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Introduction

This project is based on a three-year program that aims to improve the knowledge of the socioeconomic consequences of dementia in Norway. The project was initiated by the Norwegian Health Directorate, which also provides funding for the data collection. This project was developed applying a collaborative approach including the following research partners:

Centre for Old Age Psychiatry Research, Innlandet Hospital Trust (leader of the project), Dept. of Health Management and Health Economics, University of Oslo, Helse Sør-Øst Health Services Research Centre, Akershus University Hospital and The Regional Centre for Elderly Medicine and Cooperation (SESAM), Stavanger University Hospital.

Rationale

The knowledge of the cost of dementia in Norway is limited. Only one study on the cost of dementia has included a Norwegian sub-sample as part of a Nordic sample. Inferences from other European countries are limited by differences in the organization of the care systems. A recent review of European studies concluded that there was a large variation in total cost estimates due to differences in study methodology, setting, type and severity of the patients included, the range of costs assessed and the choice of principle for valuing informal care (Jonsson & Wimo 2009). Furthermore, few studies have assessed the aspects of disease severity other than cognitive function. This is a major limitation because a number of studies have highlighted the important contribution of neuropsychiatric symptoms and the level of functioning to caregiver stress, institutionalization and total care costs (Herrmann et al. 2006; Murman et al. 2002). In order to make informed decisions regarding the planning of the care system for people with dementia and to predict the cost-benefit of interventions, robust studies applying validated instruments are needed. The costs of both formal and informal care should be included in the analysis. Patient-level data that includes valid measures of possible predictors of care costs should be collected. The symptom domains that need to be assessed are: cognitive symptoms, neuropsychiatric symptoms, and level of functioning. Previous publications have recommended stratifying the sampling of study subjects so that an adequate sample size is attained within each care setting (Jonsson & Wimo 2009).

Methods

Planning the study

This program is to be completed within three years, while the duration of dementia may be considerably longer. To collect information regarding all stages of dementia we suggested

establishing samples at three levels of dementia and from three different care settings—people visiting a memory clinic, people receiving in-home care, and people being admitted to a nursing home. In addition, we would include a sample of old people without dementia as a control sample. It was a prerequisite for the program to base the estimates on longitudinal data covering a minimum time-span of two years in each sample. To attain this goal we had to identify ongoing projects in which baseline assessments already had taken place. This was possible because we already conducted a study including a representative sample of people 70 years of age or older receiving in-home care. Furthermore, we could contact people included in the Norwegian Dementia Registry to include them in follow-up assessments. Both these studies included baseline measures relevant to the present project. The two last samples will be established during the project period.

Study design

The study includes participants in four samples:

1. People visiting a memory clinic at Ullevål University Hospital, St Olav Hospital or Innlandet Hospital Trust (n=400). The patients will be assessed three times over a three-year follow-up. Baseline inclusion started in January 2010. The final assessments will take place in spring 2014.
2. People 70 years of age or older receiving in-home care recruited from municipalities in Hedmark, Oppland, Oslo, Østfold and Buskerud (n=995). The patients will be assessed three times over a three-year follow-up period. Baseline inclusion started in April 2009 and the final assessments will take place in December 2013.
3. People admitted to a nursing home recruited from municipalities in Hedmark, Oppland, Nord-Trøndelag and Bergen (n=1000). Baseline assessments take place when the person is admitted to the nursing home. The patients will be assessed every six months over a three-year follow-up period. The first participant was included in March 2012, and baseline inclusion will be completed in December 2013.
4. People without dementia recruited from Nord-Trøndelag, Drammen and Oslo (n=400). The participants will be assessed three times over a three-year follow-up period. Baseline inclusion will take place in autumn 2012 and the last follow-up will take place in autumn 2015.

