Home-dwelling persons with dementia. The impact of individual and organizational factors on the use of health resources and quality of life

by

Arnt Egil Ydstebø

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University of Stavanger
NO-4036 Stavanger
NORWAY
www.uis.no

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Scientific environment

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Summary

Background and aim

The prevalence of dementia increases with age, and as the world's population is growing older, the number of people with dementia is rising rapidly. Dementia is a progressive disease causing the affected to become increasingly care dependent and possibly experience reduced quality of life (QoL). A projected steep increase in the prevalence of persons with dementia poses a major threat to the sustainability of the primary health care sector. To enable this sector to absorb the massive increase in care needs, we have to enhance our knowledge about the factors that drive the need for care. In this thesis, we addressed some of these topics. We aimed to assess the use of primary health care services in home-dwelling persons with dementia and to assess relations between the use of formal and informal care and individual and organizational factors. In addition, we studied changes in the QoL of home-dwelling persons with dementia and its associated factors.

Methods

Adopting a quantitative approach, we analysed two datasets based on elderly recipients of municipality care services. For Papers I and II, we draw sub-samples from a cohort of 1,001 home-dwelling persons aged 70 years or older that was followed over three years (599 persons in Paper I and 412 persons in Paper II). In Paper I, we described the frequency of the use of general practitioners (GPs), and in Paper II, we assessed the longitudinal patient- and proxy-rated QoL. For Paper III, we drew a sub-sample of 395 persons from a cohort of 696 persons recently admitted to a nursing home. We described the use of formal care and of informal care rendered by primary caregivers and the wider social network, and analysed clinical and sociodemographic factors associated with the use of care during the last month before nursing home admission (NHA).

Results

We found that people with moderate to severe dementia made fewer visits to their GP than people with mild or no dementia. Older age, symptoms of agitation and psychosis were associated with fewer visits to the GP, while symptoms of apathy, anxiety, and depression were associated with a higher number of visits.

Regarding QoL, we found three separate groups with different QoL trajectories for both patient- and proxy-rated QoL among home-dwelling persons with dementia. Changes in QoL over the 18 months study period were small and mostly non-significant, and the agreement between patient- and proxy-ratings was poor. Belonging to the group with the lowest QoL trajectory was associated with more depressive symptoms in proxy- and patient-rated QoL independent of the dementia status. Poor and fair physical health as compared to good and excellent physical health was associated with lower QoL independent of the dementia status in patient ratings. Impaired functioning in personal and instrumental activities of daily living was associated with reduced patient rated QoL among persons with dementia.

In the month before NHA, half of the sample received formal care, and the amount of informal care was considerably higher than formal care. Help from the wider social network accounted for less than 5% of the informal care rendered. Co-residency was associated with more informal care compared to non-co-residency. Among co-resident participants, younger age of the participants, and non-working status of the caregivers were associated with more informal care provided by the primary caregivers. A higher provision of formal care was associated with poorer physical health.

Conclusion

As home-dwelling persons with moderate to severe dementia seem to be less active in seeking help from their GPs, we need to ensure that they

are routinely followed up in order to secure handling of medical problems as well as mental and social issues related to dementia.

Depression and other neuropsychiatric symptoms, poor physical health, and impairment in personal and instrumental activity of daily living function seem to reduce the QoL of persons with dementia and should be diagnosed and treated as far as possible. However, the QoL of persons with dementia appears to be more complex than what can be explained only by the clinical factors related to dementia.

There is possibly an unrealized care potential in the wider social networks of persons with dementia that might help relieve the burden of primary caregivers. Future research should explore this potential. Future programs should also explore new and innovative formal and informal care services tailored to the specific needs of persons with dementia and their caregivers.

Abbreviations

AD	Alzheimer’s disease
BL	Baseline
BPSD	Behavioural and psychological symptoms in dementia
CDR	Clinical Dementia Rating Scale
CSDD	Cornell Scale for Depression in Dementia
FU	Follow-up
FTD	Fronto-temporal dementia
GBTM	Group Based Trajectory Modelling
GMHR	General Medical Health Rating Scale
GP	General practitioner
IADL	Instrumental activity of daily living
ICD-10	International Statistical Classification of Disease and Related Health Problems, 10th revision
LBD	Lewy body dementia
MCI	Mild cognitive impairment
NH	Nursing home
NHA	Nursing home admission
NPI	Neuropsychiatric inventory
NPS	Neuropsychiatric symptoms
PADL	Personal activity of daily living
PAF	Population attributable fraction
PSMS	Physical Self-Maintenance Scale
QoL	Quality of life

QoL-AD	Quality of life in Alzheimer’s disease
REDIC	Resource Use and Disease Course in Dementia
REDIC-NH	Resource Use and Disease Course in Dementia – nursing home study
RUD	Resource Utilization in Dementia questionnaire
VD	Vascular dementia
WHO	World Health Organization

List of papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

I. Ydstebo AE, Bergh S, Selbaek G, Benth JS, Luras H, Vossius C. (2015) The impact of dementia on the use of general practitioners among the elderly in Norway. *Scandinavian journal of primary health care*. *33*(3):199-205. doi:10.3109/02813432.2015.1067516

II. Ydstebø AE, Bergh S, Selbæk G, Benth JŠ, Brønnick K, Vossius C. Longitudinal changes in quality of life among elderly people with and without dementia. *Int Psychogeriatr*. 2018;30(11):1607-1618. doi:10.1017/S1041610218000352

III. Ydstebø AE, Benth J, Bergh S, Selbæk G, Vossius C. Informal and formal care among persons with dementia immediately before nursing home admission. BMC geriatrics. 2020;20(1):296. doi:10.1186/s12877-020-01703-8

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Table of Contents

Table of Figures

List of Tables

Appendices

1 Introduction

The World Health Organization (WHO) has estimated that 50 million people have dementia worldwide and that 10 million people develop dementia each year (2). At the societal level, dementia demands substantial resources, mostly from family caregivers and the primary health care services, especially in late stages when persons with dementia might require care and supervision around the clock (3). The global cost of dementia in 2015 was estimated to be US $818 billion, equivalent to 1.1% of global gross domestic product (2).

There are 40,000 nursing home beds in Norway (4), and 84% of persons admitted to long-term care in NH have dementia (5). Given the presumed increase in prevalence of persons with dementia, this will require a doubling of the number of nursing home beds until 2040 (3, 6). Consequently, this will put a heavy economical burden on the health care system. Hence, there is a political vision to delay or, if possible, avoid nursing home admission (NHA) in persons with dementia. The current Norwegian dementia strategy aims at helping all persons with dementia to live at home as long as possible (7). However, we know little about the situation at home for this patient group, and thus might not approach this task in the most effective way. In this thesis, we have therefore explored some aspects regarding home-dwelling persons with dementia and their use of health services.

Firstly, we wanted to know more about how home-dwelling persons with dementia used their general practitioners (GPs). The design of the Norwegian health system places a critical responsibility for the detection of dementia on the patient’s GP, as the GP is the responsible agent for investigating and diagnosing dementia as well as closely monitoring the disease progression and the patient’s need for formal care (8). However, very little research has been conducted on the use of GPs by persons with dementia. The first paper describes the use of GPs and municipality emergency services among home-dwelling persons with dementia and analyses the associations between the use of health services and individual and demographic variables.

Secondly, we explored longitudinal changes in quality of life (QoL) in persons with and without dementia. As we have yet to find a cure for dementia, QoL has gained interest as an outcome measure in intervention studies targeted at persons with dementia. There are, however, few studies addressing QoL in persons with dementia living at home and few that assess QoL longitudinally.

The third paper aims at describing the use of formal and informal home care to persons with dementia in the last month before NHA. Caregiver burden is a relevant risk factor for NHA (9, 10), and we know from previous research that a considerable amount of informal care was contributed in the period before NHA (3). However, there is little knowledge about the persons rendering care, and the care contribution from the wider social network.

This thesis is part of the project Resource Use and Disease Course in Dementia (REDIC) that is presented in more detail under chapter 4.1.

2 Background

2.1 General aspects of dementia

2.1.1 Aetiology, pathophysiology and epidemiology.

Aetiology

The definition of dementia according to the ICD-10 is as follows: dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation (11). Although dementia is common among the elderly, it is not a normal part of ageing. There are several possible brain diseases causing dementia (2). The most common form is Alzheimer's disease possibly contributing to 60-70% of cases followed by vascular dementia (VD) (20%), dementia with Lewy bodies (DLB) (15%), and frontotemporal dementia (FTD) (5%) (12-14). Less common causes of dementia are Parkinson's disease, Huntington's disease, Prion disease, traumatic brain injury, and HIV infection dementia. Dementia are also often caused by several aetiologies at the same time, like AD and VD (15).

Dementia caused by AD, VD and DLB in people above 65 years usually has a gradual onset with slow progression in early stages, while in people younger than 65 years it is more common with inherited forms of AD (20-34%) that progress more rapidly (15-17).

Pathophysiology

In AD, extracellular amyloid plaques and accumulated intracellular neurofibrillary tangles induce injury to the brain cells and inflammatory processes that damage the cholinergic neurons, and cause brain atrophy (18).

The pathophysiology of VD may include the sequelae after large infarcts or multiple small ischaemic or haemorrhagic infarcts to strategic areas of the brain (12). In DLB abnormal aggregates of alpha-synuclein protein, known as Lewy bodies and Lewy neurites, are found within the neurons in the central nervous system. The Lewy bodies reduce neurotransmission and eventually cause neuronal death (19). As with AD pathology, it is common to have an accumulation of amyloid plaques in DLB (14). FTD is not a single diagnosis but a group of degenerative dementias deriving from focal neurodegeneration of the frontal or temporal lobes of the brain (13).

Epidemiology

The global prevalence of dementia was 20,2 million in 1990 increasing by 117% to 43,8 million in 2016. The all-age prevalence over the same period show an increase of 54,7% globally. The age-standardised prevalence was, however, only up 1,7% from 701 per 100.000 population in 1990 to 712 per 100.000 population in 2016. The age-standardised increase in prevalence was highest (8,1%) in countries with a high-middle Socio-demographic index (SDI) and negative in countries with low-middle SDI (-2,7) and low SDI (-3,0) and as well in high-income North-America (-1,6) (20). The incidence rate is nearly 10 million new cases each year with the projected prevalence to reach 82 million in 2030 and 152 million in 2050 (21). In Western Europe, the prevalence was estimated to be 1.55% in the total population and 6.92% in the aged 60+ population in 2010 (22). Recent systematic reviews on worldwide trends in dementia conclude that prevalence is either remaining stable or increasing, while incidence rates have declined in some high-income countries (23-25). The most important reasons for the increasing prevalence are aging populations and higher life expectancy (24). The decreasing incidence in some countries could be due to lifestyle changes in the new generation of elderlies with reduced exposure to dementia risk factors (e.g., education and cardiovascular diseases) and increased exposure to protective factors (25, 26). A prevalence study of dementia in Norway has yet to be performed, however, based on European prevalence studies, it is assumed that about 78,000 people were living with dementia in Norway in 2013 (27). Population projections based on the medium alternative, expect the number of persons with dementia in Norway to increase to 112,000 by 2030 and 200,000 by 2060 (3).

2.1.2 Clinical symptoms

Clinical symptoms of dementia depend on the severity and the aetiology of the underlying disease. The most common symptom of dementia is impaired memory, but in addition to memory loss you will as well find the impairment of other cognitive functions. Due to the brains capacity to compensate for the shortfall in memory, altered behaviour including passivity, withdrawal, or altered communicative capabilities may be the first observable symptoms (28). Memory deficits may include loss of recall of recent events and names of recent visitors, confabulations, confusion, and distortions of memory. In the severe stages of dementia, recall of close relatives, and significant events in the past may also be lost. Cognitive deficits common in dementia are problems with planning and organizing (executive functions), finding words and names of objects (dysphasia and aphasia), inability to do tasks (apraxia), and inability to recognise objects and stimuli using senses (agnosia). Non-fluent speech, paraphrasing, and conveying information inappropriately are also common (18).

The neuropathological changes may also affect motor functions, reducing the ability of persons with dementia to carefully move their body or perform tasks with their hands or body that demand high precision. Motoric symptoms also include incontinence and difficulties with swallowing (dysphagia), which are more common in the severe stages of dementia (29).

Neuropsychiatric symptoms (NPS), also termed behavioural and psychological symptoms in dementia (BPSD), constitute a heterogenous group of signs and symptoms that are frequently observed in persons with dementia. Examples of psychiatric symptoms are delusions, hallucinations, depressive symptoms, anxiety, and euphoria; while behavioural symptoms include agitation, aggression, apathy, and disinhibition (30). Most persons with dementia exhibit NPS, and the frequency and severity of the symptoms increase with disease progression (6). Systematic reviews of studies on the frequency of NPS in persons with dementia have found it present in more than 80% of the patients in both home-dwelling and NH populations (30, 31).

2.1.3 Clinical course and prognosis

The clinical course of dementia can be divided into stages according to symptom severity. The dementia severity evaluation tool Clinical Dementia Rating scale (CDR) describes three stages of dementia in addition to mild cognitive impairment (32).

In mild dementia, memory loss is moderate, especially for recent events, and interferes with daily activities. Individuals have moderate difficulty with solving problems; they cannot function independently at community affairs, and they have difficulty with daily activities and hobbies, especially complex ones.

In the moderate stage, the memory loss is more profound, and the individual only retains well-learned material. Individuals are usually disoriented in time and often place; they lack good judgment and have difficulties in handling problems. They have little to no independent function at home, can only do simple chores, and have few interests.

In the severe stage, memory loss is severe with only fragments remaining. The individual is not oriented with respect to time or place; they are unable to make judgments or solve problems and cannot participate in community affairs outside the home. They require help with all tasks of daily living and most of personal care and are often incontinent (33).

The severe stage of dementia also comprises end stage dementia, which is typically referred to as a state of profound physical and cognitive disability, characterized by memory deficits causing inability to recognize family members, total functional dependence, incontinence, and immobility. Infections and eating problems are common in this period, increasing the risk of death (34).

Memory loss is more common in AD than other causes of dementia such as FTD. Thus, the stages described in the CDR are more associated with AD dementia.

Average life expectancy for persons with dementia is dependent on the person's age at onset of the disease. In the majority of studies on survival time, the median survival time from onset of the disease ranges from 7-10 years, while the median survival time from the time of diagnosis ranges from 3.2 - 6.6 years (35-37). In a large population-based study in the US, the mean age at diagnosis was 83.4 years, and the survival time post diagnosis ranged from 3.1 to 4.4 years depending on ethnicity (38).

2.1.4 Diagnosing dementia

A timely and accurate diagnosis of dementia is the first step to provide the appropriate treatment and disease management (39), meaning that the diagnosis is set at a time when the person with dementia and the family caregivers can benefit from intervention and support (26). Involvement of the nearest caregiver in asking about and examining common symptoms is an essential first step.

In Norway, dementia is diagnosed in accordance with the International Statistical Classification of Disease and Related Health Problems, 10th revision (ICD-10) criteria (11). Dementia is diagnosed in two steps. The first is to diagnose the dementia syndrome according to standardised criteria (below) (40). The second step is establishing the specific disease causing the dementia syndrome.

<u>Diagnosing the dementia syndrome:</u>

I. Both of the following:
    1. Memory impairment, especially for new information
    2. Impairment of other cognitive functions (judgement, planning, thinking, abstraction)

    <u>Mild:</u> Affects the person’s capacity to cope with everyday activities but not so severe as to be incompatible with independent living.

    <u>Moderate:</u> The person cannot live independently.

    <u>Severe:</u> Continuous care is required.

II. Clear consciousness

III. Impairment in emotional control or motivation, or change in social behaviour in at least one of the following:
    1. Emotional instability
    2. Irritability
    3. Apathy
    4. Coarsening of social behaviour

IV. A duration of at least six months

It is essential to be aware that symptoms mimicking dementia may be caused by reversible conditions (e.g., depression, delirium, sensory impairment, side-effects from drugs) (41). The basal investigation at the

GP’s office should therefore include a physical examination, blood tests, tests to rule out delirium and drug side-effects, a referral to CT or MRI (preferred), interview with the next of kin, cognitive tests, and evaluation of BPSD (8).

Further investigation in specialist health care services is recommended in young persons, in cases where the basal investigation has not been sufficient to decide on a diagnosis or in cases were reversible symptoms is suspected, in order to perform extensive cognitive testing, purposeful imaging technologies, or cerebrospinal fluid assessment to exclude other cerebral pathologies (8).

2.1.5 Treatment and disease management

There are guidelines available for the treatment and management of dementia in Europe, the US, and Australia. The Norwegian guidelines recommend that the GP leads examination, diagnosing, and follow-ups of persons with suspected dementia in cooperation with an interdisciplinary team from the primary health care services. Regular follow-ups should be carried out every 6-12 months. Attention to accompanying medical problems is essential as persons with dementia may have reduced capacity to report symptoms of pain or illness or possible adverse effects from medical treatment (39). Besides assisting in basal examinations, the interdisciplinary dementia team should coordinate the care of the patient in partnership with the primary carer. A person-centred approach comprising physical activity, monitoring of BPSDs, nutrition, oral health, and meaningful activity should be offered, as well as respite care services are strongly recommended (8).

Pharmacological treatment

Cholinesterase inhibitors and Memantine have shown effect on cognition as well as global and ADL functioning in mild and moderate stages of dementia caused by AD, LBD and Parkinson’s disease. These drugs are, however, only considered to be symptomatic therapies and are not neuroprotective or capable of altering the underlying causes of degeneration (39).

Antidepressants are not recommended as a first-line treatment for depression in dementia, as the effects of antidepressants on depression in dementia have not been sufficiently verified in clinical trials and these drugs carry side effects. It is recommended to treat mild to moderate depression in dementia with increased activity, decreased social isolation, and talking therapies (psychological therapy, interpersonal therapy, counselling therapy, or cognitive stimulation therapy), and only using antidepressants in cases where the patient has a history of depression or has not responded to the first-line therapy and is moderate to severely depressed (26).

Sleep disorders in dementia are heterogeneous and may be caused by pain or discomfort. Evidence of the effects of medication for sleep are inconclusive, and this is therefore not recommended unless used for a diagnosed REM sleep behaviour disorder in LBD (26).

The use of antipsychotics for psychosis and severe agitation in dementia has become increasingly controversial due to many harmful side-effects and increased risk of mortality. The first-line treatment is therefore non-pharmacological intervention (42).

Non-pharmacological and psychosocial treatments

Cognitive interventions aim to improve memory, attention and general cognitive function. Cognitive stimulation therapy, cognitive training, and cognitive rehabilitation have all shown effect in treatment of persons with mild to moderate dementia (26). Cognitive stimulation therapy is a group activity arranged by a facilitator aiming to mentally stimulate participants through cognitive activities that includes reminiscence and multisensory stimulation in a group setting. Cognitive stimulation therapy is the cognitive intervention that has the most robust evidence for improving cognition in mild to moderate dementia, but it is not known whether the cognitive exercises or the social stimulation is more effective (43). Cognitive training is a guided practice, individualised or in groups, that involves a set of structured and standardised tasks designed to train individuals in defined cognitive domains such as speed of information processing, attention, memory or problem-solving. Cognitive rehabilitation is a more individualised approach were the persons with cognitive impairment work together with their families and a health professional to identify personally relevant goals related to improving everyday tasks and functioning in a real-life context (44). There are encouraging results from single trials for both cognitive training and cognitive rehabilitation; however, in total the evidence is too weak to appropriately evaluate their efficiency (26).

Exercise programs where persons with dementia take part in 60-minute training units three times weekly have shown positive effects on functional ability, or at least have been shown to reduce the functional decline in persons with dementia. Single studies have also found positive effects from repeated physical exercise on cognitive function, depression, and NPS. However, when summarized the evidence is insufficient (45). In addition, as most studies have only included persons with dementia living in institutions, we do not know what the effect would be in the home-dwelling population.

Occupational therapy to train patients and caregivers in the use of assistive technologies, coping behaviours and other strategies to compensate for the functional decline has also been found effective in improving functional abilities and reducing caregiver burden (46).

Case management and person-centred care (PCC)

Case management is a recommended method of delivering care to home-dwelling persons with dementia. “Case management is delivered by a specific individual or a team through an individualised, collaborative, evidence-based plan of care with and for patient and family needs.” The inter-professional team may include physicians, nurses, psychologists, physical and occupational therapists, and social workers. Although there is a considerable variation in how case management has been implemented around the world, systematic reviews show a low to moderate effect on patients' QoL and adherence to practice recommendations. They have also reduced burden and depression in family caregivers (26). The concept of PCC to persons with dementia has gained increasing recognition since it was proposed by Thomas Kitwood in the 1990s and is now strongly recommended in guidelines for the treatment of dementia (8). According to Kitwood, the PCC approach is to view dementia as a dialectic condition between personal, social, and neurological factors. Personal factor refers to the unique person (core self), including the person's values, life history, preferences, and beliefs that have to be recognised by the caregiver regardless of cognitive decline. The social factor recognises that the social environment impacts the person with dementia and that we have to preserve their personhood. The neurological factor refers to the neuropathological process in the person's brain, causing a progressive decline in cognition and impairment in function (47).

2.2 Resource use in dementia

2.2.1 Burden of disease in dementia

Globally, dementia caused 2.4 million (4.4% of all) deaths in 2016. In the 70+ years population, dementia caused 2.2 million deaths, which was 8.6% of all deaths in 2016 (20).

Dementia was the 23rd largest cause of disability-adjusted life years (DALYs) worldwide in 2016 with a total of 28.8 million DALYs. Of these 23.9 million DALYs were lost among person aged 70+ years. Both years lived with disability (YLDs) and years of life lost (YLLs) due to dementia increases sharply in people over the age of 70. The YLL rates, however, increase steeper than YLDs with age (20).

In Norway, dementia was the tenth leading cause of DALYs in men and the third leading cause of DALYs in women in 2016. Both the number of deaths and DALYs, due to dementia, decreased in Norwegian males and females between 2006 and 2016 by 3.3% and 2.7%, respectively (47). The global cost of dementia estimated in 2015 by the WHO was US$ 818 billion, which is equivalent to 1.1% of the global gross domestic product (GDP). The total cost as a proportion of GDP varied between low- and middle-income countries to high-income countries from 0.2% to 1.4% (2). The REDIC study estimated that in Norway a total of about 3.4 billion Euros (2013) per year, or 10% of the Norwegian health care cost, could be attributed to dementia, costs for informal care not included (3).

Estimates by Prince et al. show that US$ 113 billion (43% of total costs) were spent on direct formal care costs, and US$ 98.9 billion (37.6% of total costs) were spent on informal care costs to persons with dementia in Western Europe. In the same region, the mean cost per person with dementia was estimated to US$ 35,255 in 2015 (48). In Norway, the direct cost per person with dementia per year was estimated to NOK (2013) 360,000 (US$ 59,196 in 2013). The main cost drivers identified were nursing home stays (60%), home nursing (20%), and in-hospital stays (11%). Informal care per persons with dementia per year, in Norway, was estimated to 569 hours. Depending on the value per hour of informal care, the cost per year per person with dementia, in Norway, was NOK (2013) 98,870-209,392 (US$ 16,252-34,419) (3).

The REDIC project found that the costs for direct medical care were highest in the phase from onset of symptoms to the point of diagnosis. The direct medical care costs, then, decreased slightly in the second phase, from the point of diagnosis to NHA, and were further reduced in the third phase, defined as the period in a nursing home. Costs related to formal care, on the other hand, increased throughout all the three phases, especially in the institutionalized phase. The findings from the REDIC project is coherent with results in other COI studies (49).

2.2.2 Primary health care in Norway

In Norway, primary health care is the responsibility of the individual municipality while specialist health care is a state responsibility. Home care services and nursing homes are run by the municipality while the majority of GPs have a contractual relationship with the municipality (50). Aiming to improve continuity of primary care, especially among elderly and chronically ill people, Norway established a GP scheme in 2001 that allocated a GP to every resident. The GPs' main tasks are to provide diagnosis and treatment at the primary level and to serve as gatekeepers for specialist health services (50). The GP is also responsible for the medical follow-up of persons with chronic diseases living at home. Recently, there has been an increasing focus from governing bodies to provide early and timely diagnosis of dementia in order to promote optimal management (7, 51). The contribution from the GPs is to initiate and lead the diagnostic procedures. In 2017 the mean number of GP consultations per capita was 2.7, and more than 70% of the population had one or more consultations (52).

The organization of home care services and nursing homes, often referred to as the Nordic model (53), includes the following key aspects: Every citizen has equal rights to health and social care. Care is mainly provided by the public sector (municipalities or private trusts on behalf of the municipality), and the care services are sufficient, universal, and needs-tested (54). In practice, care services are allocated based on an application by the client and an assessment of needs conducted by health and social care workers from the municipality allocation office (53).

Although the municipalities maintain governance of the primary health care services, the central government continues to control health services through legislation and instructions, directives, guidelines, and financial incentives (50). In addition to the public home care services, informal care rendered by spouses, children, family, and friends constitutes a large proportion of the total care provided in Norway (55).

2.2.3 Formal and informal care

International studies published during the last two decades show that the amount of formal and informal care rendered to home-dwelling persons with dementia varies considerably from 30 to 92 hours per month of formal care, and 148-360 hours per month of informal care (56-65). Early work by Leon and colleagues on societal expenditures on formal and informal care across stages of Alzheimer’s disease in the U.S. found that costs increased by disease severity and comorbidity (66).

In Norway, at the time of diagnosis, home-dwelling persons with dementia used 60-80 hours of informal care, increasing to a mean of 160 hours immediately before admission to a nursing home. Formal care, in the form of home nursing, was rendered for 9 hours per month at the point of diagnosis, increasing to 16 hours per month before NHA. Home nursing was the most used formal care service in Norway, rendered to approximately 50% of home-dwelling persons with dementia (3).

Co-residential status seems to be an important factor in determining the extent of formal care rendered to the patient. This finding is coherent with findings in the REDIC project were the factor “living alone” was positively associated with more use of formal care (3, 56, 57). Other factors commonly associated with a higher use of formal care are older age, female gender, lower cognition more severe dementia, more BPSD, higher PADL dependency, and more depressive symptoms (3, 59, 62, 65, 67).

Co-residency seems as well to be an important factor determining the extent of informal care rendered. The lowest estimates of informal care

are found in samples with better cognition, younger age, and a lower percentage of co-resident participants (57, 62, 65) compared to the higher estimates where the cohorts consists of participants with higher age, lower cognitive functioning and fewer co-residents (56, 58, 61, 64, 65, 68).

Studies that have compared informal care between co-resident and non-co-resident participants, show a difference of 200 hours per month versus 40 hours per month, and 300 hours per month versus 100 hours per month, respectively (63, 69). Informal care provided by persons other than the primary caregiver is only reported in one previous study, which reported one hour per week in a subgroup that was living alone (69).

