



# Measuring resource use: RUD Lite and other instruments

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# Conflicts of interest Anders Wimo

- Drug companies: Lundbeck, Pfizer, Merz, Forest, Novartis, Janssen-Cilag, Astra-Zeneca, Sanofi, Neurochem, Wyeth, Lilly
- Authorities and similar: National board of health and welfare, Social Ministry, Medical Products Agency, Swedish Council on Health Technology Assessment (SBU), Swedish Reimbursement Authority (LFN), Local drug committees, municipalities, county councils, OECD, EU
- Patient/caregiver organisations: Swedish Alzheimer Association, Alzheimer Europe, Alzheimer Association (USA)

# COI studies

| Country | Medical care | Formal non medical care | Informal care | Source (+ et al)      |
|---------|--------------|-------------------------|---------------|-----------------------|
| Belgium | 56%          | 36%                     | 8%            | Scuvee-Moreau         |
| Spain   | 10%          | 12%                     | <b>77%</b>    | Boada                 |
| UK      | 8%           | 56%                     | 36%           | Alzheimer Society     |
| USA     | <b>61%</b>   | 14%                     | 25%           | Alzheimer Association |
| Sweden  | 5%           | <b>85%</b>              | 10%           | Wimo                  |

# COMPREHENSIVE RU- battery

Aim: RU data to calculate costs from a societal perspective in phase III and phase IV (?) trials

- Direct medical cost
- Direct non medical cost
- Indirects costs (production losses of patients)

# CRUCIAL: COLLECTING DATA OF RU

## Informal care

- Interviews, diaries, observations/clock (computerized time measurement)
- Time: last 24h-last week, typical day

BADL: day (week)

IADL: week-month

Supervision: various

## Formal care

- Interviews, medical records, registers (computerized time measurement)

# Resource utilization instruments in Dementia trials

Instruments

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|                           |                                     |
|---------------------------|-------------------------------------|
| Donepezil (Wimo et al )   | RUD                                 |
| Donepezil (Feldman et al) | CAUST + informal care:<br>BADL+IADL |
| Donepezil (AD2000)        | CATS, CAS                           |
| Memantine (Wimo et al)    | RUD                                 |

# Caregiver Activities Time Survey (CATS) (Clipp & Moore, 1995)

## UNPAID CARE

- Estimates of typical day (hours, minutes/day)
- Some basic ADLs: feeding, toileting, bathing, dressing
- Some IADLs: administering medications, housekeeping, transportation
- Supervision and other activities

## PAID CARE

- Visiting nurse, home health aide, attendant, housekeeper, meals on wheels, day care, transportation

# The Caregiver Activity Survey (CAS) (Davis et al, 1997)

## UNPAID CARE

- Estimates of last 24 hours(hours, minutes/day)
- Six items
- Communication
- Some basic ADLs: transportation, dressing, feeding, grooming/appearance
- Supervision
  
- Validated vs ADAS Cog, MMSE, PSMS. Reliability

# Canadian Utilization of Services Tracking questionnaire (CAUST)

## PATIENT

- Community medical care: (in home nursing, ambulatory physician services, physiotherapy, occupational therapy, podiatry, chiropractic services, day hospital)
- Hospitalizations,
- Community care (home help, meal delivery, day center) residential care (respite stay, nursing home placement)

## CAREGIVER

- Hospital care
- Physician visits
- Medications
- Counseling

# AD 2000

- Informal care: CATS, shift to CAS
- Formal care: parts of CATS? Visiting nurse, social worker, domestic help, meals on wheels, day care, day hospital, family doctor, hospital doctor, hospital care, nursing home, residential home
- Time frame: 2 weeks to 12 weeks
- Censored at institutionalization

# Purpose of the Resource Utilization in Dementia (RUD) Instrument

- To assess resource utilization of demented patients and caregivers, aiming at calculating costs from a societal perspective
- To be useful in different countries/multinational trials

# RUD consists of the following parts

## PATIENT

Accommodation/long term care  
Respite care  
Hospital care  
Out care visits\*  
Social service  
Home nursing care  
Day care\*  
Drug use\*  
Work status

## CAREGIVER

Caregiver time (for patient)  
Work status  
Hospital care\*  
Out care visits\*  
Social service\*  
Home nursing care\*  
Day care\*  
Drug use\*