Inclusion and exclusion criteria

Table 1. Inclusion and exclusion criteria in REDIC

	Inclusion criteria	Exclusion criteria
Memory clinic sample	All patients examined at a memory clinic with mild cognitive impairment or mild dementia	
In-home care sample	Persons 70 years of age or older receiving in-home care from the municipality	
Nursing-home sample	All persons admitted to the nursing home with an expected stay of more than four weeks. Participants should be 65 years or older, unless established dementia disease, in which case younger persons also will be included	Life expectancy of less than six weeks
Control sample	Persons 65 years or older without any sign of dementia	

Assessors

Memory clinic sample: Data are collected by clinical staff (physicians, nurses, occupational therapists) following a standardized protocol. All assessors have wide experience from clinical work with people who have cognitive impairment.

In-home care sample: Data are collected by health workers in the municipality. All assessors participate in a two-day training program prior to the baseline assessment, the first follow-up and a six-hour training program prior to the second follow-up assessment.

Nursing-home sample: Data are collected by health workers in the nursing home in collaboration with project nurses from the study partners. The project nurses completed a five-day training program and the health workers in the nursing homes participated in a three-day training program prior to the first assessments.

Sample of older people (> 65 years) without dementia: Data are collected by project assistants with experience from working in the health care system. All assessors participate in a one-day training program prior to the first assessment.

Assessment instruments

Similar assessment instruments will be used in all of the samples. The choice of instruments is adapted to the level of cognitive impairment in each sample.

The following domains will be assessed: cognitive function, level of dementia, depression, neuropsychiatric symptoms, level of functioning, quality of life (QoL), somatic health, medication and caregiver burden.

At each assessment regular medication will be recorded with ATC-codes and defined daily doses (DDD) (WHO Collaborating Centre for Drug Statistics Methodology 2007). In addition, in the nursing home sample all changes in the use of psychotropic drugs and pain medication will be recorded throughout the follow-up period.

Tables 2 and 3 give an overview of the assessment instruments.

Table 2. Assessment instruments at baseline

	Memory clinic	In-home care	Nursing home	Control group
Resource use				
RUD		X ¹	X	X
Quality of life				
QoL-AD		X	X	
QUALID			X	
EQ-5D			X	X
15D			X	X
Neuropsychiatric symptoms				
NPI	X ²	X	X	X
CSDD	X	X	X	
MADRS	X			X
CAM			X	
Diagnoses				
Depression ICD-10				
Depression DSM-IV				
Type of dementia according to an algorithm			X	
Type of dementia – examination by specialist	X			
Cognition				
MMSE	X	X	X	X
SIB-8			X	
IQ-code	X	X	X	X
CDR	X	X	X	X
Ten-word test	X			X
Clock drawing test	X	X		X
Trail-Making A and B	X			X
COWA – verbal fluency	X			
Level of functioning				
I-ADL	X	X		X
PSMS	X	X	X	
Physical measures				
Blood pressure and pulse	X		X	X
BMI			X	X
SPPB			X	
Miscellaneous				
Drug use (regular prescription)	X	X	X	X
GMHR		X	X	X
Charlson's co-morbidity index			X	X
MOBID-2			X	
UPDRS-6			X	
RSS – caregiver stress	X		X	

¹Performed in 300 of the baseline sample.

² NPI-Q

Table 3. Assessment instruments at follow-up

	Memory clinic	In-home care	Nursing home	Control group
Resource use				
RUD	X	X	X ³	X
Quality of life				
QoL-AD	X	X	X	
QUALID			X	
EQ-5D	X	X ¹	X	X
15D	X		X	X
Neuropsychiatric symptoms				
NPI	X ²	X	X	X
CSDD	X	X	X	
MADRS	X			X
CAM			X	
Cognition				
MMSE	X	X	X	X
SIB-8			X	
Ten-word test	X			X
Clock-drawing test	X			X
Trail-Making A and B	X			X
COWA – verbal fluency				
CDR	X	X	X	X
Level of functioning				
I-ADL	X	X		X
PSMS	X	X	X	
Physical measures				
Blood pressure and pulse	X		X	X
Body Mass Index			X	X
SPPB			X	
Miscellaneous				
Drug use (regular prescription)	X	X	X	X
GMHR	X	X	X	X
MOBID-2			X	
UPDRS-6			X	
SPPB	X		X	

¹ Performed in 300 out of 1000, ²NPI-Q, ³RUD-FOCA or similar adapted to nursing homes.