Factors that are commonly associated with a higher amount of informal care are higher ADL dependency (62, 65, 68, 70, 71), co-residency (57, 58, 63, 65, 72), worse cognition (57, 63, 65, 67, 70), more severe dementia (58, 61, 70, 73), severe neuropsychiatric symptoms (58, 61, 70), lower number of home care visits (59), more comorbid conditions (65), and more formal care (57, 58, 68), while less use of informal care was associated with higher frailty (63) and employment of the primary caregiver (62).

2.2.4 GP and specialist health care

The REDIC project found no differences between persons with and without dementia on the use of GP and frequency of hospital admissions, outpatient appointments, and visits to the emergency department. The mean number of GP visits per year was 5.6, and dementia was the reason for 5.2% of all visits. The cost of GPs consultations and percentage of total direct costs among persons with dementia were 200 NOK (2013) per month (1.5%) in the period from symptom debut to the point of diagnosis, and 150 NOK (2013) per month (0,8%) in the period from point of diagnosis to institutionalization (3).

Only a few studies have previously addressed the use of GPs among persons with dementia. Nelson et al. studied factors associated with the care utilization in a group of people aged 65 and over. They found that dementia was a negative predictor of GP use and hospital consultations. Furthermore, they showed that persons with dementia used health services such as GP, outpatient appointments, and in-hospital stay less than persons without dementia (74).

2.3 Quality of life in dementia

2.3.1 Quality of life

QoL is a broad multidimensional concept that includes subjective evaluations of positive and negative aspects of life. In addition to health, QoL also covers areas such as work, housing, schools, and the social network (75). Over the last four decades, QoL has become an essential outcome measure in research on social policy, development of new programmes supporting individuals or groups, and in service evaluation (76). The rationale for measuring QoL as an outcome of service use is the recognition that scientific, medical, and technological advances alone may not result in improved life. Personal, family, community, and societal well-being, as well as values, perceptions, and environmental conditions will as well influence the outcome of service use (77).

As there is currently no cure for dementia, one of the aims of care and treatment should be to promote well-being and maintain an optimal QoL. Traditionally, the goals of dementia treatment have been to alleviate severe symptoms, delay cognitive decline, reduce BPSD, and maximize ADL and IADL functioning. However, due to modest results from interventions targeting these goals, researchers now more often include assessments of the effect from interventions on QoL (78). An advantage of assessing QoL in persons with dementia is that it can help researchers to conclude whether an intervention made an essential difference in the patient's life. Also, monitoring of changes in QoL in persons with dementia may suggest new areas of intervention to maintain or improve QoL (78).

2.3.2 Assessing quality of life in persons with dementia

Assessing QoL in persons with dementia is not as straightforward as in mentally healthy persons. Cognitive impairment might reduce the participants' ability to evaluate and communicate their own QoL. Hence, some of the assessment scales developed to assess QoL in persons with dementia have been made for both patient-rating, where the persons with dementia rate their own QoL (patient version), and for proxy ratings, where the caregiver rates the QoL of the person with dementia. The proxy-patient versions may also be used by health professionals to evaluate the patients' QoL. However, we know little about what is considered as good QoL from the perspectives of persons with dementia. Although the person with dementia rates their own QoL, they evaluate something that we, who do not have dementia, consider to be important for QoL.

Whether to use a patient version or a proxy-patient version is most dependent on the cognitive level of the patient. In studies of QoL in dementia, it is common to apply both patient versions and proxy-patient versions. The patient version of the Quality of Life in Alzheimer's Disease (QoL-AD), for example, has shown excellent reliability and validity in patients with an MMSE score above 10 (78) and has been validated in a cohort that included participants with MMSE scores as low as three (79). Another recommended tool is the Dementia Quality of Life questionnaire (DQOL) (80). The DQOL is, however, more comprehensive regarding QoL details than the QoL-AD and may appear repetitive for patients, and also its use is probably limited to people with mild to moderate dementia (81).

2.3.3 Previous research on QoL in home-dwelling persons with dementia

In studies that have included both patient and proxy evaluations of the patients' QoL, the patients generally score their QoL better than the proxies score them (82-88). Changes to QoL have not been detected in studies with observation periods shorter than 12 months (89, 90). In longitudinal studies with observation periods longer than 12 months, patient-rated QoL is mostly stable over time, while the proxy evaluations often decline during the observation periods (82-84, 86, 87, 91). At the same time, large fluctuations in subgroups of the samples are observed, especially in patient-rated QoL, where often one part of the sample has a significant decline. In contrast, another part has a significant increase in QoL (90-92). Small sample size is a weakness that is common in most studies of QoL in persons with dementia.

In one study, the proxies' mental health was found to be associated to the proxy ratings of the participants' QoL, which led to the conclusion that the proxies might project their own QoL onto the participants in their assessments (93).

The factor most frequently associated with reduced levels of QoL, in both patient- and proxy-ratings, are symptoms of depression (82-90, 94-96). A systematic review from 2009 concluded that depression is consistently associated with changes in both patient and proxy ratings of QoL, especially in mild to moderate dementia (88).

The impact of neuropsychiatric symptoms (NPS) on QoL is not clear. Most studies find that more NPS, as measured by the NPI scale or other measures of NPS, is associated with reduced proxy-rated QoL (82, 83, 87-89, 94, 96). It is, however, uncertain if NPS have a negative impact on self-perceived QoL as only one study reports a significant association between the two (83).

There is some evidence of a relation between the severity of impairment in cognition and low QoL. One study found slightly higher correlations between cognitive impairment and QoL rated by health personnel than in correlations with patient or proxy rated QoL. The level of association in all correlations was, however, low (88). Bosboom and colleagues, in a more recent study, found an association between proxy-rated QoL and cognitive deterioration (97). Most studies that show a decline in proxy-rated QoL also show a decline in cognition in the same period (83, 87).

The influence of ADL limitation on QoL is also uncertain. Banerjee and colleagues found strong associations between low QoL and low PADL function in proxy ratings and in cohorts with severe dementia (88). Andrieu and colleagues found that lower PADL function was associated with reduced self-reported QoL, but not in proxy-rated QoL (87). Heggie and colleagues found this relation in both patient- and proxy-rated QoL (89).

Giebel and colleagues investigated the deterioration of PADLs through stages of dementia severity and its impact on proxy rated QoL. They found that in some European countries, the impact of lower PADL functioning was only associated with the QoL of groups with mild dementia, while in other countries (France and Germany), there were associations with low PADL functioning and QoL across all stages of dementia severity. When analysing the impact of the total study population, they found that impairments in PADL were associated with QoL at all stages of dementia severity, though not on all PADL items. While dressing, bathing, and transfer were the most affected areas, transfer, feeding, and toileting were less affected by dementia severity and were not associated with poor QoL (98).

Other factors that have been included in analyses of associations with QoL where there is low or no evidence of association are age, education, ethnicity, gender, dementia subtype, insight or awareness, caregiver characteristics, and care setting (88).

2.4 Conceptual framework

2.4.1 Health service research

“Health service research (HSR) is a branch of health research that is concerned with the relation between the provision, effectiveness, and efficient use of health services and the health needs of the population.” The primary goal of health service research is to produce a reliable and valid knowledge base to guide the development of appropriate, effective, cost-effective, efficient, and acceptable health services on the primary and secondary levels (99).

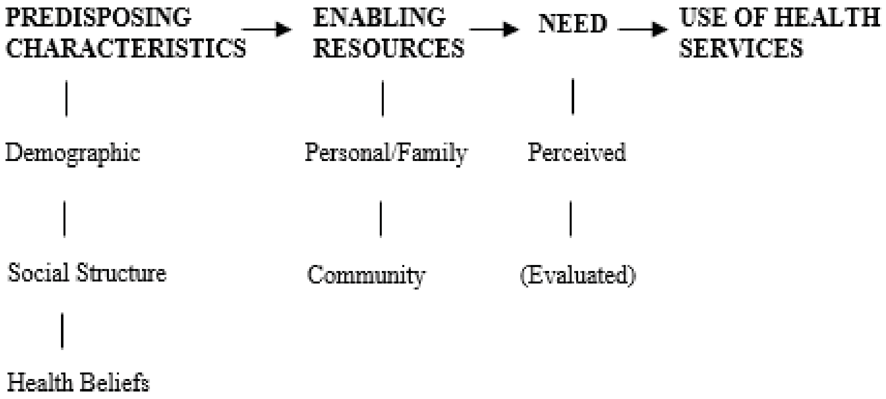
The main points of interests are the population’s need and demand for health services in relation to the supply, use, and acceptability of health services, quality and efficiency, the appropriateness of health services in relation to cost-effectiveness, and patient outcomes regarding health and perceptions of health, health-related quality of life, and satisfaction with the outcome (99).

2.4.2 Andersen’s Behavioural Model of Health Service Use

The main focus of the thesis was to gain more knowledge about the situation at home for persons with dementia by describing different aspects in care use, identifying factors influencing care utilization and investigating changes in the QoL and analysing factors associated with these changes. Andersen’s Behavioural Model of Health Service Use was used to provide a conceptual framework for formulation of research questions and design of the studies presented in this thesis (1). The model was initially developed by Ronald M. Andersen in the late sixties in the U.S., aiming to inform and explain the use of health care from an individual consumer’s perspective by predisposing, enabling, and need factors (Figure 1). Later, the model was expanded, now includes not only health care use but also health outcome, including QoL, and feedback loops.

The original behavioural model "suggests that people's use of health services is a function of their predisposition to use services, factors which enable or impede use, and their need for care."

Figure 1. The initial behavioural model (1)

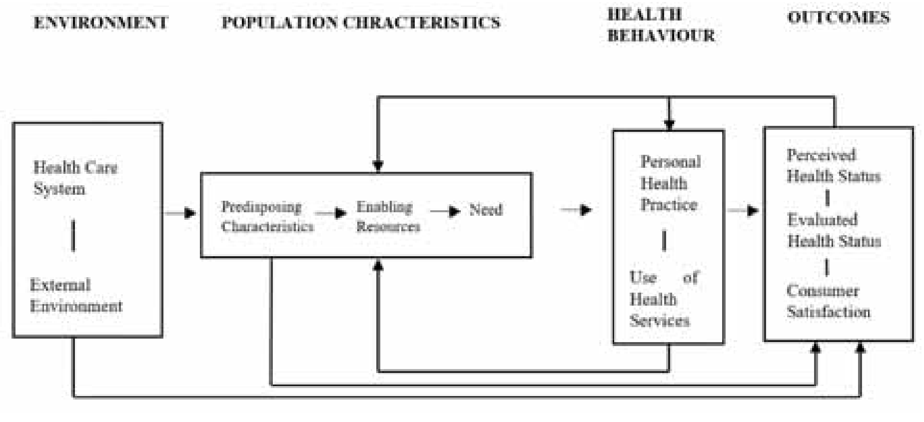


The predisposing characteristics in the original model include demographic characteristics such as age and gender, which represent biological imperatives suggesting the likelihood of health-seeking behaviour. Social structure is a broader concept "determining the status of a person in the community, his or her ability to cope with presenting problems and commanding resources to deal with these problems, and how healthy or unhealthy the physical environment is likely to be." Measures to assess social structure are typically education, occupation, and ethnicity. Also, social networks, social interactions, and culture may influence social structure. "Health beliefs are attitudes, values, and knowledge that people have about health and health services that might influence their subsequent perceptions of need and use of health services.” Later, also genetic factors and psychological characteristics, including mental dysfunction, cognitive impairment, and autonomy have been suggested as predisposing characteristics.

The enabling resources include resources that are both personal and those in the community. To enable health-seeking behaviour, the community needs health personnel and facilities available where people live and work. The people must have the “means and the know-how to get to those services and make use of them.” Examples of measures for enabling resources are income, health insurance, a regular source of care, and travel and waiting times. The organization of health care delivery is also an important enabling resource. For example, in Norway, the health system is divided between primary and specialist care, where specialist care is run by the state, while municipalities run primary care. There are possible differences in the organization and delivery of health care between municipalities and health regions that can influence the individuals’ use of healthcare, such as geographical distance to hospitals and the availability of nursing home beds.

According to Andersen, need can be interpreted both as a biological imperative and as a “perceived need,” which is largely a social phenomenon. When appropriately modelled perceived need can be explained by social structure and health beliefs, while need as a biological imperative is better represented by the professionally evaluated health status and need for medical care. “While perceived need can help us understand care-seeking and adherence to a therapeutic regimen, evaluated needs are more closely related to the kind and amount of treatment provided after a patient has presented himself to a professional health care provider.” As the behavioural model evolved, “Health Care System” was included, “giving recognition to the importance of national health policy and the resources and organization in the health care system as important determinants of the population’s use of services, as well as patterns over time.” “Consumer Satisfaction” was also added as a specific outcome of service use as it was realized that utilization needs to be examined in the context of health outcomes and will work as a feedback loop effecting future care seeking behaviour. Later “External Environment” was added as a determinant of health care use in recognizing that the physical, political, and economic environment plays a role in the use of health services. At the same time, “Personal Health Practices” was added to recognize that diet, exercise, and self-care interact with the use of formal health services to influence health outcomes. Over time, the behavioural model became more dynamic and recursive and included health status outcomes explicitly (Figure 2). The emerging model “portrays the multiple influences on health services’ use and, subsequently, health status. The feedback loops show that “outcome, in turn, affects subsequent predisposing factors and perceived need for services as well as health behaviour.” The initial concept of the behavioural model has been criticised for favouring increased use of health services. Andersen, on the other hand, advocates that the model is nonnormative regarding utilization and that the purpose is to discover conditions that facilitate or impede utilization (1).

Figure 2. A revised version of Andersen’s Behavioural Model of Health Service Use (1)



Concept of Mutability

When new policies are implemented to increase access to health care, the degree of success is determined by the mutability of the variables targeted in the intervention, or the variables explaining utilization. Demographic variables, such as age and gender and social structures, such as ethnicity and education, are considered to have low mutability, as they cannot be altered. Need, health beliefs and enabling factors are, on the other hand, believed to have medium and high mutability, respectively, as they can be altered and are more strongly associated with utilization. Need was initially considered non-mutable as it was regarded as the “immediate reason for use to take place.” However, as the model developed, it has been discovered that perceived need may be increased or decreased through health education programs, or by changing the financial incentive to seek service. Also, evaluated need may be altered by the imposition of clinical guidelines or managed care systems (1).

Measures of access and health outcome

The behavioural model provides measures of access to health care. “Potential access is defined as the presence of enabling resources. More enabling resources provide the means for use and increase the likelihood that use will take place. Realized access is the actual use of health services, while equitable and inequitable access is defined according to which predictors of realized access are dominant.” Equitable access occurs when demographic characteristics and need factors account for most of the variance in use, while inequitable access takes place when social structure, health beliefs, and enabling factors account for most of the variance in use. When health outcome was included in the model in the nineties, there was a growing “recognition that health services should have something to do with maintaining and improving the health status of the population. Both as perceived by the population and as evaluated by professionals.” The inclusion of health outcomes provided the possibility to extend measures of access particularly important for health policy and reform. “Effective access” is achieved when the use of health services leads to improved health status and improved satisfaction, and "efficient access" is realized when the level of health status or satisfaction increase relative to the amount of health care services consumed (1).

Quality of life

QoL is a health outcome that is closely related to HSR. Andersen and colleagues describe a symbiotic relationship between HSR and QoL where the HSR paradigm provides guidance for including structure and process in designing QoL studies as well as to suggest what leads to QoL improvement. "HSR supplies ways to conceptualize and relate many important forces that contribute to QoL in addition to specific clinical interventions." While the goal of studies of health service utilization in the early years of the HSR paradigm (70's and 80's) was to improve access to care, and change the organization and delivery of care, QoL has become a key outcome. "QoL outcomes indicate the ultimate value of studies of organization, finance or use of health services" (100).

"Evidence that QoL is improved on, or at least maintained by, interventions in the way health services are organized and financed (structure) or by changes in type, mix and ways of providing these services (process) validates HSR." QOL and physiological health are the key health status outcomes in the HSR paradigm. While HSR informs us what structure and process that works best, increased QoL is the payoff of improved health service.

Relevance for this thesis

Andersen's Behavioural Model is firmly anchored in the HSR paradigm and provides an excellent framework for designing health care utilization studies. The model links demographic, social, and clinic factors to the outcome variables, health service use, and QoL, and thus can be applied to all three studies included in this thesis. In work with the thesis, Andersen's Behavioural Model provided a conceptual framework for selecting dependent and independent variables in the three studies, although within the limits of the datasets. It also provided a framework in which to contextualize and interpret the findings.

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3 Aims and research questions

I. To explore the use of primary health care services in home-dwelling persons with and without dementia receiving municipal care services and to analyse the associations between the outcome and individual and demographic factors.

II. To describe longitudinal changes in patient- and proxy-rated QoL in a home-dwelling population, to assess the difference in QoL between persons with and without dementia and to explore whether dementia and other factors are associated with changes in QoL.

III. To describe the resource use in formal and informal care in home-dwelling persons with dementia during the last month preceding NHA, to describe providers of informal care - both the closest caregivers and the extended social network - and to analyse clinical and sociodemographic factors potentially associated to the use of care.

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4 Material and methods

4.1 The REDIC project

This thesis is part of the project Resource Use and Disease Course in Dementia (REDIC) conducted in Norway in 2012-2015 (3). The REDIC project was funded by the Norwegian Directorate of Health and led by the Research Centre for Age-related Functional Decline and Disease at Innlandet Hospital Trust with contributions from other Norwegian research centres[1]. The REDIC project was designed to improve knowledge about the disease course of dementia and the use of health care resources by persons with dementia (101). This was done by evaluating the use of health and social services in primary and secondary health care as well as measuring the extent of informal care provided to persons with dementia. Additionally, the Norwegian Directorate of Health wanted an estimate of the costs related to dementia, factors predicting utilization and costs, projection of the future number of persons with dementia, and an exploration of the health-related QoL. Representative samples of persons with dementia at different stages of the disease were followed up to three years, and data on the use of health and social services were collected in order to estimate the resource use from a societal point of view. In the following chapters, findings from the REDIC project relevant to the scope of thesis, will be presented.

In all, 5,630 persons from five cohorts were included in the REDIC project. Cohort 1 from the Norwegian dementia registry (NorDem) included 3,821 persons from memory clinics in Norway. Dementia was diagnosed in 1,716 (45%) of the included.

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[1] 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.

Cohort 2 – DemiNor included 229 home dwelling persons recruited by municipality dementia teams around Norway. Based on the clinical data, 197 of the participants in the DemiNor cohort were classified with dementia. Cohort 3 – Course of Dementia and Neuropsychiatric Symptoms Among Community-dwelling Elderly Receiving In-home Care (CONSIC) - included 1,001 randomly selected home dwelling recipients of municipality health and social care aged 70 years or older. After the procedures described in chapter 4.5.1., dementia was diagnosed in 415 participants (41%) at BL. The first follow-up assessment (FU1) was completed after 18 months and included 599 participants of which 241 (40%) were diagnosed with dementia. The second follow-up assessment (FU2) was completed after 36 months including 453 participants of which 158 (35%) were diagnosed with dementia. Cohort 4 – REDIC-Nursing Home (REDIC-NH) - included 696 patients newly admitted in nursing homes that were followed every six months or until death. According to the procedures described in chapter 4.5.1., dementia was diagnosed in 580 participants at BL. Cohort 5 – “the controls” - consisted of 112 participants without dementia or depression. Controls were recruited by newspaper ads, at a senior centre, and some home care recipients.

In the five included cohorts of the REDIC project, a total number of 2,771 participants had dementia. In November 2015, a comprehensive report titled Resource Use and Disease Course in Dementia (REDIC) (3) was published (a summary of the report is provided in the appendix).

In this thesis, Paper I and Paper II are based on data derived from the CONSIC study (cohort 3), while Paper III is based on REDIC-NH (cohort 4).

4.2 Research design

We adopted a quantitative research design that enabled us to describe outcomes of interest and to analyse variables associated with the outcomes.

In Paper I we applied a prospective longitudinal design over the course of 18 months. We collected demographic and clinical data about the participants and the caregivers from the CONSIC cohort and merged the data with the 18-months' use of primary health care services.

In Paper II we applied a prospective longitudinal design over 18 months using the first and second follow-up data of the CONSIC cohort to describe developmental trajectories of QoL in the cohort.

In Paper III we used a cross-sectional design. Data on the use of formal and informal care during the month before admission to a nursing home was obtained from the REDIC-NH cohort, a cohort of newly admitted patients and their caregivers.

4.3 The CONSIC cohort

Papers I and II are based on data from the CONSIC cohort. An overview of all measures obtained from the CONSIC and the REDIC cohort is presented in Table 1.

4.3.1 Setting, inclusion criteria, and data collection

The CONSIC cohort consisted of people 70+ years old receiving in-home care. Participants were recruited from 19 municipalities in the counties Hedmark, Oppland, Oslo, Østfold, and Buskerud. Both rural and urban municipalities of various sizes participated in the study.

To be included, participants had to be aged 70 years or older, receiving domiciliary care, and have a next of kin who looked after them at least once a week. The data were collected at three time-points: at baseline (BL), after 18 months (FU1), and at 36 months (FU2). BL inclusion started in April 2009, and the final assessment took place in December 2013. In total, 134 assessors, mostly nurses, physiotherapists, and occupational therapists interviewed participants and their next of kin. All assessors participated in a two-day training program prior to the BL assessment and the first FU assessment as well as a six-hour training program before the second FU assessment. Most of the interviews were completed in the participants' own homes simultaneously with participants and their next of kin. However, due to practical considerations, 67 next of kin interviews (6.7%) were completed by telephone within two weeks of the participant interview. Written informed consent was collected from participants and their next of kin before the interview. If the participants lacked the ability to consent, their next of kin were given the opportunity to deny the participation. This was in accordance with the ethical approval. A detailed overview of measures included in the CONSIC study and of the measures analysed in Papers I and II is provided in Table 1. The interviews with the participants included demographic data about the participants, level of physical activity and nutrition, medications, quality of life, cognitive status, and level of need of care. The following data were obtained from interviews with the next of kin: a proxy evaluation of the participants' QoL, assessments of the participants' physical and instrumental ADL functioning, NPS, symptoms of depression, and clinical evaluation of dementia severity. An evaluation of the use of health services was performed by applying the instrument Resource Utilisation in Dementia (RUD), though on BL assessments RUD was only performed with the last 300 participants.

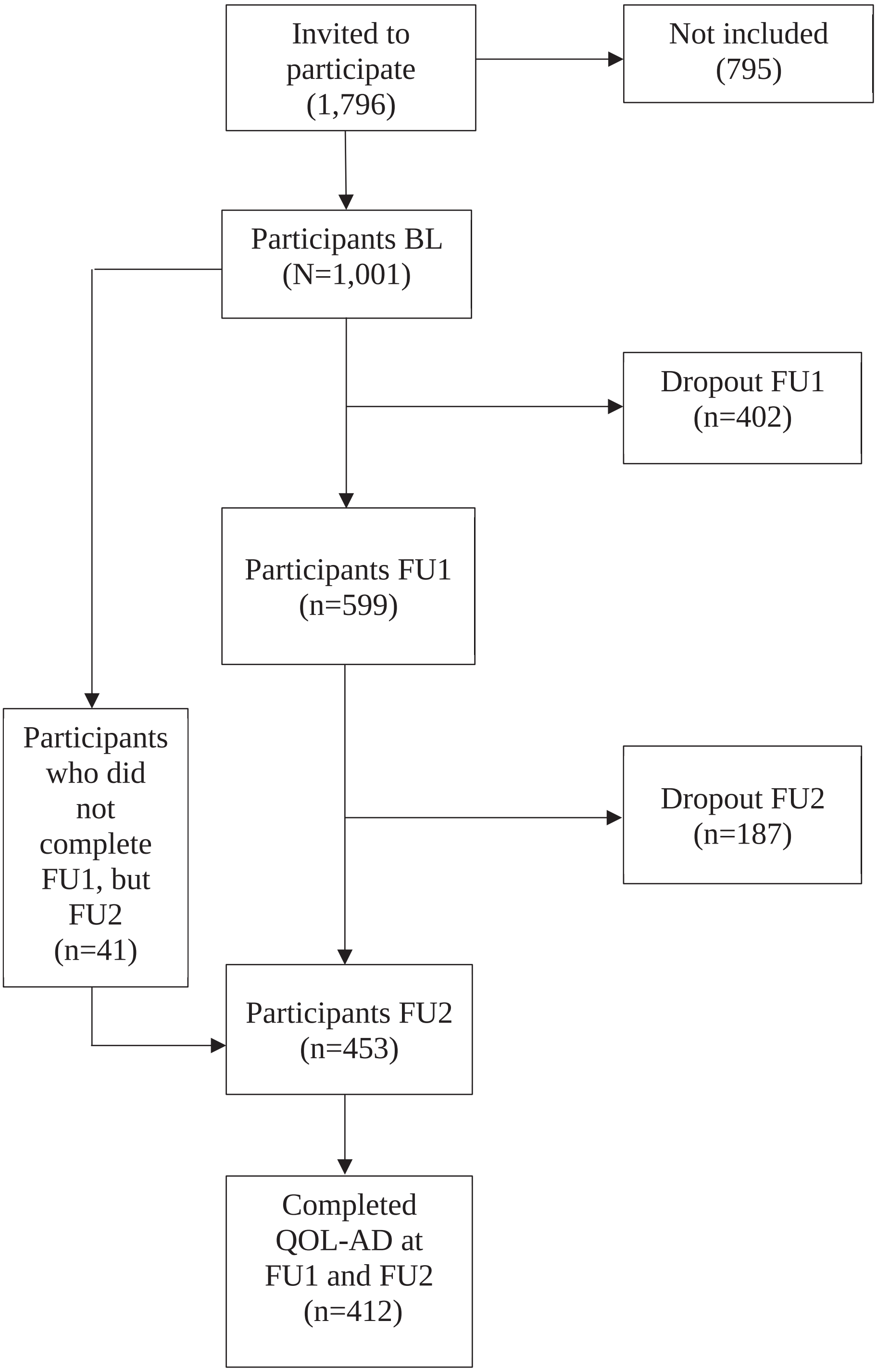
4.3.2 Participants

Of all eligible persons, 1,796 were randomly selected and invited to participate. Of these, 795 refused participation. Thus, 1,001 were included in the BL assessment. A flowchart of the inclusion and dropouts in CONSIC is provided in Figure 1. Data on the 795 eligible persons not included were not collected. Hence, we could not perform comparative analysis between included persons and persons not included at BL.