\*excluded in RUD Lite

## RUD - CRF is available in > 60 languages

- Afrikaans
- Arabic (Israel)
- Bulgarian
- Chinese (Hong Kong)
- Chinese (Malaysia)
- Chinese (Singapore)
- Chinese (Taiwan)
- Croatian
- Czech
- Danish
- Dutch (Belgium)
- Dutch (The Netherlands)
- English (Australia)
- English (Canada)
- English (Israel)
- English (Malaysia)
- English (New Zealand)
- English (Philippines)
- English (Singapore)
- English (South Africa)
- English (UK)
- Estonian
- Finnish
- French (Belgium)
- French (Canada)
- French (France)
- German (Austria)
- German (Germany)
- German (Switzerland)
- Greek
- Hebrew
- Hungarian
- Hindi (India)
- Italian
- Japanese
- Kannada (India)
- Korean
- Malay
- Malayalam (India)
- Mandarin Chinese (China)
- Marathi (India)
- Norwegian
- Polish
- Portuguese (Brazil)
- Portuguese (Portugal)
- Romanian
- Russian (Israel)
- Russian (Russia)
- Russian (Ukraine)
- Russian (Estonian)
- Slovak
- Slovenian
- Spanish (Argentina)
- Spanish (Chile)
- Spanish (Mexico)
- Spanish (Peru)
- Spanish (Spain)
- Spanish (USA)
- Swedish
- Tamil (Malaysia)
- Tagalog (Philippines)
- Turkish
- Urdu (Pakistan)

# ACCOMODATION/LONG TERM CARE

- Own home
- Intermediate not dementia specific living  
(e.g. home for the aged, old peoples home, service houses)
- Dementia-specific residential accomodation  
(e.g. group homes, group living, group dwellings)
- Long-term institutional care

# CAREGIVER TIME

ADL (PADL, BADL): Eating, dressing, hygiene etc

IADL: Shopping, economy, transportation, food preparation etc

SUPERVISION/SURVEILLANCE: to prevent potential dangerous events (fire, traffic accidents, out in the cold etc)

# VALIDATION APPROACHES

- Language
- Care concepts.
- Caregiver time assessments: is 1 h 36 min really 1 h 36 min?
- Reliability
- Utilization of formal care resources

# Informal Care in Sweden

Wimo A, Nordberg G, Jansson W, Grafstrom M. Assessment of informal services to demented people with the RUD instrument. Int J Geriatr Psychiatry. 2000 Oct;15(10):969-971

|                 | Minutes/<br>day | % of all<br>time | % of active<br>time |
|-----------------|-----------------|------------------|---------------------|
| ADL             | 152             | 11               | 16                  |
| IADL            | 288             | 20               | 30                  |
| Supervision     | 495             | 34               | 52                  |
| Others          | 10              | 1                | 2                   |
| All active time | <b>945</b>      | <b>66</b>        | <b>100</b>          |
| Nothing         | 495             | 34               |                     |
| <b>ALL</b>      | <b>1440</b>     | <b>100</b>       |                     |

# Correlation between observed (clock) and estimated time

|             | Staff in institution | Spouse at home |
|-------------|----------------------|----------------|
| ADL         | 0.81                 | 0.81           |
| IADL        | 0.29                 | 0.68           |
| Supervision | 0.51                 | 0.67           |
| All         | 0.56                 | 0.69           |

# Correlation between diaries and estimated time (spouses at home)

|             | Correlation | Intraclass correlation |
|-------------|-------------|------------------------|
| ADL         | 0.87        | 0.93                   |
| IADL        | 0.60        | 0.75                   |
| Supervision | 0.77        | 0.87                   |
| All         | 0.84        | 0.91                   |

# Instrumental ADLs (spouses)

|                                  | Minutes per 24<br>hours (SD) | Per cent |
|----------------------------------|------------------------------|----------|
| IADL as support only for patient | 46                           | 15       |
| IADL as joint production         | 266                          | 85       |
| Total                            | 312                          | 100      |

# Measuring resource utilization and costs from an international perspective

Studies: single national claiming to be generalizable to other countries, or multi-national.

## Issues

- Perspective (informal care included?)
- Method for collecting data on resource utilization and costs in each country
- Aggregating data: resource use, costing on a country level
- Care systems comparable (organizing and financing care)?
- Care culture?



SWEDISH  
**brain**  
**POWER**



Game over!  
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# CONCLUSION

RUD is a valid and reliable instrument for the assessment of resource use of demented persons.

# Worldwide perspective

- Insufficient country specific care organisation data
- Different organisation and financing of care
- Formal vs informal care is complicated
- Patterns of informal care are cultural and country dependent