A short description of the assessment scales

Resource Utilization in Dementia (RUD) (Wimo et al. 2009)

- Measures formal and informal care in dementia
- Interview with the patient and the closest family carer

Resource Utilization in Dementia – Formal Care (RUD-FOCA) (Luttenberger & Graessel 2010)

- Measures direct care time required in nursing homes in three areas: activities of daily living, instrumental activities of daily living and supervision
- Interview with nursing home staff

Quality of Life in Alzheimer's Disease (QoL-AD) (Logsdon et al. 2002)

- Measures disease-specific QoL
- Interview with the patient and the closest care provider

Quality of Life in Late-Stage Dementia (QUALID) (Weiner et al. 2000)

- Measures QoL (psychological well-being) in severe dementia
- Interview with the closest care provider

EQ-5D (Euro-QoL group 1990)

- Measures health-related QoL
- Filled in by the patient (or the closest care provider in patients with severe dementia)
- Includes a VAS-scale

15-D (Sintonen 2001)

- Measures health-related QoL
- Filled in by the patient

Neuropsychiatric Inventory (NPI) (Cummings 1997)

- Measures 12 types of neuropsychiatric symptoms
- Frequency, intensity and occupational disruptiveness
- Interview with the closest care provider
- The NPI-Questionnaire (NPI-Q) is a brief clinical form of the NPI (Kaufer et al. 2000).

Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al. 1988)

- Measures depression in persons with dementia
- Interview with the closest care provider

Confusion Assessment Method (CAM) (Inouye et al. 1990)

- Assesses the occurrence of delirium
- Appraisal by the closest care provider

Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh 1975)

- Screening test for cognitive impairment
- Interview with the patient

Severe Impairment Battery, eight-question version (Schmitt et al. 2009)

- Test for cognitive impairment in severe dementia
- May differentiate when MMSE has reached a "floor effect"

Informant Questionnaire of Cognitive Decline in the Elderly (IQ-CODE) (Jorm & Jacomb 1989)

- Interview with a family proxy
- Measures change over the past 10 years on 16 areas of cognition and function

Clinical Dementia Rating Scale (CDR) (Hughes et al. 1982)

- All available information may be used
- Assessment of level of dementia in six areas (cognition and ADL)
- Five levels - from "no dementia" to "severe dementia"
- A total score is calculated based on an algorithm giving priority to memory

General Medical Health Rating (GMHR) (Lyketsos et al. 1997)

- Four-category scale (excellent, good, fair, poor) with a score based on an overall assessment by the caregiver

Short Physical Performance Battery (SPPB) (Guralnik et al. 1994)

- Measures chair stand, balance and walking

Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID) (Husebo et al. 2007)

- The scale is caregiver-rated and includes 10 items in which pain is assessed on a scale from 0 to 10 based on movement and localization
- There is another item assessing overall pain (0 to 10)

Unified Parkinson's Disease Rating Scale, six-item version (UPDRS-6) (Ballard et al. 1997)

- Assessment of extrapyramidal symptoms by a health-worker. Shortened version of the UPDRS.

Relative's Stress Scale (RSS) (Greene et al. 1982)

- A scale consisting of 15 items measuring caregiver burden, with five alternatives from "never" to "always/very often"
- Interview with the closest family caregiver

Lawton's scales for assessment of functioning (Lawton & Brody 1969)

- Performed as an interview with the caregiver
- Physical Self-Maintenance Scale (PSMS)
 - o Basal ADL
 - o Six items
- Instrumental ADL scale (IADL)
 - o Eight items

Charlson co-morbidity index (Charlson et al. 1987)

- Assessment of co-morbid conditions with a possibility of weighing

Various neuropsychological tests

- The Ten-Word test, the Clock-Drawing test, the Trail-Making tests A and B and the Verbal Fluency test assess delayed recall, attention, executive function and verbal fluency. These tests are included in the standard assessment of people admitted to a Norwegian memory clinic.