Between BL and FU1 there was a dropout of 402 participants (40.2%). Besides death (180, 18.0%), the most frequent reason for dropping out was lack of consent for further participation (146, 14.6%), as new consent for further participation was needed due to a revised study protocol. Other reasons for dropping out were moving out of the area (2, 0.2%) and miscellaneous (74, 7.4%). For many participants in the miscellaneous group, the examination was not possible within the required timeframe. Comparative analysis of included participants versus dropouts at FU1 showed that dropouts were older ($p=0.013$), were marginally more often males ($p=0.038$), had slightly lower IADL functioning ($p=0.017$), had lower PADL ($p<0.001$), and had poorer general medical health ratings ($p<0.001$).

Between FU1 and FU2, another 187 (31.2%) participants were lost due to death (70, 11.7%), admission to long-term care (36, 6.0%), refusal to participate (30, 5.0%), moved out of the area (1, 0.2%), and miscellaneous reasons (50, 8.3%). Compared with the participants at FU2, the dropouts were older ($p<0.001$) and had more impaired cognitive function ($p<0.001$), lower IADL ($p<0.001$) and PADL ($p<0.001$), and poorer GMHR ($p<0.001$). Also, the proportion of women was higher ($p=0.040$).

Figure 3: Flow chart of CONSIC.



4.4 The REDIC-NH cohort

Paper III is based on data from the REDIC-NH cohort.

4.4.1 Setting, inclusion criteria, and data collection

The Resource Use and Disease Course in Dementia - Nursing Home (REDIC-NH) cohort was one of five cohorts employed in the REDIC project. All measures included in the REDIC-NH study and those analysed in Paper III are provided in Table 5.

The REDIC-NH was a convenience sample of people newly admitted to nursing homes from municipalities in Hedmark, Oppland, Nord-Trøndelag, and the municipality of Bergen. Inclusion criteria were persons a) 65 years or older, or b) with dementia irrespective of age at admission to the NH, and c) with an expected stay in the NH of more than four weeks and expected survival of six weeks or more as judged by the nursing home physician. The participants and the next of kin were included at admission to the NHs.

The REDIC-NH study aimed to include participants and collect BL data within four weeks after NH admission with FU assessments taking place every six months until death. Inclusion of participants started in March 2012 and ended in November 2014.

In total, 47 small and large nursing homes located in rural and urban areas took part in the data collection. Four nursing homes withdrew during the study period because of a substantial workload related to the data collection. The data was collected by healthcare workers, mainly registered nurses (74%), in the nursing homes. The data collection was supervised by ten research nurses from the study partners. Before the BL assessment, the research nurses underwent a five-day training program, while the health workers in the nursing homes underwent a three-day training program. Data were collected through structured interviews with the patients, the next of kin, and the caregivers in the nursing homes. Demographic data were collected through a review of patient documentation. Although the data collection at BL was planned to be completed within four weeks after inclusion, this time frame could not be maintained, and the mean interval between admission and completion of the BL assessments was 10.7 weeks (ranging 0-56).

In Paper III we used a subsample of the REDIC cohort (N=395). The inclusion criteria for the subsample were a diagnosis of dementia, permanent admission to the nursing home, and a completed Resource Utilization in Dementia (RUD) questionnaire.

Table 1. Measures in CONSIC and REDIC-NH and measures used in paper I-III.

Data collected	CONSIC	Paper I	Paper II	REDIC-NH	Paper III
Resource use					
RUD	X[1]			X	X
Quality of life					
QoL-AD	X		X	X	
QUALID				X	
EQ-5D	X			X	
15D				X	
Neuropsychiatric symptoms					
NPI	X	X	X	X	
CSDD	X		X	X	
Diagnosis					
Type of dementia according to an algorithm				X	
No dementia, MCI, or dementia according to experts	X	X	X	X	X

Cognition					
MMSE	X	X	X	X	
SIB-8				X	
IQCODE	X			X	
CDR	X	X	X	X	X
Clock-drawing test	X				
Level of function					
PSMS-IADL	X	X	X		
PSMS-ADL	X		X	X	X
IPLOS	X				
Physical measures					
Blood pressure and pulse				X	
BMI				X	
SPPB				X	
Miscellaneous					
CAM				X	
Drug use (regular prescription)	X			X	
GMHR	X	X	X	X	X
CCI			X	X	
MOBID-2				X	
UPDRS-6				X	
RSS-caregiver stress				X	

[1] *Performed in 300 of the BL sample*

RUD = Resource Utilization in Dementia, QoL-AD = Quality of Life in Alzheimer's Disease, QUALID = Quality of Life in Late Stage Dementia, NPI = Neuropsychiatric Inventory, CSDD = Cornell Scale for Depression in Dementia, CAM = Confusion Assessment Method, MCI = Mild Cognitive Impairment, MMSE = Mini Mental Status Examination, SIB-8 = Severe Impairment Battery – 8 items, IQCODE = Informant Questionnaire on Cognitive Decline in the Elderly, CDR = Clinical

Dementia Rating, I-ADL = Instrumental Activity of Daily Living, PSMS = Physical Self Maintenance Scale, BMI = Body Mass Index, SPPB = Short Physical Performance Battery, GMHR = General Medical Health Rating, CCI = Charlson's Co-morbidity Index, MOBID-2 = Mobilisation Observation Behaviour Intensity Dementia, UPDRS = Unified Parkinson's Disease Rating Scale, RSS = Relative Stress Scale.

4.5 Clinical assessments

In this chapter, the clinical assessments used in the three papers will be presented and discussed.

4.5.1 Assessment of cognitive function, severity of dementia, and research diagnosis of dementia

To assess the cognitive status of the participants, the Mini Mental State Examination (MMSE), a screening tool for cognitive decline that measures cognitive abilities such as attention and orientation, recall, calculation, language skills, and construction, was used. The MMSE is scored from 0-30, where higher scores denote better cognition (102). The MMSE is a valid and reliable test for cognitive function that separates persons with cognitive impairment from persons with unimpaired cognition and can detect changes in cognitive state when a person recovers or deteriorates. Other advantages are that it is widely used, swiftly administered, has relatively low practice effect, and can therefore be used for serial measurements (102). However, the MMSE has been criticized for having too few assessments of memory (3 out of 30 points), therefore being less sensitive to mild cognitive impairments and dementia. Moreover, executive functions are under-represented, causing the MMSE to show low sensitivity to frontal lobe dysfunction. It also has an educational bias in which subjects with higher educational levels systematically score higher than those with lower levels (103).

To assess the severity of dementia, we used the Clinical Dementia Rating (CDR) scale (33). The CDR covers six domains of cognitive and functional performance (memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care) and is evaluated based on all available information about the patient. Each item is scored 0, 0.5, 1, 2, or 3, where higher scores denote higher impairment. A global score is calculated using an algorithm that gives precedence to the memory item. A global score of ‘0’ indicates no dementia; ‘0.5’ indicates questionable dementia; ‘1’ is considered to indicate mild dementia, ‘2’ moderate dementia, and ‘3’ indicates severe dementia. For statistical purposes, we applied the CDR Sum of Boxes (CDR-SOB) where all the item scores of the CDR are added giving a total score that ranges from 0-18 and is treated as a continuous variable (104).

Participants in both cohorts were given a research dementia diagnosis by psychiatrists Geir Selbæk, M.D., and Sverre Bergh, M.D., based on all collected information regarding cognitive function, ADL, functioning, and neuropsychiatric symptoms (NPS). The two experts independently classified whether the participants were without cognitive impairment, had a minimal cognitive impairment according to the Winblad criteria (105), or had dementia according to the ICD-10 criteria (106). If the two experts did not reach consensus, they consulted a third expert. Although this is a swift method for evaluating dementia status retrospectively, the precision may be questionable. The expert did not meet the participants and had to decide whether the participants had MCI, dementia, or no dementia based on assessments completed by other health professionals. Although these assessments included several measures of cognitive impairment, there was less available information about possible concurrent infections or comorbidities that may have caused temporary impairments of cognition in the participants.

4.5.2 Assessment of ADL functioning

To assess physical and instrumental functioning, we used the Physical Self-Maintenance Scale (PSMS) containing a six-item PADL scale and an eight-item IADL scale (five items for men) (107). The PADL scale places dependencies into the following six categories: toileting, eating, dressing, grooming, physical ambulation, and bathing. Each item is scored from ‘1’ = total independence to ‘5’ = total dependence. The total score thus ranges from 5 to 30. The IADL scale is made up of eight items for women and five for men (historically the items food preparation, laundering, and housekeeping are excluded) (107). Each item on the scale is scored either ‘0’ (dependent) or ‘1’ (independent), and a mean score is calculated by adding all item scores and dividing by the number of items.

4.5.3 Assessments for neuropsychological symptoms

Symptoms of depression were assessed with the Cornell Scale of Depression in Dementia (CSDD). The CSDD is conducted based on an interview with caregivers or health professionals and the patients and includes 19 items that are scored either ‘0’ indicating symptom not present, ‘1’ indicating mild or intermittent symptom, or ‘2’ indicating severe symptom. The total score is calculated by adding all item scores, resulting in a score ranging from 0-38, where a higher score indicates more severe depression, and 8 or higher indicates depression (108).

Neuropsychiatric symptoms (NPS) were assessed using the Neuropsychiatric Inventory (NPI) (109). The NPI is based on interviews with the caregivers and considers 12 types of NPS that are evaluated based on presence (no/yes/not applicable), frequency (1-4), and intensity (1-3). A total score ranging from 0-144 is calculated by multiplying frequency by intensity on present symptoms and adding all items. A higher score denotes more severe NPS.

Using BL data from the CONSIC cohort, we identified three sub-syndromes of the NPI based on a principal component analysis with direct oblimin rotation. The components were extracted based on the Kaiser criterion (factors with eigenvalues under one are dropped) and inspection of the screen plot. We termed the sub-syndromes ‘agitation’, ‘psychosis’, and ‘affective symptoms.’ ‘Agitation’ was composed of the items agitation/aggression, euphoria, disinhibition, aberrant motor behaviour, and irritability; ‘psychosis’ was composed of the items delusions and hallucinations; and ‘affective symptoms’ was composed of the items depression, anxiety, and apathy. The item agitation/aggression also correlated with the ‘psychosis’ subsyndrome, but in line with previous research and clinical experience, we chose to include it in the ‘agitation’ sub-syndrome (110).

4.5.4 Assessment of physical health

Physical health was assessed by the categorical General Medical Health Rating scale (GMHR) which rates health into four categories: poor, fair, good, and excellent. The GMHR was developed to evaluate physical health in persons with dementia and is scored by health professionals who know the patients and their past medical history. The inter-rater reliability is excellent (weighted kappa = 0.91), and it has strong predictive qualities for comorbid conditions, impaired ADL, falls, and mortality (111).

4.5.5 Assessment of the use of GP and municipality emergency health services in Paper I

In Paper I we merged the demographical and clinical data of the included participants with registry data on the use of GP and municipality emergency health services from the Norwegian Health Economic Administration, the public agency responsible for financial reimbursement of primary care services in Norway. In addition to the use of GP and emergency services, the diagnoses causing the contact as registered according to the International Classification of Primary Care (ICPC-1) were obtained from the Norwegian Health Economic Administration.

4.5.6 Assessment of QoL in Paper II

To assess QoL, we used the dementia-specific tool Quality of Life in Alzheimer's Disease (QoL-AD) (112). The QoL-AD was developed to assess QoL in cognitively impaired individuals and is a well-established and recommended disease-specific QoL instrument (81, 113). An evaluation of QoL questionnaires' suitability for psychosocial interventions in dementia suggested that QoL-AD is the preferred measure for QoL in Alzheimer's and related dementias (81).

The QOL-AD was introduced by Logsdon and colleagues in 1999 and tested for reliability and validity in a large sample of persons with Alzheimer's disease and their caregivers (78, 112). It consists of a patient version and a proxy version, where both versions rate the patient's current QoL. The QoL-AD consists of 13 domains (Figure 4), which reflect four conceptual domains of QoL in older adults previously described by Lawton ("perceived QoL," "behavioural competence," "psychological status," and "interpersonal environment") (114). The QoL-AD questionnaire is written in clear and direct language that facilitates its use with cognitively impaired persons. Responses are structured in a four-choice format (1 'poor' to 4 'excellent') consistent across all questions. The score is calculated by adding the scores on all items giving a total score ranging from 13 to 52 (78).

Figure 4. The QoL-AD (Participants Version) (74)

Instructions: Interviewer administers according to standard instructions. Circle participants responses.

Physical health	Poor	Fair	Good	Excellent
Energy	Poor	Fair	Good	Excellent
Mood	Poor	Fair	Good	Excellent
Living situation	Poor	Fair	Good	Excellent
Memory	Poor	Fair	Good	Excellent
Family	Poor	Fair	Good	Excellent
Marriage	Poor	Fair	Good	Excellent
Friends	Poor	Fair	Good	Excellent
Self as a whole	Poor	Fair	Good	Excellent
Ability to do chores around the house	Poor	Fair	Good	Excellent
Ability to do things for fun	Poor	Fair	Good	Excellent
Money	Poor	Fair	Good	Excellent
Life as a whole	Poor	Fair	Good	Excellent

Comments:

The QoL-AD has good psychometric properties and can be used in a wide range of dementia severity. Both the patient- and proxy-rated version of QoL-AD have shown excellent reliability (α=0.84 and 0.86, respectively), however, agreement between patient-ratings and proxy-ratings is low (r=0.19) (78). Content validity, when assessed qualitatively by a large group of health workers, is good, and construct validity assessed by Pearson correlation coefficients between the QoL-AD and the four hypothesized domains were mostly significant in favour of the hypothesized directions (e.g., higher QoL related to less impairment in behavioural competence) (78, 79). Although Logsdon and colleagues discourage the use of the QoL-AD with persons who have an MMSE score lower than 10 because of difficulties understanding and answering the questions adequately, persons with an MMSE score as low as three have been able to complete the questionnaire satisfactorily (79).

In Paper II we assessed participant- and proxy-rated QoL separately at FU1 and FU2 in the CONSIC sample using the QoL-AD. To simplify this for the reader, we chose to refer to FU1 as BL and FU II as FU I in Paper II and in the synopsis, when referring to Paper II. The participants evaluated their own QoL, while the proxies were asked to evaluate the participants' QoL-AD based on how they believed the participants would evaluate their own QoL. In addition to total QoL scores, we also calculated scores on three subscales of the QoL-AD previously identified by Revell et al. (115). The three subscales were *physical well-being*, containing the items physical health, energy, ability to do chores, and ability to do things for fun; *social well-being*, containing the items living situation, family, marriage, friends, and money; and *psychological well-being*, containing the items mood, memory, self, and life as a whole.

4.5.7 Assessment of resource use in Paper III

To assess the use of formal and informal care, we used the Resource Use in Dementia questionnaire. Developed by Wimo and colleagues to capture resource use in persons with dementia in a clinical trial setting, the RUD questionnaire has been used in several cost of illness studies (116). It collects information about the participants' use of formal and informal care. Formal care data include length of in-hospital stay, reason(s) for admission, and type of ward; visits to emergency rooms; use of other primary care services including GP (number of visits); use of home care services (home nursing, home help, food transportation, day care, transportation, and others). Informal care includes demographic data on the closest caregiver, including the caregiver's working situation, and direct care time by the closest caregiver concerning ADL, IADL, and supervision of the participant. In a revised version of RUD applied in Paper III, the evaluation of informal care also includes information about other contributors of informal care and the time they spent caring for the participant.

In Paper III the assessments were carried out through interviews with the patients and the closest family caregivers. Outcome variables were hours of formal care provided by the professional home services, informal care by the primary caregivers, and informal care by the wider social network captured from the RUD questionnaire. The information regarding informal care by the primary caregiver was recorded in regard to three aspects: 1) the time used to help the participant with personal activity of daily living (PADL), 2) the time used on instrumental ADL (IADL), and 3) the time used on supervision such as helping the participant with orientation or preventing behaviour that is distressing to the participant. The total informal care time by the primary caregiver was calculated by summarizing all three aspects. In some cases, this sum exceeded 24 hours per day, and we therefore had to set the total informal care time to 24 hours per day. Despite the challenge with the recall of the caregivers, the RUD has been validated in both residential and community care settings and is considered a reliable measure of resource utilization (116, 117).

4.6 Statistical analysis

Descriptive statistics: Means, standard deviations, numbers, and percentages were calculated to describe demographical and clinical variables in the study cohorts.

Comparison of groups: In Paper I a comparison of included versus not included participants, as well as those who did not visit their GP versus those who had at least one consultation per year, was performed by Student’s t-test for continuous variables and χ^2-test or Fisher’s exact test for categorical variables. In Paper II differences between participants with and without dementia and included versus dropouts at FU1 and FU2 were assessed by Student’s t-test (with unequal variances assumed in the dementia versus the non-dementia group) for continuous variables and by χ^2-test or Fisher’s exact test for categorical variables. In Paper III, using Student's t-test, we compared hours of formal and informal care in co-resident participants versus non-co-resident participants, female versus male participants, and participants with primary caregivers holding jobs versus participants with caregivers who did not work. In all papers, we assessed the distribution of continuous variables by inspecting the histograms to ascertain whether the variables were normally distributed.

Assessments of the relationships between dependent and independent variables:

In Paper I the dependent variable of interest was consultations with the GP. Due to a strongly skewed distribution, we categorized the number of GP visits into 0, 0-2, 2-4, 4-7, and >7 consultations. We then assessed the relationship between the categorized GP consultations and a set of pre-defined patient characteristics as independent variables. First, bivariate ordinal regression models were estimated, followed by a multiple ordinal regression model without and with adjustment for a confounder GMHR.

In Paper II, as an exploratory approach, we estimated group-based trajectory models (GBTM) to identify potential distinct homogenous subgroups of participants following similar paths in patient-rated and proxy-rated QoL-AD. The GBTM approach is motivated by historical tradition of group-based theorizing that there might be subgroups in the population following similar developmental trajectories in an outcome of interest. The GBTM method is designed to identify clusters of individuals, or groups, based on individual profiles by using certain statistical criteria. After identification, key characteristics and clinical symptomology of individuals sharing similar developmental pathways can be assessed and compared between identified groups. To determine the number of groups that best represents the heterogeneity in developmental trajectories, or the best model fit, a set of decision criteria is applied. Bayesian information criteria (BIC) and Akaike's information criterion (AIC) are commonly employed to assess model fit by balancing model complexity (numbers of parameters) versus goodness of fit to the sample data. A smaller value of AIC or BIC means a better model. Entropy is then employed in the model selection to evaluate classification accuracy by averaging individual posterior probabilities within each class, with values closer to 1 indexing greater precision (ranging 0 to 1) (118).

Using GBTM, we were able to identify the subgroups with similar longitudinal changes. AIC and BIC were applied to identify the best-fitting models. In addition, a reasonable sample size in each group, non-overlapping 95% confidence intervals (CI), and average within-group probability higher than 0.7 was required.

Kappa statistic was calculated to assess the agreement between the group-belonging of patients and proxies. A low kappa value (close to 0) indicates poor agreement (patient and proxy often belong to different groups), while a high kappa (close to 1) indicates high agreement (patient and proxy are often in the same group).

Bivariate and multiple nominal regression models were then estimated to identify potential characteristics associated with group membership. We included interaction terms between all independent variables and the dichotomous variable dementia into the multiple regression models and eliminated excessive interactions by AIC. Results were presented as odds ratios (OR) with the corresponding 95% CI and p-values.

In Paper III bivariate and multiple linear mixed models were estimated to assess the associations between predefined covariates and the three outcome variables: informal care by the primary caregiver, informal care by the wider social network, and formal care. Random effects for nursing homes were included in the models. We performed stratification by the living situation by including interaction terms between the dichotomous variable co-residency and all covariates. Interactions with $p<0.1$ were kept in the model.

All statistical tests were two-sided, and results with p-values below 0.05 were considered statistically significant. In Paper I we used the program SPSS^{TM} 22.0 (SPSS Inc, Chicago, USA) for all statistical analyses. In Paper II we used SPSS^{TM} 23.0 and STATA version 14, and in Paper III we used SPSS^{TM} 25.0 and SAS version 9.4.

Additional statistical procedures performed after publication of Paper I.

Due to the substantial loss of participants during follow up in the study, important differences between included and excluded participants might have occurred. This is illustrated in Table 1 of Paper I. We have applied the inverse probability weighting to account for selection bias as good as available data allows. Baseline characteristics listed in Table 1 of Paper I were entered into a logistic regression model with included/excluded as outcome variable. The multiple logistic regression model was reduced by AIC. In this way, we excluded several unimportant covariates with respect to the outcome variable. According to AIC, the following variables were kept in the model: age, gender, MMSE, GMHR, and dementia status. The model was then used to predict the probability of participation for each participant in the sample. The inverse of this probability was used to define weights for each participant included into the ordinal regression model.

4.7 Ethical considerations

The data collected was treated and analysed in accordance with the Helsinki Declaration. Participation in CONSIC and REDIC-NH was based on informed consent by the participant or the next of kin in cases where the participant him/herself was not able to consent. In the published version of Paper I and Paper II it was stated that “all participants gave informed written consent”. This statement is inaccurate as consents were also obtained from caregivers in cases were the participant did not have the capacity to consent. The data collection in CONSIC was approved by the Regional Ethics Committee south-east 2010/119 and for REDIC-NH by the Regional Ethics Committee south-east 2011/1738.

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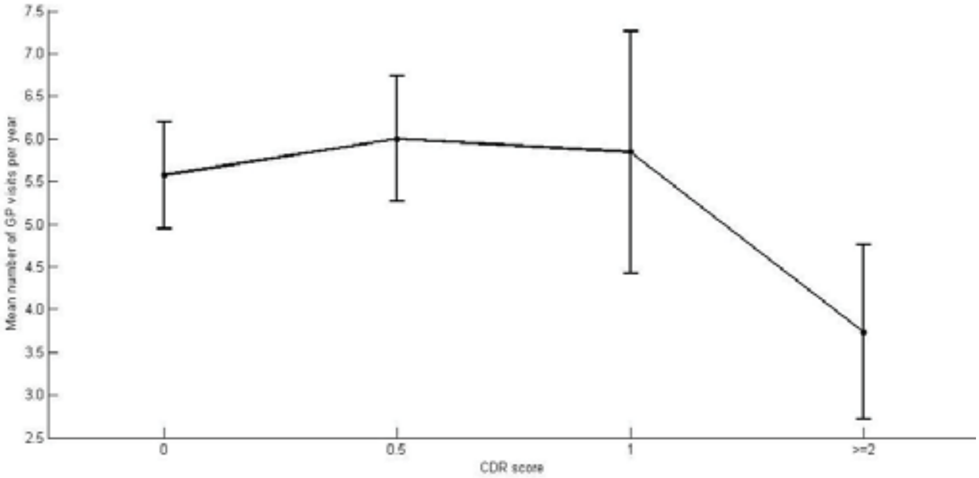
5 Summary of the results

5.1 Paper I

We report that people with moderate to severe dementia had fewer consultations with their GP compared with those with mild or no dementia (3.7 versus 5.8 per year, p=0.004) (Figure 2). Higher age was associated with fewer visits to the GP, while a heavier burden of affective symptoms was associated with more visits.

Figure 5: GP visits per year related to CDR score.



CDR 0: N=214; CDR 0.5: N=212; CDR 1: N=104; CDR 2: N=57; CDR 3: N=3; missing = 9

CDR 2 and CDR 3 are combined into one category (CDR score >=2) due to a low number of patients with CDR 3.

CDR = Clinical Dementia Rating scale, GP = General Practitioner

The additional analysis including an inverse probability weighting to account for selection bias due to high drop-out rate between BL and FU1 in the CONSIC cohort provided slightly different results. The previously published bivariate and multiple ordinal regression models (table 2) show that two more variables (agitation and psychosis) became significant after applying the inverse probability weighting approach. For every point increase on the agitation subscale the odds for belonging to a higher category of GP visits is reduced by 4%, while for every point increase on the psychosis subscale the chance for belonging to a higher category of GP visits is reduced by 8%.

Table 2. Ordinal regression (reference category >7) – published results adjusted by applying inverse probability weighting approach to adjust the estimates for dropouts and in this way to control for possible bias.

Variable	Bivariate regression		Multivariate regression unadjusted for confounder		Multivariate regression, adjusted for confounder	
	Coeff (95% CI)	p-value	Coeff (95% CI)	p-value	Coeff (95% CI)	p-value
Age	0.95 (0.93; 0.97)	**<0.001**	0.94 (0.92; 0.97)	**<0.001**	0.94 (0.92; 0.96)	**<0.001**
Sex (ref – men)	0.88 (0.70; 1.12)	0.301	0.92 (0.71; 1.21)	0.570	0.97 (0.73; 1.28)	0.833
Living alone (ref –						0.080
yes)	1.27 (1.00; 1.61)	0.050	1.28 (0.97; 1.68)	0.079	1.28 (0.97; 1.69)	0.412
CDR sum score	0.93 (0.90; 0.96)	**<0.001**	0.98 (0.93; 1.03)	0.360	0.98 (0.93; 1.03)	0.065
IADL mean	2.62 (1.74; 3.96)	**<0.001**	2.08 (1.04; 4.16)	**0.039**	1.98 (0.96; 4.10)	**0.036**
Agitation	0.96 (0.93; 0.99)	**0.005**	0.96 (0.93; 1.00)	**0.032**	0.96 (0.93; 1.00)	**0.023**
Psychosis	0.95 (0.90; 1.00)	0.059	0.93 (0.87; 1.00)	**0.039**	0.92 (0.86; 0.99)	**0.004**
Affective	1.02 (0.99; 1.04)	0.261	1.04 (1.02; 1.07)	**0.001**	1.04 (1.01; 1.07)	
GMHR						0.826
Poor	0.86 (0.55; 1.35)	0.509			0.94 (0.56; 1.58)	0.852
Fair	0.80 (0.56; 1.13)	0.207			0.96 (0.66; 1.41)	0.948
Good	0.90 (0.64; 1.27)	0.552			1.01 (0.71; 1.45)	-
Excellent – ref.	1	-			1	

5.2 Paper II

Three groups in patient-rated QoL-AD and three groups in proxy-rated QoL-AD were identified, with trajectories illustrated in Figure 6 and Figure 7, respectively. There were three different BL levels of patient-rated QoL-AD (Group-1 *n* = 80, Group-2 *n* = 249, Group-3 *n* = 83) and three different BL levels of proxy-rated QoL-AD (Group-1 *n* = 165, Group-2 *n* = 199, Group-3 *n* = 48), as judged by non-overlapping 95% CI. For both patient- and proxy-rated QoL, Group-1 represents the participants with the lowest QoL score at BL. The changes in QoL were, however, small and non-significant except for Group-2, which showed a small but statistically significant reduction in patient-rated QoL. The agreement between the group-belonging for patient and proxy ratings was low, indicating that patients and proxies assess QoL differently.

Figure 6. Trajectories for 18-month change in patient-rated QoL-AD. P-values refer to change in QoL from BL to FU within each group.

