia Quality of Life scales***

<b>Instruments</b>	<b>Related studies</b>
<b>AAIQOL</b>	Rare published data for dementia patients
<b>ADRQL</b>	Several studies including change of QOL over time
<b>CBS</b>	Rare published data for dementia patients
<b>DCM</b>	Many studies for change over time to evaluating treatment response, psychometric properties, some comprehensive reviews, and translated to other languages
<b>DQoL</b>	Several studies including change over time after specific treatment
<b>PWB-CIP</b>	Some longitudinal data for psychometric properties in dementia patients
<b>QUALID</b>	Several studies including change over time to evaluating antipsychotics treatment response, psychometric properties, and translated to other languages
<b>QOL-AD</b>	Many studies for change over time to evaluating specific treatment response, psychometric properties, some comprehensive reviews, perceptual view, and translated to other languages
<b>QOLAS</b>	Rare published data for dementia patients
<b>GQOL-D</b>	Rare published data for dementia patients

# Future directions and conclusions

- Advances in recent years to conceptualize, define, and systematically measure QOL in dementia
- Many applicable instruments with psychometric data
- Future research on QOL in dementia
  - **Change over time for evaluating response to treatment and determining the effects of disease progression on QOL**
  - **Identify factors that affect reports of QOL: patients and caregiver factors**
  - **Determine the effect of QOL perceptions on decisions regarding the care of dementia patients**
  - **Develop interventions to increase patient QOL**