Organisational variables

Data from Kommunal Stat Rapportering (KOSTRA) will be used to characterize the care system in the municipalities included in the project. The following data will be collected from the nursing homes included in the study:

Table 4. Organizational variables in nursing homes

Part 1: Nursing home: Places, staffing and financing (to be filled in once)
1. Number of full-time places at the nursing home?
2. How many of these are long-term care?
3. Number of units?
4. Number of single rooms?
5. Number of double rooms?
6. Number of places in a secure unit?
7. Number of places in a unit with enhanced staffing (if this is not congruent with the secure unit)?
8. Is there an assisted living community attached to the nursing home?
9. If yes in question 8 – how many places?
10. Are there apartments for adjusted housing attached to the nursing home?
11. If yes in question 10 – how many apartments?
12. Is there a day care centre attached to the nursing home?
13. If yes in question 12 – how many places?
Staffing
14. Full-time equivalent (FTE) of nurses
15. FTE of other health workers
16. FTE of untrained personnel
17. Number of employees with an engagement less than 30 %
18. Sick leave rate during the last accounting year in percent
19. FTE of occupational therapist/ physiotherapist
20. FTE of physician
21. FTE of administrative positions (management, secretary, etc.)
Financing (last year)
22. Labour costs health workers and administrative positions
23. Labour costs physician
24. Sq. meter area at disposal
25. Costs for food
26. Costs for medications
27. Costs for medical care products
28. Costs for laundry services
29. Service costs (cleaning, janitor, energy, other)
Comments
Part 2: Unit* level (is to be filled in once a year)
1. Type of unit
2. Number of places
2.a Number of long-term places
3. Number of single rooms
4. Number of residents with dementia
5. FTE of nurses
6. FTE of other health workers
7. FTE of untrained personnel
8. FTE of unfilled positions
9. Number of employees with an engagement less than 30 %
10. Sick leave rate during the last year
11. Number of health workers with relevant additional training
12. Does the unit have its own head nurse?

* Unit = smallest entity with own personnel group during the day

Interview with nursing-home staff

Data on psychological and social factors at work will be assessed with the relevant subscales of the QPS Nordic Questionnaire (Dallner et al. 2000). An observational instrument, the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH), will be applied for the assessment of the physical environment in the nursing homes (Sloane et al. 2002). The culture of care, more specifically the extent to which the culture of care in the nursing home is person-centered, is assessed with the Person-centered Care Assessment Tool (P-CAT), a staff self-report assessment scale (Edvardsson et al. 2010; Rokstad et al. 2012).

Data storage

Data will be stored at the Research Server, Innlandet Hospital Trust, after going through a predefined quality check procedure.

Ethics

Participation in the memory clinic sample requires the ability to give an informed consent. The baseline and follow-up assessments were approved by the Regional Ethics Committee 2009/206 and 2011/1738. Participation in the in-home care sample is based on an informed consent by the patient or a caregiver when the patient him/herself is not able to consent. The baseline and follow-up assessments were approved by the Regional Ethics Committee 2010/601 and 2010/119.

Participation in the nursing-home sample is based on an informed consent from the patient or consent by a caregiver when the patient him/herself is not able to consent to participation. The baseline and follow-up assessments were approved by the Regional Ethics Committee 2011/1738.

Conclusion

This project is unique, nationally and internationally. Large groups of people with varying levels of dementia are followed longitudinally. Individual data are collected using well-established instruments that cover the relevant aspects of the disease course and resource use. These data will be linked with organizational data. Consequently, the respective contribution of organizational and individual variables in predicting the disease course and resource use in dementia may be estimated. The database created by this project will provide a valuable basis for a number of research projects that may shed light on the pathways of the care of people with dementia.

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