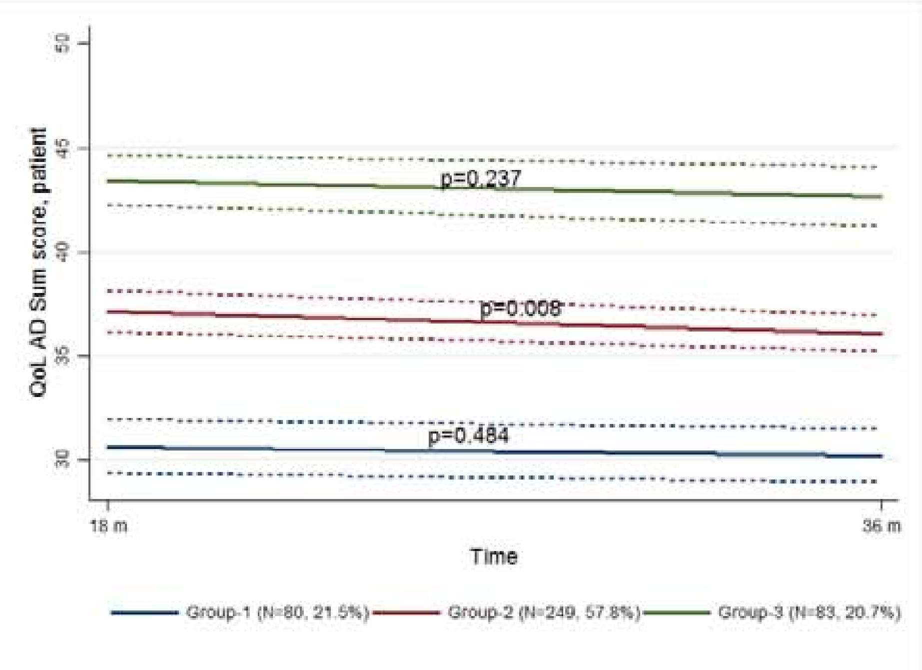
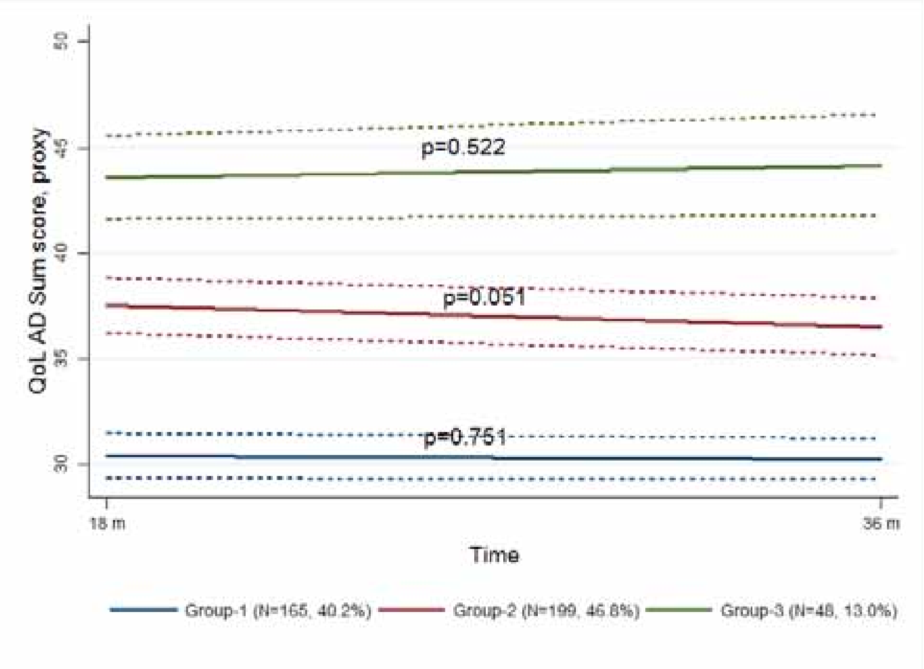


Figure 7. Trajectories for 18-month change in proxy-rated QoL-AD. P-values refer to change in QoL from BL to FU within each group.



In Table 3 of the published version of Paper II, data for the variables CSDD and NPI-Affective have been skewed to a different column. Please see the correct version of Table 3 in the synopsis appendix. Analysis of associations between individual characteristics and group-belonging (Group-1 versus Group-2 and/or Group-3) in patient-rated QoL showed that more depressive and affective symptoms and poorer GMHR were associated with higher chances of belonging to Group-1 compared to Group-2 or Group-3 independent of dementia diagnosis. Also, poorer GMHR and lower PADL and IADL functioning were associated with higher chances of belonging to Group-1 compared to Group-2 or Group-3 in persons with dementia.

Regarding group-belonging in proxy-rated QoL, more symptoms of depression and higher age were associated with higher chances of belonging to Group-1 compared to Group-2 or Group-3 independent of dementia diagnosis. Higher age was associated with lower chances of belonging to Group-1 versus Group-3 in persons with dementia. For persons without dementia, higher age was associated with lower chances of belonging to Group-1 versus Group-2.

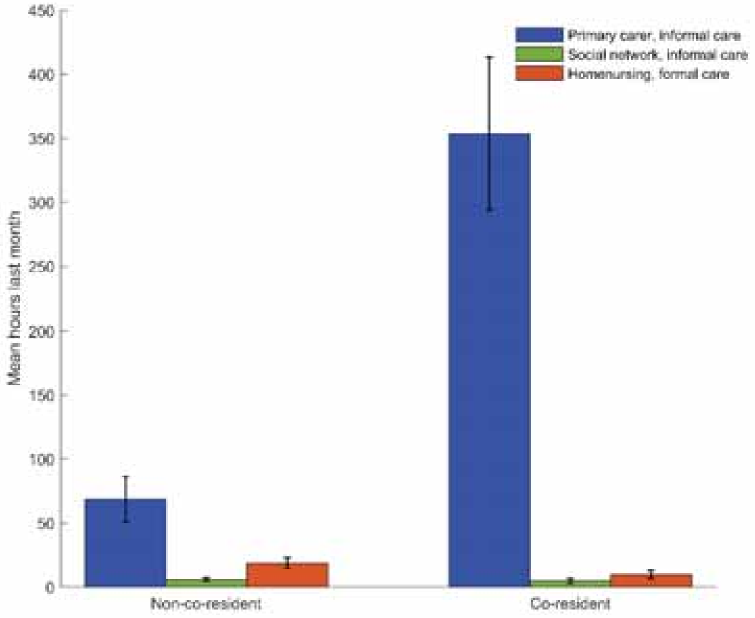
Analysis for differences in clinical variables between BL and FU showed a statistically significant decline in cognition (MMSE mean difference 1.63 [p<0.001]), CDR mean difference 0.23 [p<0.001]), physical function (PADL mean difference 0.26 [p<0.001]), physical health (GMHR [p>0.001]) and symptoms of depression (CSDD mean difference 0.55 [p=0.043]). Changes in instrumental functioning (IADL) and NPS as well as NPI sub-categories were non-significant.

5.3 Paper III

In Paper III we found that care for persons with dementia in the last month before admission to a NH relies heavily on the primary caregiver. Only half the sample received help from their extended social network, and the hourly contribution from both the wider social network and formal care were very low compared to that provided by the primary caregiver. Co-resident participants received significantly more informal care from the primary caregiver and less formal care than non-co-resident participants (Figure 8). The ratios of informal to formal care were 37.7:1 for co-resident participants and 3.2:1 for non-co-resident participants.

Analysis for associations between predefined covariates and informal care by the primary caregiver showed that male gender of the caregiver was associated with less informal care provision compared to female gender and that co-residency was associated with more care time compared to non-co-residency with differences varying depending on caregiver relation, age, and work status. More formal care was associated with poorer physical health.

Figure 8: Time used to care for participants during the last month before NHA.



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6 Discussion

6.1 Methodological considerations

6.1.1 Critical appraisal of the CONSIC study cohort

With one thousand participants at BL, the CONSIC study consists of a large cohort that despite the attrition during the FU period allows for inclusion of a larger number of covariates into the regression analyses. Representativeness of the original sample was strengthened by recruiting participants from a large part of Norway including both rural and urban municipalities. Unfortunately, we did not have data available to compare the 795 persons that refused participation with those included. The fact that dropouts had slightly worse cognitive function and physical health might have introduced a selection bias that is a threat to the representativeness of the samples in Paper I and Paper II. The additional analyses adjusting for possible bias in Paper I were therefore performed, showing that two additional variables became significant in the multiple model. There is a possibility of increased inter-rater variability as the assessment was done by health professionals who were not used to collecting data for research. A differentiation between AD and other causes of dementia could perhaps add value to our results. However, neither of the two study cohorts included differential diagnosis.

6.1.2 Critical appraisal of the REDIC-NH study cohort

The REDIC-NH study comprises 696 participants at BL and thus allows for robust statistical analyses as well as the analysis of sub-samples. Inclusion at NH admission provides relevant data about the time interval directly preceding admission and the study will provide observations over the whole course of the NH stay (though not part of this thesis).

However, there are several methodological issues regarding sampling and data collection that influence the representativeness of the cohort. Firstly, the REDIC-NH cohort was a convenience sample, meaning that it was a sample drawn from a population that is readily available. A convenience sample is exposed to bias due to possible, and not measurable, under-representation of sub-groups. Inferences outside the sample itself can therefore not be made (119). Neither the NHs nor the participants were randomly recruited; instead, the selection of NHs was based on practicalities such as collaborating centres that could collect the data and, on the aim, to include small and large NHs from both rural and urban areas.

The REDIC-NH project aimed to include all patients admitted to long-term stays in the 47 nursing homes. In total, 696 newly admitted patients and their next of kin were recruited in 47 NHs. Four of the NHs withdrew from the study during the process of performing BL examinations due to heavy workload. To compare included versus excluded participants, 38 NHs collected information on age and gender of all eligible participants. Of the 1,331 eligible participants in these 38 NHs, 607 were included, while 724 were excluded (205 did not consent to participate), 191 died before inclusion took place, and 338 for reasons unknown). Røen et al. compared age and gender of included versus excluded participants and found that those included were slightly older (84.5 [SD 7.5] vs. 83.6 years [SD 9.3], p=0.048), and a higher proportion were women (64.4% vs. 56.6%, p=0.004) (5).

The representativeness of the sample was improved by the substantial sample size and the large area from which the cohort was recruited. The distribution of age and gender of included participants in the REDIC-NH is similar to a previous Norwegian nursing home study (6). Thus, we assume that the REDIC-NH cohort is representative of patients being admitted to Norwegian nursing homes. However, mainly due to a group of participants lacking complete RUD forms, we only used a subsample of the REDIC cohort and thereby increased the risk of bias.

Another limitation is the median 10,7 weeks delay of BL data collection after admission. This delayed assessment might introduce recall bias with regard to the RUD data that was retrospectively obtained from the primary caregivers and susceptibility of the participants to changes in clinical status due to the long period in a new care setting. Although the health professionals collecting the data completed specific training, there is a possibility of inter-rater variability.

6.1.3 Design of the studies

Paper I

In Paper I we used the BL and FU1 data from the CONSIC cohort, adopting a prospective longitudinal design.

For every participant included into FU1, we merged data from a national registry on the use of GPs and municipal emergency services, achieving a complete set of data on the selected outcome variables. Thus, the use of registry data as outcome variables strengthens the reliability of our findings. Unfortunately, we had to deal with a high dropout rate mainly due to death but also because new consents had to be obtained to perform FU1 due to a revised protocol. Comparative analysis of included versus excluded participants showed that the excluded participants were slightly older; fewer were females, and they had lower IADL functioning and poorer physical health. Thus, our sample comprised a selected group of patients, further compromising generalizability of our findings. However, despite the high attrition, the sample size was still of considerable size. Another weakness in the design of Paper I was that we used persons without dementia in the CONSIC cohort as a control group. As they were all recipients of municipality care services, they were not representative of the general home-dwelling population without dementia. In Paper I we generalized the findings to the whole elderly population of Norway as reflected in the title and conclusions. However, in light of the inclusion criteria this might not be justified. Also, in the comparison of persons with and without dementia, the GMHR measuring physical health status could be a confounding factor as persons without or with mild dementia, but in need for home-care service, may have a higher rate of comorbidity than persons with more severe stages of dementia.

The clinical variables available for the multiple ordinal regression analysis had low predictability of the frequency of GP use per year. We only included the broad four-dimensional GMHR as a measure of physical health and co-morbidity. An instrument collecting more information about comorbidities might be a better predictor of the use of GPs as the most common reasons for visiting the GP were related to physical health.

Paper II

We wanted to study the change in QoL over time in home-dwelling persons with dementia and selected a prospective longitudinal design using the CONSIC cohort. Unfortunately, measures of QoL were not included in the BL data collection in CONSIC. Hence, we had to use data from the first and second FU. Thus, the FU1 in the CONSIC study became BL in our QoL study, and the FU2 in CONSIC became FU1 in Paper II. This might have resulted in a selection bias in our sample due to the high attrition between BL and FU1 in the CONSIC study.

Between FU1 and FU2, we lost another 187 participants, mainly due to death. Comparative analysis showed that the participants who dropped out were older, had more impaired cognition, more impaired physical and IADL functioning, and more impaired physical health. Also, among the excluded participants there were more men than among those included. Thus, our study sample was selected with a bias towards better health outcomes compared to the general home-dwelling population receiving in-home care, and we cannot reject the possibility that the small changes to QoL in our study sample was perhaps an artefact of a very high attrition represented by participants with worse health outcomes than the group remaining in the study.

We hypothesized that an 18-month observation period would be long enough to detect changes in QoL. The changes were, however, small and mostly non-significant. A period of 18 months' observation is perhaps too short to detect changes in QoL. Maybe the QoL instruments are not sensitive enough to pick up longitudinal changes, or probably QoL is a stable personal characteristic.

The inclusion of persons with and without dementia and persons at different stages of dementia resulted in a heterogenic sample. An improvement to the design of the study would have been better defined inclusion criteria resulting in a more homogenous sample.

The included clinical measures in Paper II were all relevant as predictors of the outcomes, but we lacked relevant measures of caregiver burden and depression in caregivers, both of which have been associated with proxy-rated QoL in previous studies (86, 87, 89). Also, the design was not capable of assessing other more individual determinants of QoL such as the participants' personalities comprising their history, culture and beliefs, values, family relations, and individual perceptions of QoL.

Paper III

In Paper III, by analysing the REDIC-NH cohort, we applied a cross-sectional design to investigate the use of formal and informal care in home-dwelling persons with dementia in the month before admission to a nursing home.

In all, 696 participants who had completed the BL assessment were included. We decided to exclude participants without dementia (113), participants not admitted to a long-term stay (138), and participants without completed RUD forms (50). The reason for excluding these participants was to increase homogeneity and describe the use of resources in a dementia population exclusively. Comparison analysis of the included versus those who were excluded due to incomplete RUD showed no significant differences in clinical and sociodemographic measures.

A problem with the design was the retrospective approach in which information about both formal and informal resource utilization was collected from the primary caregiver. This subjective evaluation of the amount of care provided by professional home care services may have introduced recall bias. In order to increase the reliability of the formal care data, we could have asked each municipality to provide the data. However, due to earlier experience with collecting registry data from municipality administrations, this was not considered to be feasible. The self-evaluated caregiver contribution to informal care is also a concern regarding reliability, as is demonstrated by some caregivers reporting more than 24 hours of care per day.

Another weakness with the design is that all clinical assessments were completed after admission to the NH. Admission to a nursing home is such a significant event that it may have caused sudden changes in cognition, physical functioning, mood, or behaviour in the participants. Consequently, we could not use most of the clinical assessments as explanatory variables in the regression models.

We consider the information collected by the RUD instrument as sufficient to evaluate the use of formal and informal care in our sample. We could have included more formal care variables such as home help, meals on wheels, adult day care, or transportation, but we chose not to as only a small minority of the participants used these services. Perhaps organizational factors (e.g., distance to the care delivery office, municipality profile, population size, rural versus urban) could have explained more of the variation in the delivery of formal care than the clinical and demographical measures we included.

6.1.4 Statistical analysis

An experienced biostatistician took part in the entire process of the REDIC-project, co-supervised the PhD candidate, and co-authored the three papers.

Before selecting statistical methods, we first formed aims of the study and stated our hypotheses. We then consulted the biostatistician who suggested possible statistical analyses, which we discussed in the research group until a conclusion was reached. The PhD candidate prepared the data and performed descriptive analyses of the samples and tests, comparing the independent groups under the supervision of the main supervisor. The entire group of authors was involved in decisions regarding the explanatory variables to be included in the regression models. The biostatistician performed the final analysis in all three papers and supervised the candidate with the interpretation of the results.

Both the CONSIC and the REDIC cohorts were established for other purposes than the present doctoral thesis and the candidate did not participate in the planning or execution of the data collection. The candidate has, therefore, limited knowledge of initial considerations regarding sample size and power. In the planning of Paper I, Paper II, and Paper III, the candidate and the co-writers considered the two cohorts to be large enough to perform the chosen statistical analyses.

Initially, in the work with Paper II, we found only small differences in BL QoL between persons with and without dementia. Thus, instead of stratifying the cohort into persons with and without dementia, which would also considerably reduce the sample size, we applied the group-based trajectory models that explores the data by looking for groups of participants that follow similar patterns in the outcome variable, QoL. The identified groups may later be compared with respect to participants' characteristics, for example, dementia status. One or more identified groups could mainly include persons with dementia, while other(s) mainly persons without dementia. Our results did in fact show that

Group-3 of patient-rated QoL includes fewest persons with dementia, while Group-1 of proxy-rated QoL includes more than half of the persons with dementia in the sample. The GBTM is a recognized statistical methodology for analysing developmental trajectories and the evolution of an outcome over time (120). While the standard methods of studying developmental trajectories such as hierarchical modelling and latent curve analysis are designed to study the individual's variability around a mean population trend, the GBTM, under the assumption that the general population is composed of distinct subpopulations, divides the sample into two or more meaningful subgroups that share similar and distinctive developments in the outcome. Thus, the BL values of the identified groups were not decided in advance. On the contrary, the "cut-offs" were decided based on the individual trajectories that were grouped together according to recognized statistical criteria. Despite being technically sophisticated, the GBTM method provides a graphic presentation of the distinct trajectories of development, which have the advantage of being easy to comprehend (120).

Nominal regression models were estimated to assess the covariates associated with group-belonging. To analyse the impact dementia had on these associations, we included interactions between the covariates and dementia status in the multiple regression models. Significant interaction implies different type of association among those with and without dementia.

6.2 Results and implications

6.2.1 The use of primary health services and care among home-dwelling persons with dementia

In Papers I and III we assessed two aspects of primary care resource use among home-dwelling persons with dementia: 1) the use of GP and municipal emergency services, and 2) the use of formal and informal care in the last month before NHA.

We could for the first time show that persons with moderate and severe dementia visited their GPs fewer times per year than persons with MCI or no dementia. Furthermore, we found that older age, and more symptoms of agitation or psychosis predicted fewer visits, while more affective symptoms predicted more frequent visits. There were no differences in the use of emergency services between persons with and without dementia.

In Paper I we suggested that the discrepancy in visits to the GP between persons with and without dementia might be explained by the reasons for the visits, as almost 40% of the diagnoses at GP consultations were related to cardiovascular complaints, and only 5% were related to dementia. Contrary to dementia-related problems, cardiovascular conditions and pain have proper treatment regimens that are well known to the public and other health professionals. Yet, this does not adequately explain why persons with dementia use their GP less often as they may also have cardiovascular complaints. Maybe persons with dementia seek less medical treatment due to reduced initiative caused by impairments in IADLs (121). Or perhaps the difference in GP visits is related to the patients' expectations of what services a GP can provide and what type of health problems can be cured. There is a possibility that the lack in medical follow-ups by the GPs among persons with moderate to severe dementia in the sample where substituted with adequate nursing care in the patients' homes. Unfortunately, these data were not collected.

The published ordinal regression model from Paper I with the new unpublished adjustments to control for dropouts and potential selection bias (Table 2) showed that more agitation and psychosis predict fewer GP visits. Both agitation and psychosis are symptoms frequently associated with dementia, especially in severe stages. Perhaps family caregivers or the home care services are reluctant to take a person with agitation or psychosis symptoms to the GP due to fear of enhancing the agitation or fear that the person's appearance or behaviour will reduce the chance for a successful examination.

Due to a lack of data on the use of other municipality services and specialist care services, we only presented data on GP and municipality emergency services in Paper I. There is a possibility that other services may replace the less frequent use of GP among persons with moderate to severe dementia. However, data from the REDIC-project showed no difference in the number of in-hospital stays. At the same time, persons with dementia had a lower number of outpatient appointments, suggesting that secondary health care does not serve as a supplement for the use of primary health care in persons with dementia. In a German study on the utilization of formal care services across stages of dementia, it was found that persons with moderate to severe dementia not only utilized the GP less than persons without dementia, but they also had fewer outpatient appointments and fewer planned in-hospital treatments and rehabilitation (62). As a visit to the GP or the hospital can be very troublesome for a person with moderate or severe dementia as well as for their caregiver, a measure to secure adequate follow-up of persons with dementia might consist of customized arrangements for contact with health services. A promising example is interdisciplinary 'dementia teams' that are organized in many municipalities in Norway and include GPs or geriatric specialists that cooperate in investigating and diagnosing dementia. Continued cooperation between municipal health services and

GPs may also be helpful in monitoring the progression and symptoms of the disease as well as the needs of persons with dementia living at home.

In Paper III we found that co-resident participants received significantly more informal care than non-co-residents, while provision of formal care was higher among participants in single households compared to co-resident participants. Although previous studies have shown discrepancies in the utilization and costs of formal and informal care between co-resident and non-co-resident persons with dementia, this is the first time it is reported in a large Norwegian sample (57, 62, 63, 69, 122).

The report of differences in formal care provision between co- and non-co-resident persons with dementia has sparked a discussion of whether the relationship between formal and informal care is substitutive or complementary. A positive correlation between formal and informal care would indicate that the relationship is complementary, while a negative correlation would suggest a substitutive relationship. In our sample, formal and informal care were not correlated, but the significant difference in formal care use based on the living situation suggests a substitutive relationship which is in line with the findings in several other European countries, especially in countries in the northern and western regions (59).

However, it has been suggested that the way informal care is correlated to formal care in southern European countries reflects a more explicit substitutive relationship, and that in central and northern parts of Europe, formal care actually takes over when informal care becomes too demanding or when the primary caregiver is exhausted or sick, which represents a complementary relationship (123). A north-south gradient in the balance of formal versus informal care was suggested by a study that compared informal caregiving in a Swedish and Italian home-dwelling population and found that the Italian caregivers provided almost double the number of informal care hours per day compared to the Swedish. Also, a significantly larger proportion of the Italian caregivers were co-habitants with the participants, indicating cultural differences between the two countries (124). In addition, informal care hours were associated with co-residency at the bivariate level, but when adding IADL into the multiple regression, co-residency was no longer significant, while lower IADL functioning was significantly associated with informal care hours. The authors suggested that the relationship between more informal care hours and co-residency was caused by an interaction between low IADL functioning and co-residency, meaning that the choice of co-residency might be influenced by the level of dependency of the person with dementia (124).

There are few previous studies examining the contribution of the extended social network to informal care, and this aspect might have been overlooked in previous studies. We found that the extended social network only contributed to a small degree, providing less than 5% of the total informal care. Gage et al. found in a small subsample that persons with dementia who were living alone received one hour per week from caregivers other than the primary caregiver compared to 10 hours per week from the primary caregiver (69). Almost half the participants in our sample in Paper III did not have any additional carer besides the primary caregiver, while only 7% had two or more. The sparse involvement of family and friends might be due to modern family structures in the Nordic countries where families live farther apart from each other, or the person with dementia might become more isolated over time due to disease progression.

The low contribution from the wider social network and the strain put on primary caregivers without a network might be a challenge that could be overcome by, for example, dementia information campaigns to reduce stigma and recruit more volunteers or by the use of case managers in the municipalities who work closely with the primary caregivers, offering appropriate care services to persons with dementia and support to the caregiver (125). A previous study found that caregivers receiving help and support from their wider social network were less likely to experience high levels of caregiver burden (64), hence steady support from the extended social network for persons with dementia and their caregivers might also contribute to delaying nursing home admission.

As described in chapter 2.2.3., higher use of informal care has in previous studies been associated with co-residency, more deficits in ADL, more comorbid conditions, lower cognition, worse dementia severity, more NPS, more formal care use, frailty, and non-employment status of the primary caregiver. We could not include the measures of ADL, cognition, NPS, and depression in our models because of the relatively long period from admission to BL assessments in our study. Instead, because the association with living situation was so well documented, we wanted to see if co-residency had a mediating effect on the factors that we could include in the models. We found that the difference in informal care use between co-residents and non-co-residents was higher in participants with employed caregivers compared to non-employed. Furthermore, higher age was associated with fewer hours of informal care and with a higher reduction in co-residents compared to non-co-residents. Perhaps less informal care is needed with people of older age because age is also associated with more comorbidities, poorer physical health, and more severe dementia, all causing the persons with dementia to require less supervision and surveillance. It may also be related to the higher age of co-resident primary caregivers, who in most cases are the participants' spouses.

Studies conducted in the US and central Europe have found that older age of patient and caregiver, awareness of service, caregiver with higher education, and caregivers' subjective evaluation of need for service predict more use of formal care (126). Perhaps raising the awareness of available services and services directed at the needs defined by the informal caregiver would equalize the differences in formal care provision between co-resident and non-co-resident persons with dementia.

The positive association we found between formal care and poor and fair physical health as assessed by the GMHR scale implies that the formal care services provide more services to persons who, in addition to dementia, have other comorbidities and are more physically ill. Hence, the formal care services seem to be more directed towards PADL dependencies and reduced physical health. Previous studies have found associations between formal care and PADL dependencies in dementia, while dementia severity and neuropsychiatric symptoms are seldom mentioned in relation to utilization of formal care (59, 62, 65, 67). Thus, it seems that formal care services do not have the skills or capacity to take on more typical dementia-related problems. An emerging critique of formal care services across Europe is that they are too general and are not designed to offer individualised services (127).

A recent study from the UK, where a group of informal caregivers and a group of health professionals were asked to allocate formal and informal services to five different case vignettes (home-dwelling persons at different stages of dementia either living alone or in co-residency), found that the expert health professionals allocated equal amounts of care load on both types of care, while the expert informal caregivers placed a heavier load on formal care services such as day-care and provision of hot meals (128). This finding implies that informal caregivers of home-dwelling persons with dementia search for more formal care services, especially the type of services that provide respite to the informal caregivers. In addition, both expert panels allocated vastly more hours of formal care than the average reported in studies of formal care utilization (128).