# RUD publications (1)

1. Wimo A, Wetterholm AL, Mastey V, Winblad B. Evaluation of the resource utilization and caregiver time in Anti-dementia drug trials - a quantitative battery. in: Wimo A, Karlsson G, Jönsson B, Winblad B (eds) . The Health Economics of dementia, 1998. Wiley's, London, UK
2. Wimo A, Nordberg G, Jansson W, Grafstrom M. Assessment of informal services to demented people with the RUD instrument. Int J Geriatr Psychiatry. 2000 Oct;15(10):969-971
3. Wimo A von Strauss E, Nordberg G, Sassi F, Johansson L. Time spent in informal and formal care giving for persons with dementia in Sweden. Health Policy 2002 Sep;61(3):255-68
4. Wimo A, Winblad B, Engedal K et al. An Economic Evaluation of Donepezil in Mild to Moderate Alzheimer's Disease: Results of a One-year, Double-blind, Randomized Trial. Dement Geriatr Cogn Disord. 2003;15(1):44-54.
5. Wimo A, Winblad B et al . Resource Utilization and Cost Analysis of Memantine in Patients with Moderate to Severe Alzheimer's Disease. Pharmacoeconomics (in press)
6. Wimo A, Winblad B. Resource utilisation in dementia: RUD Lite. Brain and Aging 2003;3:48-59.
7. Wimo A, Winblad B, Shah SN, Chin W, Zhang R, McRae T. Impact of donepezil treatment for Alzheimer's disease on caregiver time. Current Medical Research and Opinion 2004;20:1221-1225.

# RUD publications (2)

8. Wimo A, Nordberg G. Validity of assessments of time – comparisons of direct observations and estimates of time by the use of the RUD (Resource Utilization in Dementia) – instrument Arch Gerontol Geriatr 2007;44(1):71-81.
  
9. Nordberg G, von Strauss E, Kåreholt I, Johansson L, Wimo A. The amount of informal and formal care among non demented and demented elderly persons. Results from a Swedish population based study. Int J Geriatr Psychiatry 2005;20:862-71.
  
10. Jönsson L, Jönhagen M, Killander L, Soininen H, Hallikainen M, Waldemar G, Nygaard H, Andreasen N, Winblad B, Wimo A. Determinants of costs of care for patients with Alzheimer's disease. Int J Geriatr Psychiatry 2006;21:449-59.
  
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# Intra-rater reliability of RUD (2)

|                            | Cronbach's alpha | Intraclass correlation (ICC) | 95% CI for ICC |
|----------------------------|------------------|------------------------------|----------------|
| Hospitalized               | 0.95             | 0.91                         | 0.82-0.96      |
| Number of hospitalizations | 0.99             | 0.98                         | 0.95-0.99      |
| Hospital days              | 0.98             | 0.97                         | 0.95-0.99      |
| Family physician visits    | 0.96             | 0.91                         | 0.82-0.96      |
| District nurse visits      | 0.86             | 0.75                         | 0.51-0.88      |
| District nurse: hours      | 0.95             | 0.91                         | 0.79-0.96      |
| Home help: visits          | 0.99             | 0.99                         | 0.99-0.99      |
| Home help: hours           | 0.80             | 0.68                         | 0.39-0.85      |
| Meals on wheels: visits    | 1.0              | 1.0                          | -              |
| Day care: visits           | 0.98             | 0.97                         | 0.94-0.99      |
| Travel services: frequency | 0.95             | 0.90                         | 0.79-0.95      |
| Pedicure: visits           | 0.98             | 0.95                         | 0.89-0.98      |
| Pedicure: hours            | 0.87             | 0.78                         | 0.55-0.89      |

# Intra-rater reliability of RUD

|                    | Cronbach's alpha | Intraclass correlation (ICC) | 95% CI for ICC |
|--------------------|------------------|------------------------------|----------------|
| PADL: days         | 0.98             | 0.97                         | 0.93-0.99      |
| PADL: hours        | 0.97             | 0.94                         | 0.87-0.97      |
| IADL: days         | 0.97             | 0.97                         | 0.94-0.99      |
| IADL: hours        | 0.97             | 0.93                         | 0.86-0.97      |
| Supervision: days  | 0.91             | 0.84                         | 0.67-0.93      |
| Supervision: hours | 0.98             | 0.96                         | 0.91-0.98      |

# Utilization of formal care resources vs register data

|                            | Cronbach's alpha | correlation |
|----------------------------|------------------|-------------|
| Hospitalized               | 0.95             | 0.91        |
| Number of hospitalizations | 0.97             | 0.96        |
| Hospital days              | 0.99             | 0.99        |
| District nurse visits      | 0.89             | 0.86        |

# Major cost drivers ?

- Long term/institutional care
- Informal care
  
- Hospital care
- Home help/social services

# Resource utilization/cost profiles

|                        | Institutional care | Informal care | Hospital care | Social services |
|------------------------|--------------------|---------------|---------------|-----------------|
| COI studies (MDR) RCTs | +++                | +++           | +             | +               |
|                        | ++                 | +++           | ++            | ++              |

# COI: Turkey (Zencir et al)

|                  | Mild | Moderate | Severe |
|------------------|------|----------|--------|
| Drug costs       | 90%  | 60%      | 48%    |
| Physician visits | 2%   | 2%       | 2%     |
| Informal care    | 8%   | 38%      | 50%    |

# COI: Argentina

Drug costs : 27-56% of direct costs

# Conclusion

- Comprehensive instruments necessary
- Informal care should be included
- Drug costs in developing countries!