6.2.2 Quality of life among home-dwelling persons with dementia

The aim was to describe longitudinal course in quality of life (QoL) in a large sample of home-dwelling persons with and without dementia and to explore factors associated with QoL course. For each participant, the QoL was rated twice: by the participant herself and by the proxy. For both QoL ratings, three groups with distinctive BL QoL were identified, all with separate and almost flat trajectories. In both the patient- and proxy-rated QoL, the middle group (Group-2) experienced the most reduction in QoL. The reductions were, however, small and only significant for patient-rated QoL; hence, the clinical significance of this finding is probably low. The kappa agreement between patient- and proxy-ratings was low, indicating that patients and proxies assess QoL differently. This is also illustrated by the differences in size of the groups defined by the trajectories between the two ratings. For example, Group-1 of proxy-rated QoL included more than twice the number as the patient-rated. Hence, the proxies' score the participants' QoL lower than the participants' themselves'. The difference between self and proxy rated QoL is very much in line with other studies in which proxy ratings are almost consistently lower than self-ratings as described in chapter 2.3.3. Previous studies have not reported changes in patient-rated QoL over 12-24 months, but many studies report reductions in proxy-rated QoL alongside reductions in clinical characteristics such as cognition, ADL, and IADL function, more NPS, and more depressive symptoms (82-84, 87). Perhaps the QoL measure is not sensitive enough to pick up changes in self-perceived QoL despite the increasing load of dementia-related clinical symptoms, or maybe self-perception is altered by the dementia.

Our findings showed that higher patient-rated QoL was associated with better ADL and IADL functioning and that lower patient-rated QoL was associated with more NPS and depressive symptoms. As all these clinical measures were obtained through interviews with the caregivers, we would expect a stronger association with proxy-rated QoL than patient-rated QoL, while in fact we found the opposite. On the other hand, insight and awareness is affected by dementia and has previously been shown associated with QoL in persons with dementia (88, 95). Due to reduced awareness, the scoring of one's own QoL might be more strongly affected by a recent episode in persons with dementia than persons without dementia.

Another explanation for the lack of changes to patient-rated QoL could be that the perception of QoL may change through the course of the disease as a response to the changes accompanying dementia. Adaptation to a different life situation has been described in previous studies of persons with other diseases or disabilities and might be reflected in findings that patient-rated QoL seems to be reduced already in mild dementia where insight and self-awareness are higher (98).

Although the closest caregivers represent a vital source of information regarding the health status of persons with dementia, we should be aware of the differences between subjective and objective evaluations of QoL and that a caregiver's evaluations of the QoL of the person in their care might be affected by changes in disease symptoms, caregiver burden, and the caregiver's own QoL (87, 89, 90). It is therefore essential to evaluate both perspectives and view them as complementary (85, 93, 129).

Thus, in the present as well as in previous studies, we have probably acquired more knowledge about caregivers' perceptions of QoL of persons with dementia and the factors related to caregivers' perceptions, but not enough about factors related to the QoL in the perspectives of persons with dementia, which might to a higher degree be related to individual, cultural, and personal factors, and whether life is perceived as meaningful despite disease and disability.

Depression is common in dementia, and we found that more depressive symptoms were associated with a higher chance of belonging to both the lowest patient-rated and proxy-rated QoL-group. The association between depressive symptoms and lower QoL has been reported in numerous studies (82, 84-90, 95) and is probably the most reported significant factor in studies including self-ratings of QoL. Although this association could be due to similarities between depression and QoL scales, it is reasonable to assume that depression has a detrimental effect on QoL and should be assessed in all persons with dementia and, if found, treated.

In line with previous studies, we also found that higher scores on NPI-Affective, comprising the variables apathy, anxiety, and depression of the NPI, were associated with poorer patient-rated QoL (87).

Furthermore, the two lowest categories of GMHR, poor and fair, were associated with lower patient-rated QoL independent of dementia status. This finding suggests that poorer physical health is associated with lower QoL regardless of cognitive impairment.

Moreover, impaired PADL and IADL functioning were associated with lower patient-rated QoL in persons with dementia. This association has previously been found more commonly in the analysis of associations with proxy-rated QoL (82, 88), but a few recent studies have reported similar associations, confirming that PADL and IADL functioning is important to the QoL of persons with dementia (87, 89, 130).

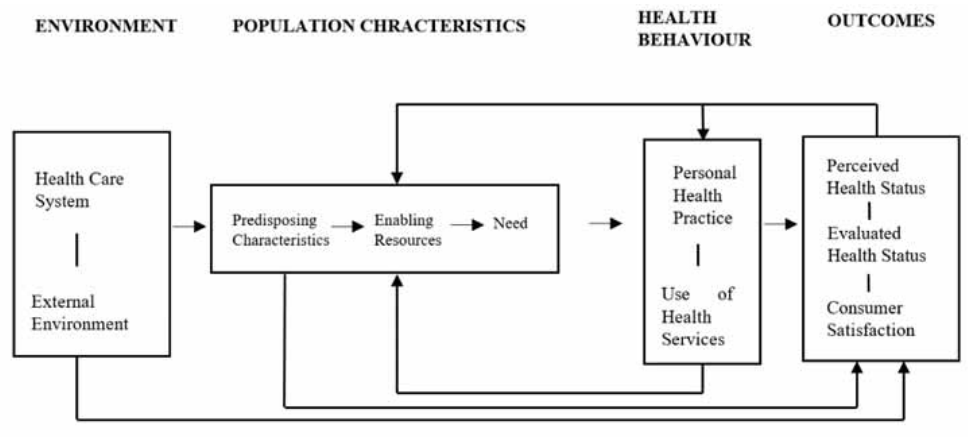
An interesting finding was that higher age was associated with higher proxy-rated QoL for persons with dementia, while for persons without dementia, higher age was associated with lower QoL. This association has previously been reported by Andrieu et al., who suggested an overestimation of the QoL of persons with dementia and that it happened because caregivers may take the patients' ages into account when assessing their QoL (87).

In the conclusion of Paper II, we stated that "despite significant changes in clinical parameters, patient- and proxy-rated QoL in an elderly population did not change substantially over a period of 18 months.” Unfortunately, the data describing changes in clinical parameters were not included in the published version of the paper manuscript. Hence. I have added the data from these analysis in chapter 5.2 “Summary of the results” in this synopsis. The additional analysis showed that there was a statistical decline in cognition, physical functioning, and physical health while symptoms of depression decreased slightly. There was no change in instrumental ADL functioning and neuropsychiatric symptoms. Although changes to clinical variables were statistically significant, they might not be clinically important as shown by the relatively low mean differences. It is also important to notice that the symptoms of depression were slightly lower at FU. The lack of notable changes in clinical variables may explain the low change to QoL and support the statement that 18 months observation time is too short to detect more pronounced changes in QoL.

6.2.3 Application of the conceptual framework

When conceiving this thesis, I applied Andersen’s Behavioural Model of Health Service Use, which aims at explaining the individual’s use of health care by predisposing, enabling, and need factors. The original model developed further to include more elements like health status outcomes and feedback loops. There have also been introduced the concept of mutability, meaning the organisation of health care services and health policies might not only act as enabling factors but also impact other enabling factors and perceived needs (Figure 9).

Figure 9. A revised version of Andersen’s Behavioural Model of Health Service Use (1)



In this thesis, we chose health behaviour as our outcome measure in Paper I and III and explored the impact of predisposing characteristics and needs (Paper I) and enabling resources (Paper III). In Paper II, we chose QoL as a health status outcome and explored the impact of predisposing characteristics and need.

However, there are a number of factors not included in our studies and were neither included in the REDIC project as a whole, namely the impact of the environment and consumer satisfaction.

The health care systems determine accessibility and out-of-pocket payments, and thus has an important impact on consumer behaviour. Compared to other European countries, the Norwegian health care system regulates access to secondary health care more strongly through the gatekeeper function of the patient's GP, while care services like home nursing or nursing home stay generate lower costs to the patient and his family. While the inclusion of these factors would warrant multinational designs and thus be beyond the scope of this thesis, it is important to keep in mind that environmental factors were not part of our analyses and that our results, therefore, might not be transferable to other countries. The same reservations apply for cultural differences. For example, might the Norwegian attitude towards accepting help from persons outside the immediate family impact the extent of informal care by the wider social network. Secondly, we examined QoL as a health outcome but did not collect data about how the use of health care services affects the patients' QoL, their health state, or the consumer satisfaction of the patients and their proxies.

I would argue that a complex model like Andersen's cannot be proven in one clinical study but has to be explored bit by bit. Still, the model is valid and relevant to place the study designs and the results into a larger picture to evaluate their transferability and to plan further research to fill in the missing links.

7 Conclusions, implications for practice, and directions for future research

To contribute to the knowledge about the course of dementia in Norway, we investigated two aspects of primary health care service use and the QoL of home-dwelling persons with dementia.

We found that persons receiving home care with moderate to severe dementia consulted their GP less often than persons with mild or no dementia. While affective symptoms predicted more frequent visits, age, agitation and psychosis symptoms predicted fewer visits to the GP. This original finding may indicate a need for better interaction between municipal care, social services, and the GPs. In order to detect and meet the needs of persons with moderate to severe dementia, routine follow-ups by their GPs should be ensured, for example, by regular home visits. We recommend better interaction between municipal care, social services, and GPs, as well as interventions that aim to strengthen the quality of medical follow-up for this group.

Since the study was conducted, the Norwegian government has released a new national dementia strategy with the aim to try out different models of municipal multidisciplinary teams that in a timely manner would examine, diagnose, and provide adequate follow-up to home-dwelling persons with dementia. Future research should investigate possible changes incurred by these models to the medical, physical, and social state of home-dwelling persons with dementia.

Our findings suggest that QoL is a highly subjective and complex measure that in addition to somatic or mental illnesses are likely to include other areas in life. Therefore, the complexity of QoL is important to consider when applying QoL as an outcome measure in clinical studies. In addition, we need to be aware that QoL is evaluated differently by participants and their proxies, and that different factors are related to the two perspectives. Depending on the type of intervention, it may be appropriate to include both measures. To lessen the reduction in QoL among persons with dementia, we need to detect and treat depression, which is very common in dementia.

We found that in the month immediately before nursing home admission, the primary caregiver provided most of the informal care in the home with very little help from the extended social network. Thus, in order to reduce the burden on family caregivers and perhaps delay NHA, we need to provide more support to informal caregivers, especially co-resident caregivers. Future research should explore innovative approaches to realizing the care potential among family, friends, and volunteers and, moreover, investigate the perceived needs of the co-resident caregivers to target them with tailored services.

The level of informal care was considerably higher than the level of formal care, independent of the living situation. The formal care services seem to mainly target physical dependencies and general health problems. Hence, we need to direct future research towards developing formal care services that better match the needs of persons with dementia. More and better services individualized to the persons with dementia and their primary caregivers' needs may have the potential to prolong the period they stay at home, delaying or reducing the need for long-term institutional care.

Due to demographic changes worldwide, the number of persons with dementia will increase in the following decades, and we should work for a society that includes and supports them.

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Appendices

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Appendix 1 – Resource use and Disease Course in Dementia (REDIC) – Summary

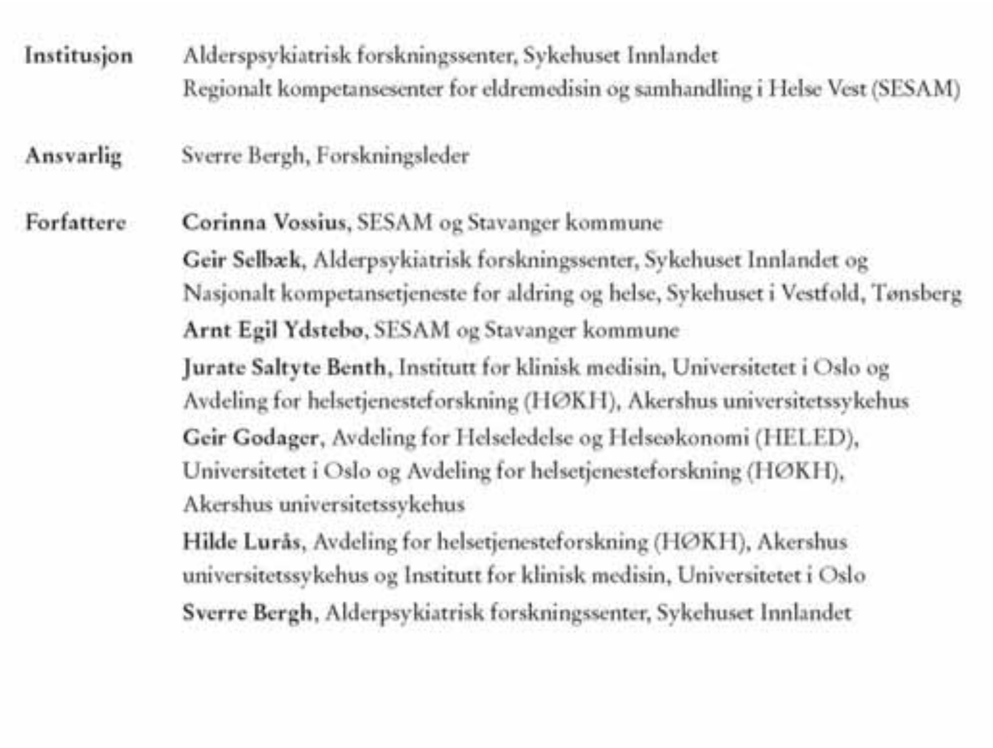
Corinna Vossius | Geir Selbæk | Arnt Egil Ydstebø | Jurate Saltyte Benth | Geir Godager | Hilde Lurås | Sverre Bergh

Ressursbruk og sykdomsforløp ved demens (REDIC) langversjon

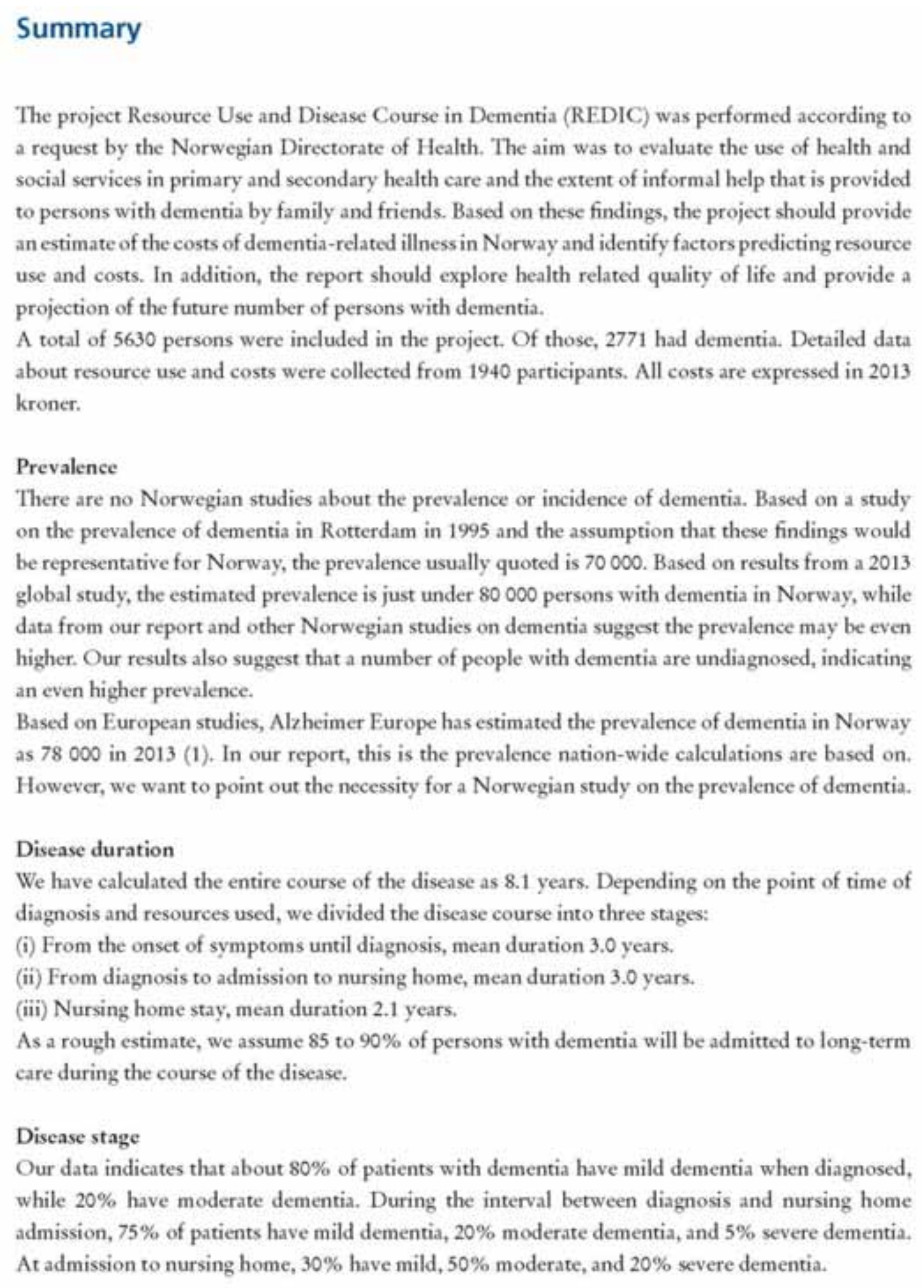
November 2015

Utgitt av:
Alderspsykiatrisk forskningssenter
Sykehuset Innlandet

Sykehuset Innlandet HF



Institusjon	Alderspsykiatrisk forskningssenter, Sykehuset Innlandet Regionalt kompetansesenter for eldremedisin og samhandling i Helse Vest (SESAM)
Ansvarlig	Sverre Bergh, Forskningsleder
Forfattere	**Corinna Vossius**, SESAM og Stavanger kommune **Geir Selbæk**, Alderpsykiatrisk forskningssenter, Sykehuset Innlandet og Nasjonalt kompetansetjeneste for aldring og helse, Sykehuset i Vestfold, Tønsberg **Arnt Egil Ydstebø**, SESAM og Stavanger kommune **Jurate Saltyte Benth**, Institutt for klinisk medisin, Universitetet i Oslo og Avdeling for helsetjenesteforskning (HØKH), Akershus universitetssykehus **Geir Godager**, Avdeling for Helseledelse og Helseøkonomi (HELED), Universitetet i Oslo og Avdeling for helsetjenesteforskning (HØKH), Akershus universitetssykehus **Hilde Lurås**, Avdeling for helsetjenesteforskning (HØKH), Akershus universitetssykehus og Institutt for klinisk medisin, Universitetet i Oslo **Sverre Bergh**, Alderpsykiatrisk forskningssenter, Sykehuset Innlandet



Summary

The project Resource Use and Disease Course in Dementia (REDIC) was performed according to a request by the Norwegian Directorate of Health. The aim was to evaluate the use of health and social services in primary and secondary health care and the extent of informal help that is provided to persons with dementia by family and friends. Based on these findings, the project should provide an estimate of the costs of dementia-related illness in Norway and identify factors predicting resource use and costs. In addition, the report should explore health related quality of life and provide a projection of the future number of persons with dementia.

A total of 5630 persons were included in the project. Of those, 2771 had dementia. Detailed data about resource use and costs were collected from 1940 participants. All costs are expressed in 2013 kroner.

Prevalence

There are no Norwegian studies about the prevalence or incidence of dementia. Based on a study on the prevalence of dementia in Rotterdam in 1995 and the assumption that these findings would be representative for Norway, the prevalence usually quoted is 70 000. Based on results from a 2013 global study, the estimated prevalence is just under 80 000 persons with dementia in Norway, while data from our report and other Norwegian studies on dementia suggest the prevalence may be even higher. Our results also suggest that a number of people with dementia are undiagnosed, indicating an even higher prevalence.

Based on European studies, Alzheimer Europe has estimated the prevalence of dementia in Norway as 78 000 in 2013 (1). In our report, this is the prevalence nation-wide calculations are based on. However, we want to point out the necessity for a Norwegian study on the prevalence of dementia.

Disease duration

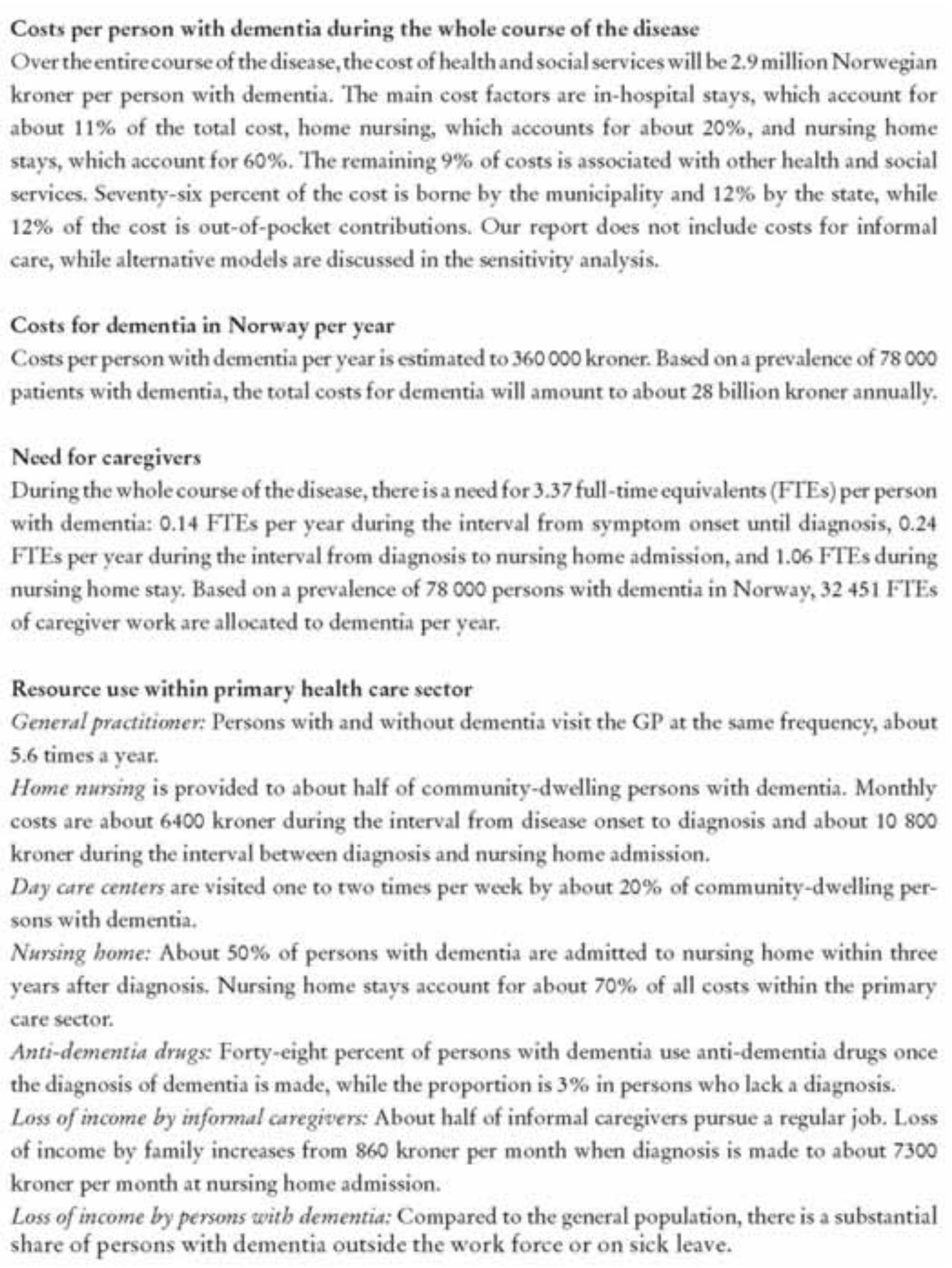
We have calculated the entire course of the disease as 8.1 years. Depending on the point of time of diagnosis and resources used, we divided the disease course into three stages:

(i) From the onset of symptoms until diagnosis, mean duration 3.0 years.
(ii) From diagnosis to admission to nursing home, mean duration 3.0 years.
(iii) Nursing home stay, mean duration 2.1 years.

As a rough estimate, we assume 85 to 90% of persons with dementia will be admitted to long-term care during the course of the disease.

Disease stage

Our data indicates that about 80% of patients with dementia have mild dementia when diagnosed, while 20% have moderate dementia. During the interval between diagnosis and nursing home admission, 75% of patients have mild dementia, 20% moderate dementia, and 5% severe dementia. At admission to nursing home, 30% have mild, 50% moderate, and 20% severe dementia.



Costs per person with dementia during the whole course of the disease

Over the entire course of the disease, the cost of health and social services will be 2.9 million Norwegian kroner per person with dementia. The main cost factors are in-hospital stays, which account for about 11% of the total cost, home nursing, which accounts for about 20%, and nursing home stays, which account for 60%. The remaining 9% of costs is associated with other health and social services. Seventy-six percent of the cost is borne by the municipality and 12% by the state, while 12% of the cost is out-of-pocket contributions. Our report does not include costs for informal care, while alternative models are discussed in the sensitivity analysis.

Costs for dementia in Norway per year

Costs per person with dementia per year is estimated to 360 000 kroner. Based on a prevalence of 78 000 patients with dementia, the total costs for dementia will amount to about 28 billion kroner annually.

Need for caregivers

During the whole course of the disease, there is a need for 3.37 full-time equivalents (FTEs) per person with dementia: 0.14 FTEs per year during the interval from symptom onset until diagnosis, 0.24 FTEs per year during the interval from diagnosis to nursing home admission, and 1.06 FTEs during nursing home stay. Based on a prevalence of 78 000 persons with dementia in Norway, 32 451 FTEs of caregiver work are allocated to dementia per year.

Resource use within primary health care sector

General practitioner: Persons with and without dementia visit the GP at the same frequency, about 5.6 times a year.

Home nursing is provided to about half of community-dwelling persons with dementia. Monthly costs are about 6400 kroner during the interval from disease onset to diagnosis and about 10 800 kroner during the interval between diagnosis and nursing home admission.

Day care centers are visited one to two times per week by about 20% of community-dwelling persons with dementia.

Nursing home: About 50% of persons with dementia are admitted to nursing home within three years after diagnosis. Nursing home stays account for about 70% of all costs within the primary care sector.

Anti-dementia drugs: Forty-eight percent of persons with dementia use anti-dementia drugs once the diagnosis of dementia is made, while the proportion is 3% in persons who lack a diagnosis.

Loss of income by informal caregivers: About half of informal caregivers pursue a regular job. Loss of income by family increases from 860 kroner per month when diagnosis is made to about 7300 kroner per month at nursing home admission.

Loss of income by persons with dementia: Compared to the general population, there is a substantial share of persons with dementia outside the work force or on sick leave.

Resource use within the secondary health care sector

There was no significant difference between persons with and without dementia regarding in-hospital stays, while persons without dementia visited outpatient clinics more often. For home-dwelling persons with dementia, costs for specialist care amounted 2000 to 4500 kroner per month. During nursing home stays, these costs decreased to 1350 kroner.

Informal care

The majority of persons with dementia (90%) receive informal care from relatives or friends. Already at diagnosis, 60 to 80 hours of informal help are provided per month. During the last period before admission to nursing home, the amount of informal care increases to 160 hours per month, equivalent to a whole FTE. During the nursing home stay, relatives provide help 6.7 hours per month, indicating that the institution's staff generally provide care.

Cost-predicting factors

The level of functioning shows the strongest association with increased resource use, both in formal and informal care settings. Furthermore, neuropsychiatric symptoms, cognitive impairment, and general health are clinical factors associated with increased resource use. Living alone is associated with increased use of municipal health and care services, but with less caregiver time. This is probably because the closest caregiver usually lives with the patient.

The analysis of demographic and organizational factors on the municipal level shows that costs are lower in municipalities with a higher population. Our data also indicates that a high coverage ratio of nursing homes is related to lower overall cost for municipalities. However, this finding is not significant in the multivariate analysis.

Health related quality of life

Our results show that proxies rate the patients with lower quality of life than the patients do themselves. The gap increases with an increasing degree of dementia. Quality adjusted life years (QALYs) are mainly lost due to premature mortality in persons with dementia and to a lesser degree due to reduced quality of life.

Projections

Based on population projections that assume a medium alternative, the number of persons with dementia increase to about 112 000 by 2030 and to 200 000 by 2060, equivalent to 3% of Norway's total population. Assumed that the use of nursing homes remains unchanged in the future, there will be a need for 40 000 nursing homes beds for persons with dementia in 2030 and 70 000 beds in 2060.

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Appendix 2 – Paper I

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The impact of dementia on the use of general practitioners among the elderly in Norway

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ORIGINAL ARTICLE

The impact of dementia on the use of general practitioners among the elderly in Norway

A.E. YDSTEBØ[1,2,3], S. BERGH[3], G. SELBÆK[3,4,6], J. ŠALTYTĖ BENTH[3,4,5], H. LURÅS[4,5] & C. VOSSIUS[1,2]

[1]*Centre for Age-related Medicine, Stavanger University Hospital, Norway,* [2]*Centre for Development of Institutional and Home Care Services Rogaland, Norway,* [3]*Centre for Old Age Psychiatry Research, Innlandet Hospital Trust, Norway,* [4]*Helse Sør-Øst Health Services Research Centre, Akershus University Hospital, Norway,* [5]*Institute of Clinical Medicine, University of Oslo,* [6]*Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway*

Abstract

Objective. To assess the use of general practitioners (GPs), in elderly home-dwelling persons in Norway and explore the impact of cognitive decline, age, and living situation. *Design.* Prospective longitudinal study. *Setting.* Data were collected from municipalities in four counties in Norway in the period from January 2009 to August 2012. *Subjects.* Home-dwelling persons 70 years of age or older, receiving in-home care. *Main outcome measures.* Use of GPs over a period of 18 months related to cognitive state, functional status, neuropsychiatric symptoms, and demographics. *Results.* A total of 599 persons were included. The mean annual number of consultations per participant was 5.6 (SD = 5.4). People with moderate to severe dementia had fewer consultations per year compared with those with mild or no dementia (3.7 versus 5.8 per year, $p = 0.004$). In the multivariate model higher age predicted fewer consultations while affective neuropsychiatric symptoms were associated with an increase in frequency of consultations. The most frequent reason to consult a GP was cardiovascular diseases (36.8% of all consultations), followed by musculoskeletal complaints (12.1%) and psychiatric diagnoses (8.7%). *Conclusion.* Our study shows that the home-dwelling elderly with moderate to severe dementia in Norway consult their GP less often than persons with mild or no dementia. This could indicate a need for better interaction between the municipal care and social services and the general practitioners.

Key Words: *Dementia, emergency service, general practice, general practitioner, municipal care, Norway*

Introduction

It has been estimated that around 70 000 Norwegians are suffering from dementia [1] and that about half of them are living at home [2]. A British study showed that 89% of those with dementia had at least one comorbid condition and that 57% were multimorbid [3]. A reasonable assumption would be that this is a group of high-frequency users of primary and specialist health care services, although the literature suggests otherwise, showing that dementia is associated with an increase in the use of municipal care and social services but no increase in the use of general practitioners (GPs) [4,5].

Norway has a list-patient system in general practice where every inhabitant is registered with a GP, and the GPs serve as gatekeepers for the specialist health care services. During weekends and outside business hours patients are entitled to contact municipal emergency units when they need a medical consultation. GPs are crucial for the coordination of municipal care services, and social services rendered by the municipality. In elderly home-dwelling persons with dementia, the GP is supposed to have a key role, working together with the municipal health care services in assessment, diagnosis, treatment, and follow-up.

Correspondence: Arnt Egil Ydstebø, Centre for Old Age Psychiatry Research, Innlandet Hospital Trust, Postboks 68, N-2312 Ottestad, Norway. Tel: +47-99025223. E-mail: arnt.egil.ydstebo@stavanger.kommune.no

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- People with moderate to severe dementia had fewer consultations with their GP per year compared with those with mild or no dementia.
- Increased age predicted fewer consultations with the GP while affective neuropsychiatric symptoms were associated with an increase in frequency of consultations.
- The findings could indicate a need for better interaction between the municipal care and social services and the general practitioners.

There are several studies exploring differences in treatment by GPs of patients with and without dementia. Two studies that explored differences between persons with and without dementia, and the use and prescription of cardiovascular medication, found that persons with dementia were less likely to use lipid-lowering drugs [6], and were prescribed fewer cardiovascular medications than the non-demented group [7]. A third study found little evidence supporting differences in treatment of diabetes, hypertension, and hyperlipidaemia between the two groups [8]. In Sweden a dementia-management programme involving GPs and community nurses in early diagnosing of dementia and drug evaluation were successful in increasing the number of persons diagnosed with dementia and appeared to improve the management of psychotropic drugs [9,10]. However, few studies have examined the behaviour of patients and how they seek contact with their GP. In order to enable the GP to follow the patient's course of dementia and to coordinate services from both specialist health care and municipal health and social care, an increasing number of contacts with the GP is expected.

The aim of this study was to assess the use of GPs in respect of elderly home-dwelling persons. We aimed at exploring the impact of cognitive decline, age, and living situation on the frequency of contacts with the GP, and whether fewer visits to the GP were related to an increased number of visits to the municipal emergency service.

Material and methods

Study population

Patients were drawn from a prospective longitudinal study including 1001 home-dwelling persons aged 70 years or older receiving municipal services such as home care, cleaning help, meals-on-wheels, day care centre, municipal housing, or a safety alarm at baseline, and where both the client and a proxy were willing to participate in the study [11]. Assessments were carried out by trained health care-workers and the patients were examined at baseline and approximately 18 months later. Baseline inclusion was from January 2009 to August 2010, and the last follow-up examinations were performed in August 2012. A detailed explanation on the data collection can be found in Wergeland et al. [11]. Of the 1001 participants included at baseline, 599 attended the follow-up examination. In the present study, only those who attended both examinations were included. The 402 patients who did not attend the follow-up examination were excluded. In detail, these dropouts were due to the following: as a consequence of a revised study protocol for the follow-up examination new written consent of all participants was necessary and 146 (14.6%) persons did not consent to follow-up. In total 180 persons (18.0%) died and two (0.2%) moved out of the area. Seventy-four (7.4%) had other reasons; for most of them an examination was not possible within the required timeframe. As compared with the included patients those who dropped out of the study were slightly older (mean age of 83.9 [SD = 5.6] versus 83.0 [SD = 5.4] years; $p = 0.013$), fewer were females (64.4% versus 70.8%; $p = 0.038$), and they had lower functioning in instrumental activities of daily living (IADL) (mean score of 0.66 [SD = 0.30] versus 0.71 [SD = 0.30], $p = 0.017$) (Table I).

The demographic and clinical data from the 599 elderly included in the study were merged with data on the use of primary health care services (both the use of GPs and the use of emergency services) from the Norwegian Health Economics Administration, the public agency responsible for the reimbursement of primary care services in Norway.

In addition to demographic data, data from the following four clinical assessments were collected. Evaluation of physical health was performed by the General Medical Health Rating (GMHR) scale [12], which rates health into the four categories poor = 0, fair = 1, good = 2, and excellent = 3 according to the rater's overall impression. Evaluation of functional status was carried out by the Lawton IADL Scale [13], which comprises the eight items "ability to use telephone", "shopping", "food preparation", "housekeeping", "laundry", "mode of transportation", "responsibility for own medications", and "ability to handle finances". Each item can be scored "0" (dependent) or "1" (independent). For women, all eight items were included in the sum score, while we excluded the items "food preparation", "housekeeping", and "laundry" for men, as these items were not applicable for many male participants in this study [13,14]. We calculated a sum score and divided it by the number of items evaluated, thus obtaining a score

Table I. Study population: Demographics, physical health, and cognitive state at baseline.

	Patients included in the study (n = 599)	Patients not included in the study (n = 402)	p-value
Age			
n	599	402	0.010[1]
Mean (SD)	83.0 (5.6)	83.9 (5.8)	
Gender			
n	599	402	0.038[2]
Male, n (%)	175 (29.2)	143 (35.6)	
Female, n (%)	424 (70.8)	259 (64.4)	
Living situation			
n	588	396	0.188[2]
Alone, n (%)	407 (69.2)	258 (65.2)	
With others, n (%)	181 (30.8)	138 (34.8)	
MMSE			
n	590	392	0.173[1]
Mean (SD)	24.6 (4.7)	24.2 (5.1)	
IADL			
n	579	387	0.017[1]
Mean (SD)	0.71 (0.3)	0.66 (0.30)	
CDR			
n	590	398	0.678[1]
Mean (SD)	0.56 (0.62)	0.58 (0.67)	
GMHR			
n	575	373	0.001[3]
Poor, n (%)	46 (8.0)	54 (14.5)	
Fair, n (%)	194 (33.7)	135 (36.2)	
Good, n (%)	230 (40.0)	143 (38.3)	
Excellent, n (%)	105 (18.3)	41 (11.0)	
Diagnosis of dementia			
n	598	402	
No dementia	185 (30.9)	123 (30.6)	
MCI	172 (28.8)	105 (26.1)	0.506[3]
Dementia	241 (40.3)	174 (43.3)	
Agitation			
n	574	392	0.390[1]
Mean (SD)	1.5 (3.8)	1.7 (5.1)	
Psychosis			
n	581	394	0.243[1]
Mean (SD)	0.6 (2.2)	0.4 (1.6)	
Affective symptoms			
n	577	395	0.980[1]
Mean (SD)	2.9 (5.4)	2.9 (5.1)	

Notes: MCI = mild cognitive impairment; SD = standard deviation; MMSE = Mini Mental State Examination; IADL = instrumental activities of daily living; CDR = Clinical Dementia Rating; GMHR = General Medical Health Rating scale. [1]Independent-samples t-test. [2]Fisher's exact test. [3]Chi-square-test.

ranging from 0 = completely dependent to 1 = completely independent in terms of IADL. The cognitive state was assessed by the Mini Mental State Examination (MMSE) ranging from 0 to 30, where a score of 30 indicates unimpaired cognitive functioning [15]. A dementia staging was performed using the six-item Clinical Dementia Rating (CDR) Scale [16] with the stages no dementia = 0, possible dementia = 0.5, mild dementia = 1, moderate dementia = 2, and severe dementia = 3, based on an algorithm giving precedence to the item memory. In addition, the CDR sum of boxes was calculated as described in previous publications [17]. In the present material, CDR and CDR sum of boxes correlated highly (Spearman correlation coefficient of 0.93). Further, an evaluation of whether the participant was without cognitive impairment, had a minimal cognitive impairment according to the Winblad criteria [18], or had dementia according to the ICD-10 criteria [19] at baseline was made independently by two experts (GS and SB) based on all available clinical information. Neuropsychiatric symptoms were evaluated by the Neuropsychiatric Inventory (NPI) [20], 10-item version. The frequency (0–4) and intensity (0–3) of each item are multiplied to produce an item score of 0–12. We identified three sub-syndromes of the NPI based on a principal component analysis with direct oblimin rotation. The components were extracted based on the Kaiser criterion (factors with eigenvalues under 1 are dropped) and inspection of the screenplot. We termed the sub-syndromes "Agitation", "Psychosis", and "Affective symptoms". "Agitation" was composed of the items agitation/aggression, euphoria, disinhibition, aberrant motor behaviour, and irritability; "psychosis" was composed of the items delusions and hallucinations; and "affective symptoms" was composed of the items depression, anxiety, and apathy. The item agitation/aggression loaded also on the "Psychosis" sub-syndrome, but in line with previous research and clinical experience [21] we chose to include it in the "Agitation" sub-syndrome.

Use of general practitioners and municipal emergency service

For every participant, data on the use of GP and municipal emergency services between 1 January 2009 and 31 December 2012 were provided by the Norwegian Health Economics Administration. The following information was provided: date of contact, whether the GP or the municipal emergency service was contacted, and the diagnoses causing the contact registered according to the International Classification of Primary Care, version 1 (ICPC-1). Only consultations during the period between baseline and follow-up examination were registered. To adjust for varying intervals between these two examinations, we calculated "consultations per year" by dividing the total number of consultations by the length of the observation period in years for each individual. This includes home visits. For participants who were admitted to a nursing home during the observation period, we considered the length of the observation period to be from baseline until nursing home admission. This is due to the fact that when patients move into a nursing home they are no longer followed up by their GP, but by nursing home doctors. Contacts by phone were evaluated as well. However, our findings added no information to the data presented in the article, and were therefore not included in the presentation of results.

Statistics

The program SPSS™ 22.0 (SPSS Inc, Chicago, USA) was used for statistical analysis. Demographic and clinical characteristics at baseline were presented as means and standard deviations (SD) or frequencies and percentages, as appropriate. Comparison of those included versus not included in the study as well as those who did not visit their regular GP versus those who had at least one consultation per year was performed by an independent-samples t-test for continuous variables and chi-square or Fisher's exact test for categorical variables. The distribution of the number of consultations with the GP was skewed. As ln-transformation was not appropriate due to many zeroes, the variable was categorized to 0 (0–2, 2–4, 4–7), and >7 consultations. To assess the relationship between the categorized number of consultations with the GP and demographic and clinical characteristics of patients, the bivariate ordinal regression model was estimated first. The following patient characteristics were included in the analysis: age, gender, living situation, CDR sum of boxes, IADL, and the neuropsychiatric sub-syndromes "agitation", "psychosis", and "affective symptoms". Next, a multivariate ordinal regression model with all considered patient characteristics was estimated. Finally, the multivariate model was adjusted for confounder, GMHR. A test of parallel lines was applied to assess the assumption for ordinal regression.

Two-sided p-values lower than 0.05 were considered statistically significant.

Ethics

The regional ethics committee (registration number 2010/119) approved the study. All participants gave informed written consent.

Results

Study population

A total of 599 participants with a mean age of 83.0 (SD = 5.6) years were included; 175 (29.2%) were males. Table I contains the demographic characteristics, physical health, and cognitive state of patients included.

Consultations with the GP

The mean number of consultations per year and participant were 5.6 (SD = 5.4). People with moderate to severe dementia had fewer consultations with their GP per year compared with those with mild or no dementia (3.7 versus 5.8 times per year, p = 0.004). Figure 1 illustrates the association between the CDR score and number of GP visits per year. Seventy-nine (13.2%) participants did not visit their GP at all during the observation period, making the distribution highly skewed. Number of consultations per year was therefore categorized into five different groups for further analysis (Table II).

A bivariate ordinal regression analysis between the number of consultations per year and patient characteristics (Table III) showed that higher age, a decline in cognitive function (higher CDR sum of

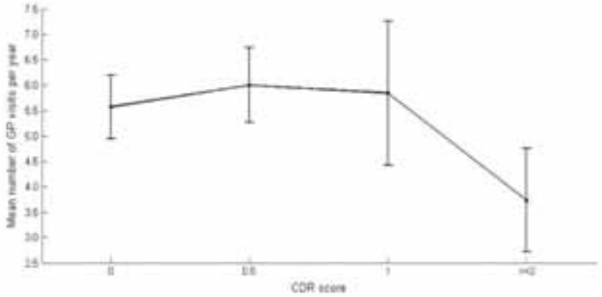

Figure 1. GP visits per year related to CDR score. Notes: CDR 0: n = 214; CDR 0.5: n = 212; CDR 1: n = 104; CDR 2: n = 57; CDR 3: n = 3; missing = 9. CDR 2 and CDR 3 are combined into one category due to low number of patients with CDR3. CDR = Clinical Dementia Rating, GP = general practitioner.

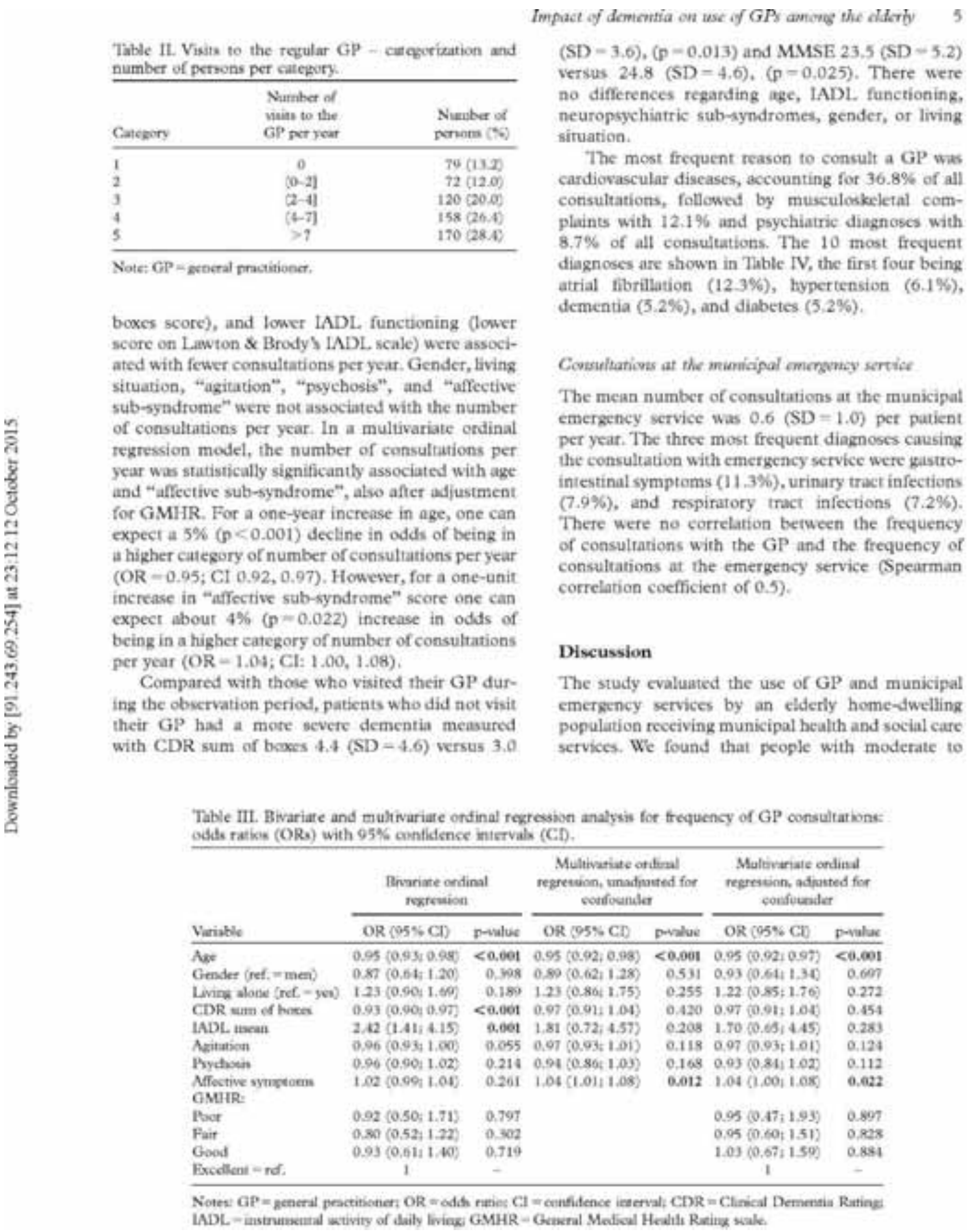

Table II. Visits to the regular GP – categorization and number of persons per category.

Category	Number of visits to the GP per year	Number of persons (%)
1	0	79 (13.2)
2	(0–2]	72 (12.0)
3	(2–4]	120 (20.0)
4	(4–7]	158 (26.4)
5	>7	170 (28.4)

Note: GP = general practitioner.

boxes score), and lower IADL functioning (lower score on Lawton & Brody's IADL scale) were associated with fewer consultations per year. Gender, living situation, "agitation", "psychosis", and "affective sub-syndrome" were not associated with the number of consultations per year. In a multivariate ordinal regression model, the number of consultations per year was statistically significantly associated with age and "affective sub-syndrome", also after adjustment for GMHR. For a one-year increase in age, one can expect a 5% ($p < 0.001$) decline in odds of being in a higher category of number of consultations per year (OR = 0.95; CI 0.92, 0.97). However, for a one-unit increase in "affective sub-syndrome" score one can expect about 4% ($p = 0.022$) increase in odds of being in a higher category of number of consultations per year (OR = 1.04; CI: 1.00, 1.08).

Compared with those who visited their GP during the observation period, patients who did not visit their GP had a more severe dementia measured with CDR sum of boxes 4.4 (SD = 4.6) versus 3.0 (SD = 3.6), ($p = 0.013$) and MMSE 23.5 (SD = 5.2) versus 24.8 (SD = 4.6), ($p = 0.025$). There were no differences regarding age, IADL functioning, neuropsychiatric sub-syndromes, gender, or living situation.

The most frequent reason to consult a GP was cardiovascular diseases, accounting for 36.8% of all consultations, followed by musculoskeletal complaints with 12.1% and psychiatric diagnoses with 8.7% of all consultations. The 10 most frequent diagnoses are shown in Table IV, the first four being atrial fibrillation (12.3%), hypertension (6.1%), dementia (5.2%), and diabetes (5.2%).

Consultations at the municipal emergency service

The mean number of consultations at the municipal emergency service was 0.6 (SD = 1.0) per patient per year. The three most frequent diagnoses causing the consultation with emergency service were gastrointestinal symptoms (11.3%), urinary tract infections (7.9%), and respiratory tract infections (7.2%). There were no correlation between the frequency of consultations with the GP and the frequency of consultations at the emergency service (Spearman correlation coefficient of 0.5).

Discussion

The study evaluated the use of GP and municipal emergency services by an elderly home-dwelling population receiving municipal health and social care services. We found that people with moderate to

Table III. Bivariate and multivariate ordinal regression analysis for frequency of GP consultations: odds ratios (ORs) with 95% confidence intervals (CI).

	Bivariate ordinal regression		Multivariate ordinal regression, unadjusted for confounder		Multivariate ordinal regression, adjusted for confounder	
Variable	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
Age	0.95 (0.93; 0.98)	**<0.001**	0.95 (0.92; 0.98)	**<0.001**	0.95 (0.92; 0.97)	**<0.001**
Gender (ref. = men)	0.87 (0.64; 1.20)	0.398	0.89 (0.62; 1.28)	0.531	0.93 (0.64; 1.34)	0.697
Living alone (ref. = yes)	1.23 (0.90; 1.69)	0.189	1.23 (0.86; 1.75)	0.255	1.22 (0.85; 1.76)	0.272
CDR sum of boxes	0.93 (0.90; 0.97)	**<0.001**	0.97 (0.91; 1.04)	0.420	0.97 (0.91; 1.04)	0.454
IADL mean	2.42 (1.41; 4.15)	**0.001**	1.81 (0.72; 4.57)	0.208	1.70 (0.65; 4.45)	0.283
Agitation	0.96 (0.93; 1.00)	0.055	0.97 (0.93; 1.01)	0.118	0.97 (0.93; 1.01)	0.124
Psychosis	0.96 (0.90; 1.02)	0.214	0.94 (0.86; 1.03)	0.168	0.93 (0.84; 1.02)	0.112
Affective symptoms	1.02 (0.99; 1.04)	0.261	1.04 (1.01; 1.08)	**0.012**	1.04 (1.00; 1.08)	**0.022**
GMHR:						
Poor	0.92 (0.50; 1.71)	0.797			0.95 (0.47; 1.93)	0.897
Fair	0.80 (0.52; 1.22)	0.302			0.95 (0.60; 1.51)	0.828
Good	0.93 (0.61; 1.40)	0.719			1.03 (0.67; 1.59)	0.884
Excellent = ref.	1	–			1	–

Notes: GP = general practitioner; OR = odds ratio; CI = confidence interval; CDR = Clinical Dementia Rating; IADL = instrumental activity of daily living; GMHR = General Medical Health Rating scale.

Table IV. The ten most frequent diagnoses for GP consultations.

Diagnosis	%
Atrial fibrillation	12.3
Hypertension	6.1
Dementia	5.2
Diabetes	5.2
Hip + knee arthrosis	4.1
Wounds	3.9
Heart failure	3.4
Stroke	3.3
Pulmonary infection	2.5
Urinary tract infection	2.2
Other	51.8

Note: GP = general practitioner.

severe dementia had fewer consultations with their GP per year compared with those with mild or no dementia. Further, we found that higher age resulted in fewer visits to the GP, while a higher burden of affective symptoms was associated with more frequent visits. It seems that the municipal emergency centre did not serve as a substitute for the use of GPs.

The strength of this study is the large cohort with participants including both rural and urban areas. The participants were assessed with a standardized protocol by trained professional health care-workers, and the participants were diagnosed for dementia by two experienced clinical dementia researchers. Complete and reliable information regarding the use of primary health care services was extracted from a national registry and merged with data from the cohort study.

The main weakness of the study is limited information on comorbidity in the study cohort, as the GMHR is only a four-dimensional description of the general health state. In 30% of all visits to the GP the main diagnosis was cardiovascular complaints, and somatic diseases seemed to be a major factor for GP contacts, even if other diseases may have an impact on the patient's decision to see the GP. Further, many additional aspects might explain the frequency of visits to the GP, like self-perceived health or the threshold for appointments (for example availability or transportation) that have not been explored in this study. The study had a dropout rate of 40.2% from baseline to first follow-up. The two main reasons for dropping out are death (18.0%) and non-consent to follow-up (14.6%). Dropouts where slightly older, had a lower functional state and worse general health state. Thus, our study cohort may comprise a selected group of patients, and our findings might not be representative for the general population.

As dementia is a progressive chronic condition that impairs cognitive functioning and the ability of independent living it is reasonable to assume that people with dementia would visit their GP more frequently than people without dementia. However, our findings indicate the opposite, and are in line with a study from the UK, where people with dementia were less likely to visit their GP, and also less likely to have had an outpatient appointment in the last three months, compared with people with depression, disability, and people in good health [22].

Connolly et al. [3] found that 80% of their study population received an annual dementia review at their GP. However, they also found that the reviews were poorly executed, that most lacked a social care review, and that discussions with carers were lacking. The results of the present study are similar to findings in studies on patients with severe mental illnesses that describe a decreased access to primary care in this patient group, and that these patients are undertreated even if they see their GP regularly [23]. A Norwegian study, conducted on the same sample population as this study, found that only 19.5% of 415 participants with dementia had a dementia diagnosis known to themselves, their caregiver, or health care workers at the home care services [11]. However, although there have been studies stating that dementia patients are undertreated for other diseases [7], newer research concludes that there are no differences in treatment [8].

Studies from the USA [24–26] show that intensive follow-up by the municipal health care system of home-dwelling persons with dementia and their relatives reduced the need for home care services and prolonged the time to nursing home admission. This indicates that the course of dementia might be positively influenced by adequate medical follow-up and sufficient support of the patient and his/her relatives. Further research should explore the impact of an increased focus on the cooperation and collaboration between GPs and the municipal care and social services.

Conclusion

Our study shows that in Norway the home-dwelling elderly with moderate to severe dementia consult their GP less often than persons with mild or no dementia. This could indicate a need for better interaction between the municipal care and social services and general practitioners. Further research should include studies on the quality of the medical follow-up for people with dementia, to see if there is any effect in more thorough and regular medical monitoring of these patients.

Declaration of interest

There are no conflicts of interest in connection with the paper. The authors alone are responsible for the content and writing of the paper.

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Appendix 3 – Paper II

International Psychogeriatrics: page 1 of 12

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Longitudinal changes in quality of life among elderly people with and without dementia

A. E. Ydstebø,[1,2,3] S. Bergh,[3,4] G. Selbæk,[3,4,5] J. Šaltytė Benth,[3,6,7] K. Brønnick[1,8] and C. Vossius[1,2]

[1] *Centre for Age-related Medicine, Stavanger University Hospital, Stavanger, Norway*
[2] *Centre for Development of Institutional and Home Care Services, Rogaland, Norway*
[3] *Centre for Old Age Psychiatry Research, Innlandet Hospital Trust, Ottestad, Norway*
[4] *Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway*
[5] *Institute of Health and Society, University of Oslo, Oslo, Norway*
[6] *Institute of Clinical Medicine, University of Oslo, Oslo, Norway*
[7] *Health Services Research Unit, Akershus University Hospital, Lørenskog, Norway*
[8] *Faculty of Social Sciences, University of Stavanger, Stavanger, Norway*

ABSTRACT

Objective: To study longitudinal changes in the quality of life (QoL) in persons with and without dementia, and explore the factors associated with baseline QoL and changes of QoL over the follow-up period.

Design: Prospective longitudinal study.

Setting: Data were collected from 17 municipalities in Norway in the period from January 2009 to August 2012. A total of 412 persons were included, 254 (61.7 %) persons without dementia and 158 (38.3 %) with dementia at baseline.

Subjects: Persons 70 years of age or older, receiving municipal care services. Main outcome measures include the following: self-rated and proxy-rated QoL over a period of 18 months, cognitive status, functional status, neuropsychiatric symptoms, and demographics.

Results: Longitudinal changes in QoL were small, despite changes in clinical variables. Proxy ratings of patients QoL were lower than the patients' own ratings. Belonging to a group with low QoL trajectory was associated with symptoms of depression, reduced physical and instrumental functioning, and more severe dementia.

Conclusion: Patients and proxies evaluated the patients' QoL differently and QoL did not necessarily correspond with deterioration in clinical parameters. To prevent impaired QoL, we need to address identified factors and keep an approach open to the individual perceptions of QoL.

Key words: quality of life, dementia, municipal care, longitudinal, elderly

Introduction

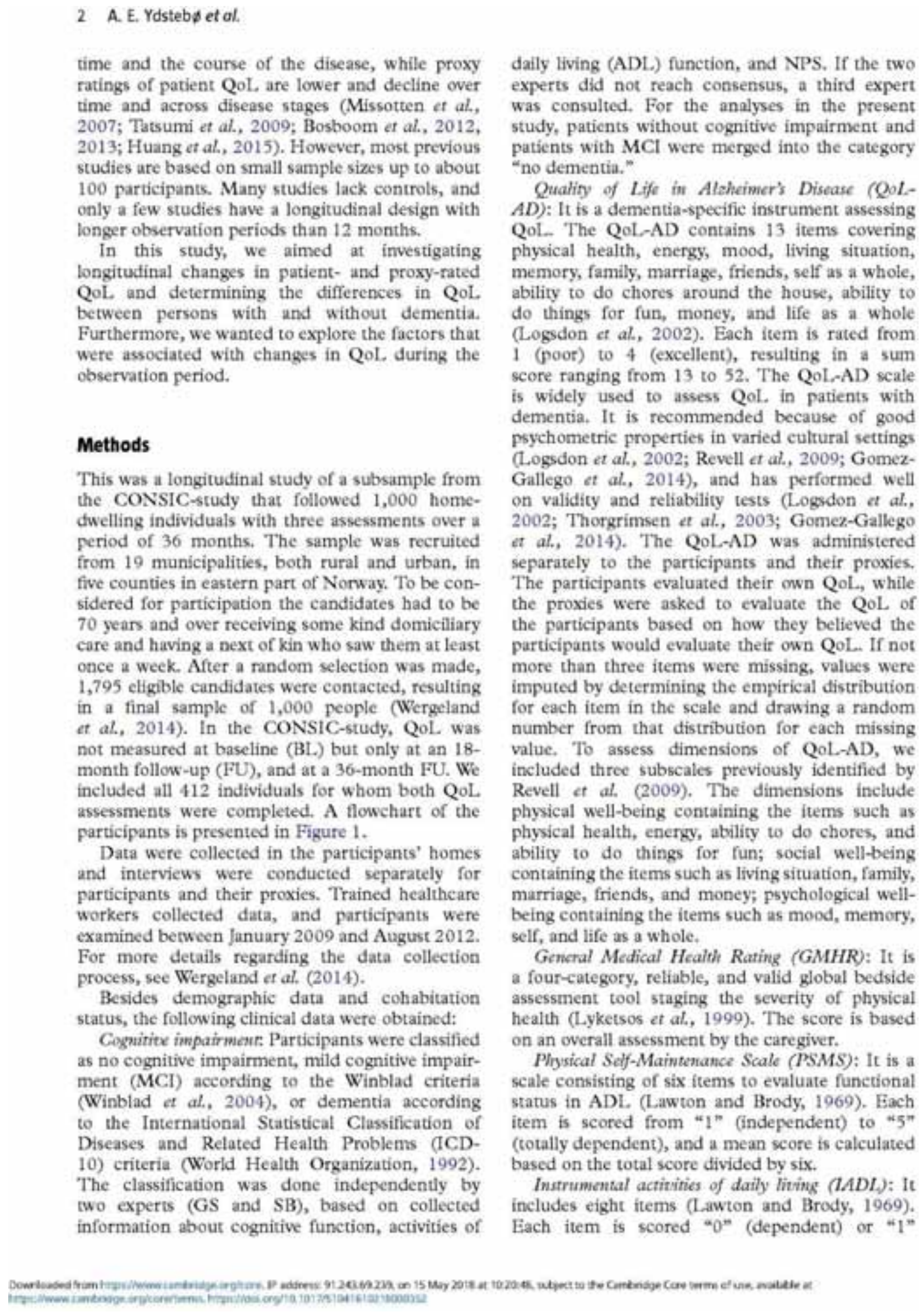
Dementia is a chronic condition caused by progressive changes in the brain, with no effective cure. The brain changes lead to loss of memory and other cognitive functions, and patients may experience distressing neuropsychiatric symptoms (NPS).

As much of our efforts aim at alleviating the symptoms of dementia, measures of quality of life (QoL) are being increasingly used as outcome scores in clinical practice and research (Thorgrimsen *et al.*, 2003).

In recent years, research on QoL in dementia has evolved considerably with the development and use of disease-specific QoL assessments (Brod *et al.*, 1999; Logsdon *et al.*, 2002; Smith *et al.*, 2005). A 2009 summary of studies showed a consistent association between QoL and depression in dementia, while clinical and sociodemographic characteristics were associated only weakly or not at all with QoL (Banerjee *et al.*, 2009).

Lately, a number of studies have been conducted to uncover QoL changes over time, QoL predictors, and agreement between patient and proxy ratings of QoL in persons with dementia. Results indicate that patient-rated QoL remains fairly stable over

Correspondence should be addressed to: Arnt Egil Ydstebø, Centre for Old Age Psychiatry Research, Innlandet Hospital Trust, Postboks 68, Ottestad N-2312, Norway. Phone: +47-99623223. Email: arnt.egil.ydstebo@stavanger.kommune.no. Received 10 Nov 2017; revision requested 10 Jan 2018; revised version received 2 Feb 2018; accepted 26 Feb 2018.



time and the course of the disease, while proxy ratings of patient QoL are lower and decline over time and across disease stages (Missotten *et al.*, 2007; Tatsumi *et al.*, 2009; Bosboom *et al.*, 2012, 2013; Huang *et al.*, 2015). However, most previous studies are based on small sample sizes up to about 100 participants. Many studies lack controls, and only a few studies have a longitudinal design with longer observation periods than 12 months.

In this study, we aimed at investigating longitudinal changes in patient- and proxy-rated QoL and determining the differences in QoL between persons with and without dementia. Furthermore, we wanted to explore the factors that were associated with changes in QoL during the observation period.

Methods

This was a longitudinal study of a subsample from the CONSIC-study that followed 1,000 home-dwelling individuals with three assessments over a period of 36 months. The sample was recruited from 19 municipalities, both rural and urban, in five counties in eastern part of Norway. To be considered for participation the candidates had to be 70 years and over receiving some kind domiciliary care and having a next of kin who saw them at least once a week. After a random selection was made, 1,795 eligible candidates were contacted, resulting in a final sample of 1,000 people (Wergeland *et al.*, 2014). In the CONSIC-study, QoL was not measured at baseline (BL) but only at an 18-month follow-up (FU), and at a 36-month FU. We included all 412 individuals for whom both QoL assessments were completed. A flowchart of the participants is presented in Figure 1.

Data were collected in the participants' homes and interviews were conducted separately for participants and their proxies. Trained healthcare workers collected data, and participants were examined between January 2009 and August 2012. For more details regarding the data collection process, see Wergeland *et al.* (2014).

Besides demographic data and cohabitation status, the following clinical data were obtained:

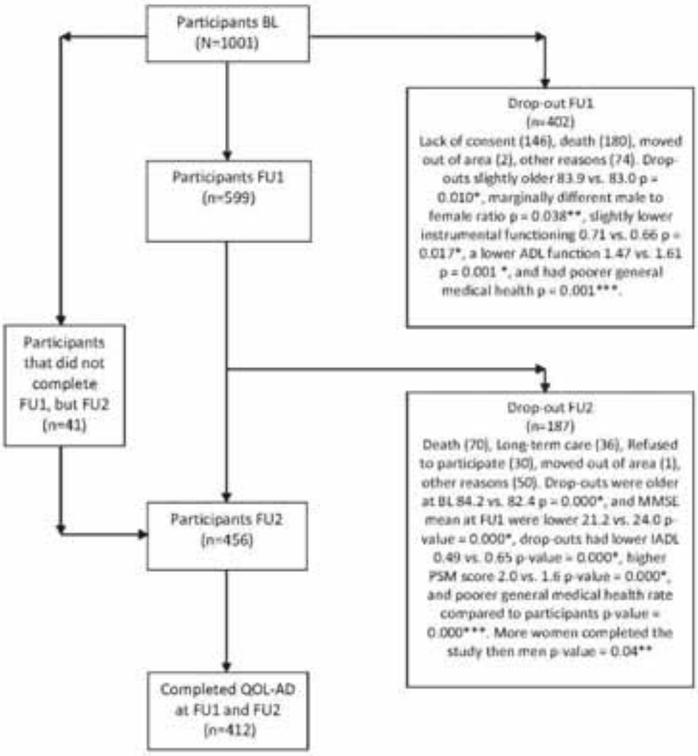
Cognitive impairment: Participants were classified as no cognitive impairment, mild cognitive impairment (MCI) according to the Winblad criteria (Winblad *et al.*, 2004), or dementia according to the International Statistical Classification of Diseases and Related Health Problems (ICD-10) criteria (World Health Organization, 1992). The classification was done independently by two experts (GS and SB), based on collected information about cognitive function, activities of daily living (ADL) function, and NPS. If the two experts did not reach consensus, a third expert was consulted. For the analyses in the present study, patients without cognitive impairment and patients with MCI were merged into the category "no dementia."

Quality of Life in Alzheimer's Disease (QoL-AD): It is a dementia-specific instrument assessing QoL. The QoL-AD contains 13 items covering physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money, and life as a whole (Logsdon *et al.*, 2002). Each item is rated from 1 (poor) to 4 (excellent), resulting in a sum score ranging from 13 to 52. The QoL-AD scale is widely used to assess QoL in patients with dementia. It is recommended because of good psychometric properties in varied cultural settings (Logsdon *et al.*, 2002; Revell *et al.*, 2009; Gomez-Gallego *et al.*, 2014), and has performed well on validity and reliability tests (Logsdon *et al.*, 2002; Thorgrimsen *et al.*, 2003; Gomez-Gallego *et al.*, 2014). The QoL-AD was administered separately to the participants and their proxies. The participants evaluated their own QoL, while the proxies were asked to evaluate the QoL of the participants based on how they believed the participants would evaluate their own QoL. If not more than three items were missing, values were imputed by determining the empirical distribution for each item in the scale and drawing a random number from that distribution for each missing value. To assess dimensions of QoL-AD, we included three subscales previously identified by Revell *et al.* (2009). The dimensions include physical well-being containing the items such as physical health, energy, ability to do chores, and ability to do things for fun; social well-being containing the items such as living situation, family, marriage, friends, and money; psychological well-being containing the items such as mood, memory, self, and life as a whole.

General Medical Health Rating (GMHR): It is a four-category, reliable, and valid global bedside assessment tool staging the severity of physical health (Lyketsos *et al.*, 1999). The score is based on an overall assessment by the caregiver.

Physical Self-Maintenance Scale (PSMS): It is a scale consisting of six items to evaluate functional status in ADL (Lawton and Brody, 1969). Each item is scored from "1" (independent) to "5" (totally dependent), and a mean score is calculated based on the total score divided by six.

Instrumental activities of daily living (IADL): It includes eight items (Lawton and Brody, 1969). Each item is scored "0" (dependent) or "1"



* *Student's t-test*

** *Fisher's Exact test*

*** *χ^2-test*

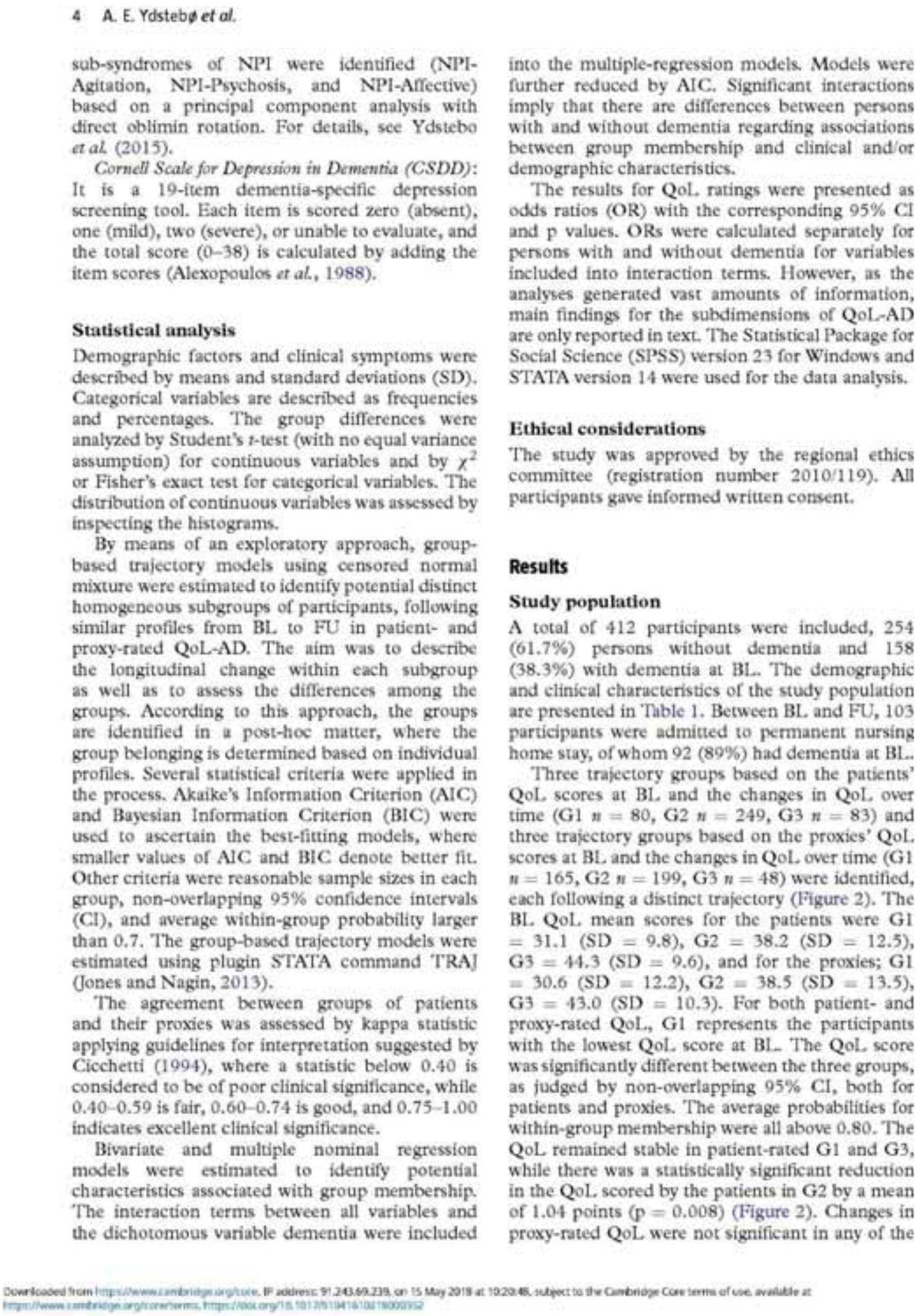
Figure 1. Flow-chart of participant inclusion and drop-out through the study.

(independent), and a mean score is calculated based on the total score divided by eight. For women, all eight items were included in the sum score, while we excluded the items "food preparation," "housekeeping," and "laundry" for men, as these items were not applicable for many male participants in this study (Lawton and Brody, 1969; Wattmo *et al.*, 2013). We calculated a sum score and divided it by the number of items evaluated, thus obtaining a score ranging from 0 = completely dependent to 1 = completely independent in terms of IADL.

Mini-Mental State Examination (MMSE): It is a screening tool that measures cognitive impairment (Folstein '*et al.*, 1975). The maximum score is 30 points.

Clinical Dementia Rating-Sum of Boxes score (CDR-SOB): It is obtained by applying the six-item CDR scale and then summing each of the domain box scores so as to end up with a total score ranging from 0 to 18. The higher the score, the more severe the dementia (O'Bryant *et al.*, 2008).

Neuropsychiatric Inventory (NPI): It assesses NPS (Cummings *et al.*, 1994). The scale considers 12 types of NPS. The presence of symptoms and their frequency and intensity are assessed based on an interview with the closest carer. A higher score denotes more severe NPS. Three



sub-syndromes of NPI were identified (NPI-Agitation, NPI-Psychosis, and NPI-Affective) based on a principal component analysis with direct oblimin rotation. For details, see Ydstebo *et al.* (2015).

Cornell Scale for Depression in Dementia (CSDD): It is a 19-item dementia-specific depression screening tool. Each item is scored zero (absent), one (mild), two (severe), or unable to evaluate, and the total score (0–38) is calculated by adding the item scores (Alexopoulos *et al.*, 1988).

Statistical analysis

Demographic factors and clinical symptoms were described by means and standard deviations (SD). Categorical variables are described as frequencies and percentages. The group differences were analyzed by Student's *t*-test (with no equal variance assumption) for continuous variables and by χ^2 or Fisher's exact test for categorical variables. The distribution of continuous variables was assessed by inspecting the histograms.

By means of an exploratory approach, group-based trajectory models using censored normal mixture were estimated to identify potential distinct homogeneous subgroups of participants, following similar profiles from BL to FU in patient- and proxy-rated QoL-AD. The aim was to describe the longitudinal change within each subgroup as well as to assess the differences among the groups. According to this approach, the groups are identified in a post-hoc matter, where the group belonging is determined based on individual profiles. Several statistical criteria were applied in the process. Akaike's Information Criterion (AIC) and Bayesian Information Criterion (BIC) were used to ascertain the best-fitting models, where smaller values of AIC and BIC denote better fit. Other criteria were reasonable sample sizes in each group, non-overlapping 95% confidence intervals (CI), and average within-group probability larger than 0.7. The group-based trajectory models were estimated using plugin STATA command TRAJ (Jones and Nagin, 2013).

The agreement between groups of patients and their proxies was assessed by kappa statistic applying guidelines for interpretation suggested by Cicchetti (1994), where a statistic below 0.40 is considered to be of poor clinical significance, while 0.40–0.59 is fair, 0.60–0.74 is good, and 0.75–1.00 indicates excellent clinical significance.

Bivariate and multiple nominal regression models were estimated to identify potential characteristics associated with group membership. The interaction terms between all variables and the dichotomous variable dementia were included into the multiple-regression models. Models were further reduced by AIC. Significant interactions imply that there are differences between persons with and without dementia regarding associations between group membership and clinical and/or demographic characteristics.

The results for QoL ratings were presented as odds ratios (OR) with the corresponding 95% CI and p values. ORs were calculated separately for persons with and without dementia for variables included into interaction terms. However, as the analyses generated vast amounts of information, main findings for the subdimensions of QoL-AD are only reported in text. The Statistical Package for Social Science (SPSS) version 23 for Windows and STATA version 14 were used for the data analysis.

Ethical considerations

The study was approved by the regional ethics committee (registration number 2010/119). All participants gave informed written consent.

Results

Study population

A total of 412 participants were included, 254 (61.7%) persons without dementia and 158 (38.3%) with dementia at BL. The demographic and clinical characteristics of the study population are presented in Table 1. Between BL and FU, 103 participants were admitted to permanent nursing home stay, of whom 92 (89%) had dementia at BL.

Three trajectory groups based on the patients' QoL scores at BL and the changes in QoL over time (G1 $n = 80$, G2 $n = 249$, G3 $n = 83$) and three trajectory groups based on the proxies' QoL scores at BL and the changes in QoL over time (G1 $n = 165$, G2 $n = 199$, G3 $n = 48$) were identified, each following a distinct trajectory (Figure 2). The BL QoL mean scores for the patients were G1 = 31.1 (SD = 9.8), G2 = 38.2 (SD = 12.5), G3 = 44.3 (SD = 9.6), and for the proxies; G1 = 30.6 (SD = 12.2), G2 = 38.5 (SD = 13.5), G3 = 43.0 (SD = 10.3). For both patient- and proxy-rated QoL, G1 represents the participants with the lowest QoL score at BL. The QoL score was significantly different between the three groups, as judged by non-overlapping 95% CI, both for patients and proxies. The average probabilities for within-group membership were all above 0.80. The QoL remained stable in patient-rated G1 and G3, while there was a statistically significant reduction in the QoL scored by the patients in G2 by a mean of 1.04 points (p = 0.008) (Figure 2). Changes in proxy-rated QoL were not significant in any of the

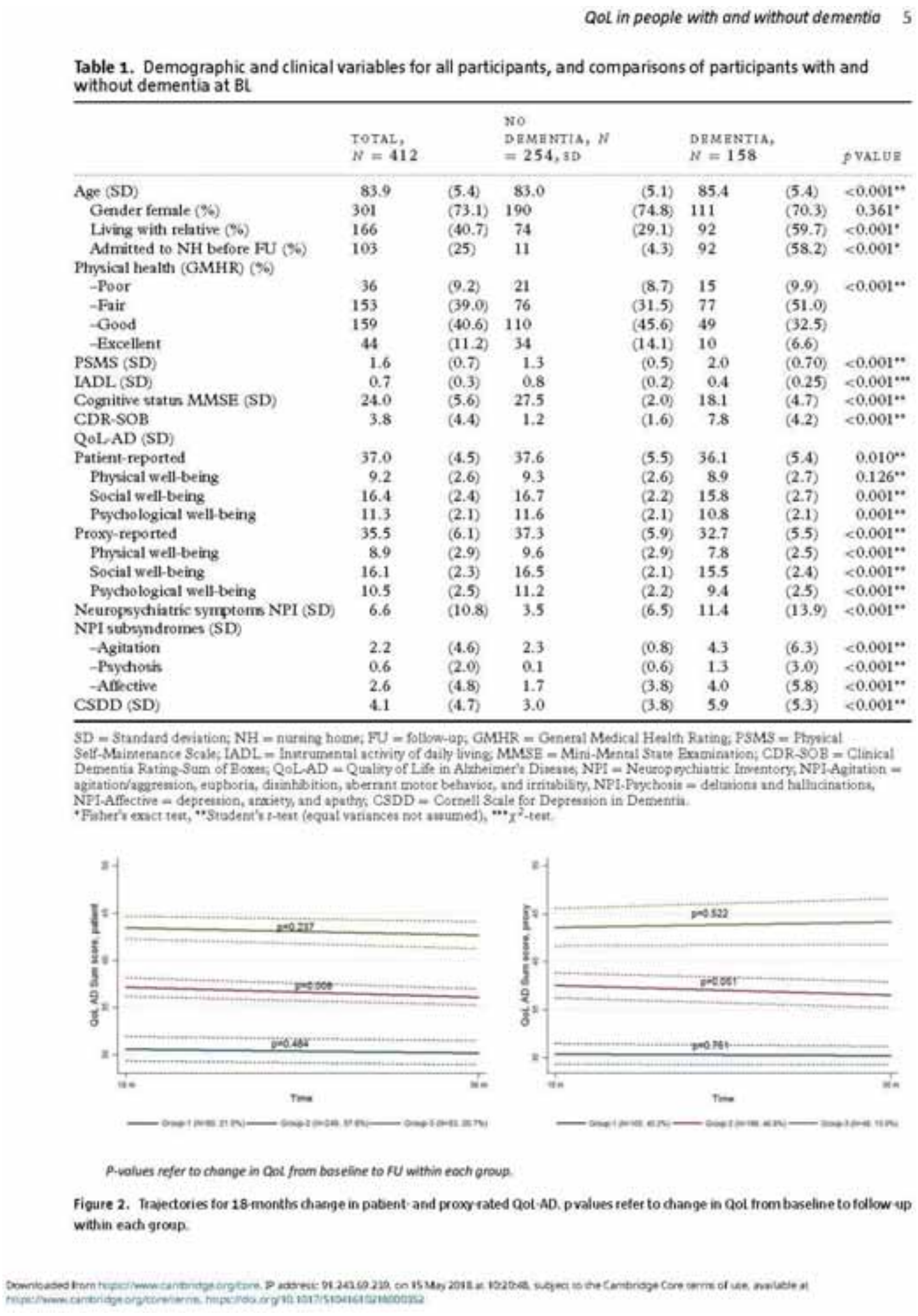


Table 1. Demographic and clinical variables for all participants, and comparisons of participants with and without dementia at BL

	TOTAL, $N = 412$		NO DEMENTIA, $N = 254$, SD		DEMENTIA, $N = 158$		p VALUE
Age (SD)	83.9	(5.4)	83.0	(5.1)	85.4	(5.4)	<0.001**
Gender female (%)	301	(73.1)	190	(74.8)	111	(70.3)	0.361*
Living with relative (%)	166	(40.7)	74	(29.1)	92	(59.7)	<0.001*
Admitted to NH before FU (%)	103	(25)	11	(4.3)	92	(58.2)	<0.001*
Physical health (GMHR) (%)							
–Poor	36	(9.2)	21	(8.7)	15	(9.9)	<0.001**
–Fair	153	(39.0)	76	(31.5)	77	(51.0)	
–Good	159	(40.6)	110	(45.6)	49	(32.5)	
–Excellent	44	(11.2)	34	(14.1)	10	(6.6)	
PSMS (SD)	1.6	(0.7)	1.3	(0.5)	2.0	(0.70)	<0.001**
IADL (SD)	0.7	(0.3)	0.8	(0.2)	0.4	(0.25)	<0.001***
Cognitive status MMSE (SD)	24.0	(5.6)	27.5	(2.0)	18.1	(4.7)	<0.001**
CDR-SOB	3.8	(4.4)	1.2	(1.6)	7.8	(4.2)	<0.001**
QoL-AD (SD)							
Patient-reported	37.0	(4.5)	37.6	(5.5)	36.1	(5.4)	0.010**
Physical well-being	9.2	(2.6)	9.3	(2.6)	8.9	(2.7)	0.126**
Social well-being	16.4	(2.4)	16.7	(2.2)	15.8	(2.7)	0.001**
Psychological well-being	11.3	(2.1)	11.6	(2.1)	10.8	(2.1)	0.001**
Proxy-reported	35.5	(6.1)	37.3	(5.9)	32.7	(5.5)	<0.001**
Physical well-being	8.9	(2.9)	9.6	(2.9)	7.8	(2.5)	<0.001**
Social well-being	16.1	(2.3)	16.5	(2.1)	15.5	(2.4)	<0.001**
Psychological well-being	10.5	(2.5)	11.2	(2.2)	9.4	(2.5)	<0.001**
Neuropsychiatric symptoms NPI (SD)	6.6	(10.8)	3.5	(6.5)	11.4	(13.9)	<0.001**
NPI subsyndromes (SD)							
–Agitation	2.2	(4.6)	2.3	(0.8)	4.3	(6.3)	<0.001**
–Psychosis	0.6	(2.0)	0.1	(0.6)	1.3	(3.0)	<0.001**
–Affective	2.6	(4.8)	1.7	(3.8)	4.0	(5.8)	<0.001**
CSDD (SD)	4.1	(4.7)	3.0	(3.8)	5.9	(5.3)	<0.001**

SD = Standard deviation; NH = nursing home; FU = follow-up; GMHR = General Medical Health Rating; PSMS = Physical Self-Maintenance Scale; IADL = Instrumental activity of daily living; MMSE = Mini-Mental State Examination; CDR-SOB = Clinical Dementia Rating-Sum of Boxes; QoL-AD = Quality of Life in Alzheimer's Disease; NPI = Neuropsychiatric Inventory; NPI-Agitation = agitation/aggression, euphoria, disinhibition, aberrant motor behavior, and irritability; NPI-Psychosis = delusions and hallucinations; NPI-Affective = depression, anxiety, and apathy; CSDD = Cornell Scale for Depression in Dementia.
*Fisher's exact test, **Student's t-test (equal variances not assumed), ***χ^2-test.

P-values refer to change in QoL from baseline to FU within each group.

Figure 2. Trajectories for 18-months change in patient- and proxy-rated QoL-AD. p values refer to change in QoL from baseline to follow-up within each group.

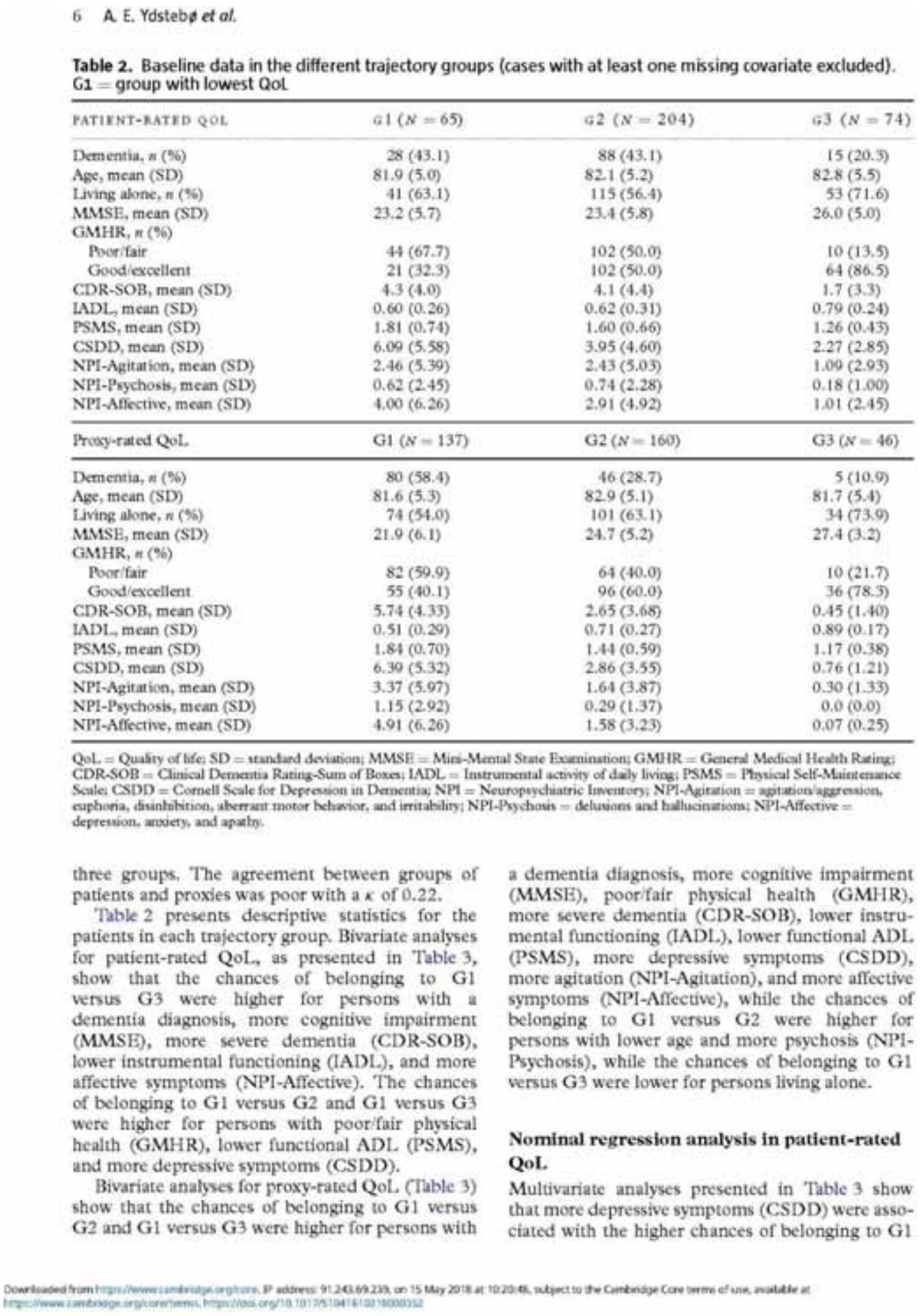


Table 2. Baseline data in the different trajectory groups (cases with at least one missing covariate excluded). G1 = group with lowest QoL

PATIENT-RATED QOL	G1 (*N* = 65)	G2 (*N* = 204)	G3 (*N* = 74)
Dementia, *n* (%)	28 (43.1)	88 (43.1)	15 (20.3)
Age, mean (SD)	81.9 (5.0)	82.1 (5.2)	82.8 (5.5)
Living alone, *n* (%)	41 (63.1)	115 (56.4)	53 (71.6)
MMSE, mean (SD)	23.2 (5.7)	23.4 (5.8)	26.0 (5.0)
GMHR, *n* (%)			
Poor/fair	44 (67.7)	102 (50.0)	10 (13.5)
Good/excellent	21 (32.3)	102 (50.0)	64 (86.5)
CDR-SOB, mean (SD)	4.3 (4.0)	4.1 (4.4)	1.7 (3.3)
IADL, mean (SD)	0.60 (0.26)	0.62 (0.31)	0.79 (0.24)
PSMS, mean (SD)	1.81 (0.74)	1.60 (0.66)	1.26 (0.43)
CSDD, mean (SD)	6.09 (5.58)	3.95 (4.60)	2.27 (2.85)
NPI-Agitation, mean (SD)	2.46 (5.39)	2.43 (5.03)	1.09 (2.93)
NPI-Psychosis, mean (SD)	0.62 (2.45)	0.74 (2.28)	0.18 (1.00)
NPI-Affective, mean (SD)	4.00 (6.26)	2.91 (4.92)	1.01 (2.45)
Proxy-rated QoL	G1 (*N* = 137)	G2 (*N* = 160)	G3 (*N* = 46)
Dementia, *n* (%)	80 (58.4)	46 (28.7)	5 (10.9)
Age, mean (SD)	81.6 (5.3)	82.9 (5.1)	81.7 (5.4)
Living alone, *n* (%)	74 (54.0)	101 (63.1)	34 (73.9)
MMSE, mean (SD)	21.9 (6.1)	24.7 (5.2)	27.4 (3.2)
GMHR, *n* (%)			
Poor/fair	82 (59.9)	64 (40.0)	10 (21.7)
Good/excellent	55 (40.1)	96 (60.0)	36 (78.3)
CDR-SOB, mean (SD)	5.74 (4.33)	2.65 (3.68)	0.45 (1.40)
IADL, mean (SD)	0.51 (0.29)	0.71 (0.27)	0.89 (0.17)
PSMS, mean (SD)	1.84 (0.70)	1.44 (0.59)	1.17 (0.38)
CSDD, mean (SD)	6.39 (5.32)	2.86 (3.55)	0.76 (1.21)
NPI-Agitation, mean (SD)	3.37 (5.97)	1.64 (3.87)	0.30 (1.33)
NPI-Psychosis, mean (SD)	1.15 (2.92)	0.29 (1.37)	0.0 (0.0)
NPI-Affective, mean (SD)	4.91 (6.26)	1.58 (3.23)	0.07 (0.25)

QoL = Quality of life; SD = standard deviation; MMSE = Mini-Mental State Examination; GMHR = General Medical Health Rating; CDR-SOB = Clinical Dementia Rating-Sum of Boxes; IADL = Instrumental activity of daily living; PSMS = Physical Self-Maintenance Scale; CSDD = Cornell Scale for Depression in Dementia; NPI = Neuropsychiatric Inventory; NPI-Agitation = agitation/aggression, euphoria, disinhibition, aberrant motor behavior, and irritability; NPI-Psychosis = delusions and hallucinations; NPI-Affective = depression, anxiety, and apathy.

three groups. The agreement between groups of patients and proxies was poor with a κ of 0.22.

Table 2 presents descriptive statistics for the patients in each trajectory group. Bivariate analyses for patient-rated QoL, as presented in Table 3, show that the chances of belonging to G1 versus G3 were higher for persons with a dementia diagnosis, more cognitive impairment (MMSE), more severe dementia (CDR-SOB), lower instrumental functioning (IADL), and more affective symptoms (NPI-Affective). The chances of belonging to G1 versus G2 and G1 versus G3 were higher for persons with poor/fair physical health (GMHR), lower functional ADL (PSMS), and more depressive symptoms (CSDD).

Bivariate analyses for proxy-rated QoL (Table 3) show that the chances of belonging to G1 versus G2 and G1 versus G3 were higher for persons with a dementia diagnosis, more cognitive impairment (MMSE), poor/fair physical health (GMHR), more severe dementia (CDR-SOB), lower instrumental functioning (IADL), lower functional ADL (PSMS), more depressive symptoms (CSDD), more agitation (NPI-Agitation), and more affective symptoms (NPI-Affective), while the chances of belonging to G1 versus G2 were higher for persons with lower age and more psychosis (NPI-Psychosis), while the chances of belonging to G1 versus G3 were lower for persons living alone.

Nominal regression analysis in patient-rated QoL

Multivariate analyses presented in Table 3 show that more depressive symptoms (CSDD) were associated with the higher chances of belonging to G1

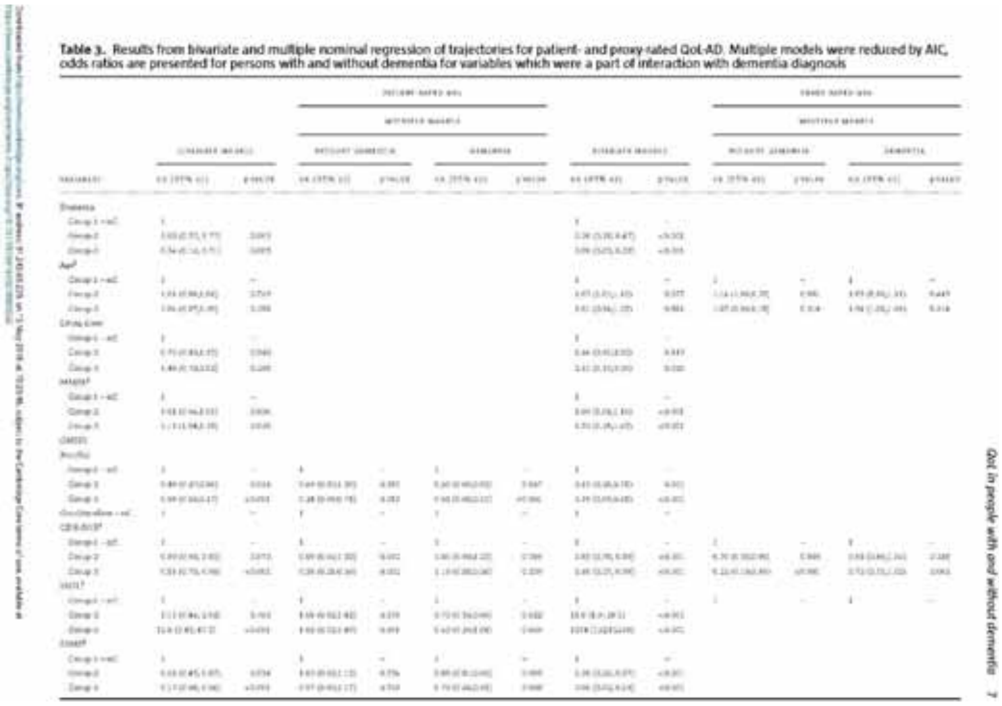


Table 3. Results from bivariate and multiple nominal regression of trajectories for patient- and proxy-rated QoL-AD. Multiple models were reduced by AIC, odds ratios are presented for persons with and without dementia for variables which were a part of interaction with dementia diagnosis

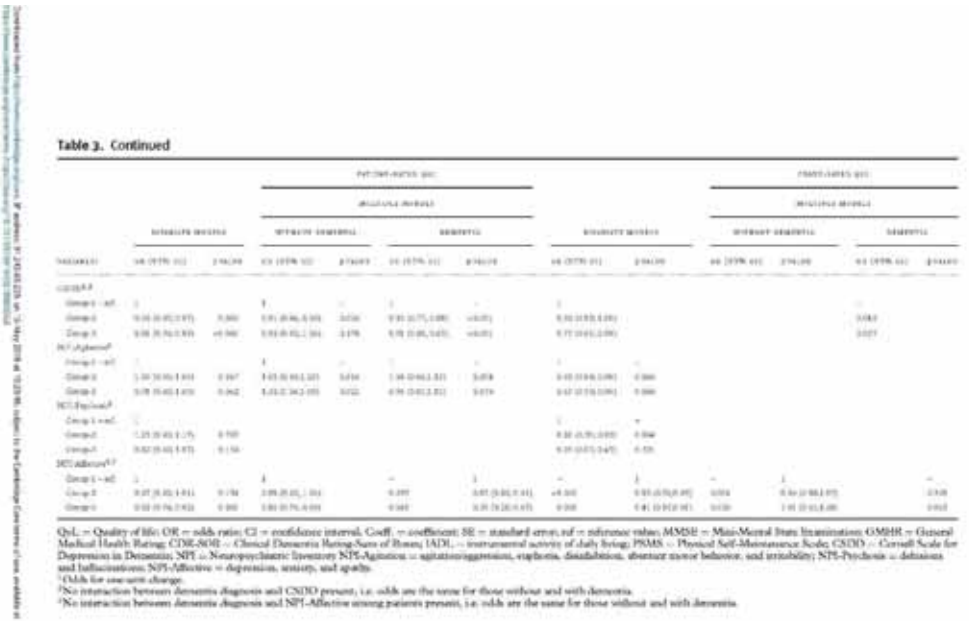


Table 3. Continued

QoL = Quality of life; OR = odds ratio; CI = confidence interval, Coeff. = coefficient; SE = standard error; ref = reference value; MMSE = Mini-Mental State Examination; GMHR = General Medical Health Rating; CDR-SOB = Clinical Dementia Rating-Sum of Boxes; IADL = instrumental activity of daily living; PSMS = Physical Self-Maintenance Scale; CSDD = Cornell Scale for Depression in Dementia; NPI = Neuropsychiatric Inventory NPI-Agitation = agitation/aggression, euphoria, disinhibition, aberrant motor behavior, and irritability; NPI-Psychosis = delusions and hallucinations; NPI-Affective = depression, anxiety, and apathy.

[1] Odds for one-unit change.

[2] No interaction between dementia diagnosis and CSDD present, i.e. odds are the same for those without and with dementia.

[3] No interaction between dementia diagnosis and NPI-Affective among patients present, i.e. odds are the same for those without and with dementia.

versus G2, while more affective symptoms (NPI-Affective) were associated with higher chances of belonging to G1 versus G3, independently of dementia diagnosis.

Persons with dementia and poor/fair physical health (GMHR) and lower ADL functioning (PSMS) were more likely to belong to G1 versus G2 and G1 versus G3. Lower instrumental functioning (IADL) for persons with dementia increased the chances of belonging to G1 versus G2.

Among persons without dementia the chances of belonging to G1 versus G3 increased with poor/fair physical health (GMHR), a higher score on the CDR-SOB scale, and a lower score on NPI-Agitation.

Nominal regression analysis in proxy-rated QoL

As presented in Table 3, more symptoms of depression (CSDD) were associated with higher chances of belonging to G1 versus G2 and G1 versus G3, independently of dementia diagnosis.

For persons with dementia, higher age was associated with lower chances of belonging to G1 versus G3. For persons without dementia, higher age was associated with lower chances for belonging to G1 versus G2. In addition, a higher score on the CDR-SOB scale as well as more affective symptoms (NPI-Affective) were associated with higher chances of belonging to G1 versus G2 and G1 versus G3.

Discussion

This study assessed longitudinal changes in QoL in persons with and without dementia and explored the factors that were associated with changes in QoL. We found three different BL levels and trajectories of QoL in both patient- and proxy-rated QoL.

The changes in QoL scores during the 18-month observation period were, however, small and mostly non-significant.

The type of QoL-trajectory group membership was associated with the severity of the symptoms of depression, dementia severity, physical health, physical and instrumental functioning, NPI-Agitation, and age, with small variations between patient- and proxy-rated QoL-AD. However, we observed that the agreement between patient- and proxy-rated QoL-AD was poor, implying that patients and proxies assess QoL differently.

While former studies have demonstrated significant reductions in proxy-rated QoL for patients with dementia over an 18–24-month period (Lyketsos *et al.*, 2003; Tatsumi *et al.*, 2009; Bosboom *et al.*, 2013; Bosboom and Almeida, 2016; Conde-Sala *et al.*, 2016a), this was not found in our study, neither for the cohort as a whole nor for the respective trajectory groups.

We saw a statistically significant QoL reduction in only one of the patient-rated trajectory groups. The total decline in QoL was, however, small and has probably only minor clinical implications.

The lack of changes to QoL could be explained by the inclusion of a larger and more heterogenic population in our study with a broader variety in age and cognitive and functional limitations than previous studies. Considering the highly subjective nature of QoL assessments (Ready and Ott, 2003) there is also a possibility that the individuals general positive or negative life perceptions has a stronger influence than dementia on their QoL evaluation. In total, the lack of QoL changes supports a former proposition that BL QoL is more strongly associated to later QoL than to QoL changes (Conde-Sala *et al.*, 2016b).

The agreement between patient ratings and their proxy ratings regarding QoL trajectory affiliation showed a low kappa score of 0.22 (Cicchetti, 1994). Such discrepancies between patient self-ratings and proxy ratings have been reported in several previous publications (Logsdon *et al.*, 2002; Tatsumi *et al.*, 2009; Thorgrimsen *et al.*, 2003; Andrieu *et al.*, 2016). Nonetheless, Bosboom *et al.* found the agreement to be reasonably high, though proxy ratings were systematically lower than patient self-ratings (Bosboom *et al.*, 2012).

The discrepancy we found might also be – as suggested by others – a result of proxy bias from higher carer burden (Andrieu *et al.*, 2016) or carers' depression (Logsdon *et al.*, 2002), causing proxies to project their own QoL onto the participants. Unfortunately, this study design does not comprise these factors.

Another confounding factor could be that the participants' lack of insight causes an overestimation of their own QoL (Conde-Sala *et al.*, 2016a). There is also a possibility that patients undergo a process of adaption to their disability and thus perceive their QoL as higher than their proxies do (Banerjee *et al.*, 2009).

Characteristics associated with QoL

More severe depressive symptoms were associated with lower QoL in both patient- and proxy-rated QoL in our study, independent of dementia status. Also, more affective symptoms covering the items depression, anxiety, and apathy in the NPI were associated with lower QoL in patient ratings independent of dementia status and in proxy ratings for persons without dementia. This relation has been described in several previous studies confirming that depressive symptoms are strongly associated with QoL (Banerjee *et al.*, 2009; Tatsumi *et al.*, 2009; Bosboom *et al.*, 2012, 2013; Heggie *et al.*, 2012; Andrieu *et al.*, 2016; Conde-Sala *et al.*, 2016b). We should therefore stress the importance of addressing depression as part of our care services.

Furthermore, being in the two lowest categories of physical health (GMHR) considerably reduced the chance of belonging to the higher QoL trajectories, independent of dementia status for patient-rated QoL, indicating that physical health affects QoL regardless of cognitive functioning. Contrary to our findings, a previous study (Huang *et al.*, 2015) could not find any association with QoL and comorbidity.

Low ADL functioning (PSMS) and low instrumental functioning (IADL) were associated with lower patient-rated QoL in persons with dementia. The association between functional ability and QoL has more often been described with proxy ratings (Banerjee *et al.*, 2009; Tatsumi *et al.*, 2009). However, in more recent studies, associations between limitations in IADL and low patient-rated QoL (Andrieu *et al.*, 2016), and between poorer functional ability (ADL) and low patient-rated QoL (Conde-Sala *et al.*, 2016b) (Heggie *et al.*, 2012), could be found.

Higher age was associated with higher proxy-rated QoL independent of dementia status. This association has been reported in a previous study, where it was interpreted as representing various levels of expectation and social support with age (Banerjee *et al.*, 2006).

In contrast to previous studies (Conde-Sala *et al.*, 2014; Huang *et al.*, 2015), we found no association between dementia severity and patient-rated QoL. As suggested previously (Bosboom *et al.*, 2012; Andrieu *et al.*, 2016), persons with dementia gradually lose insight as the disease progresses; thus, a link between dementia severity and QoL in this group is less likely with patient ratings. Proxies, to the contrary, are more likely to evaluate the patient's QoL from a disease and disability perspective rather than from an individual perspective (Bosboom *et al.*, 2012; Andrieu *et al.*, 2016). However, in our study, more cognitive impairment (CDR-SOB) was associated with a lower QoL in proxy and patient-rated QoL in participants without dementia.

We also found that higher NPI-Agitation scores were associated with higher patient-rated QoL in persons without dementia. We do not fully comprehend this finding in our population but suggest that this could indicate that the NPI may not be an appropriate assessment for persons without cognitive impairments, or that this result illustrates the difference in opinions between proxy and patient ratings, as NPI was also rated by proxy.

Limitations and strengths of the study

As QoL was first evaluated 18 months after the inclusion of patients in the original CONSIC-study, there is a possibility of selection bias towards participants with better health outcomes.

Approximately, 100 participants were admitted to nursing homes between BL and FU observation, resulting in a more heterogenic study population at FU. Data on relevant domains associated with QoL changes in dementia, such as carer burden and carers' depression, could have added more depth to the analysis if they had been included in the data collection. The observation period was probably too short to catch changes in QoL over time in such a heterogenic population.

We used the QoL-AD to assess QoL in all participants, although it has only been validated for use in persons with dementia. However, only one of 13 items in the questionnaire refers to memory impairment. We therefore consider the results as sufficiently reliable to compare QoL in persons with and without dementia.

The strengths of the study were the large cohort of 412 persons that included persons with dementia as well as persons without dementia. A further advantage was the data collection organized by experts in the field. It provided a rich characterization of clinical parameters with standard outcome measures. Another plus was the QoL assessment taken from both the patients' and the proxies' points of view, with a scale well adapted for use in longitudinal studies (Selwood *et al.*, 2005).

Conclusion

In this study, we found that, despite significant changes in clinical parameters, patient- and proxy-rated QoL in an elderly population did not change substantially over a period of 18 months.

We confirmed findings from previous studies that patients and proxies evaluate the patients' QoL differently. QoL is an important aspect of person-centered care, but obviously QoL was determined not only by the clinical aspects we examined, especially in patients with dementia. Thus, we need to focus on the patients' personalities, comprising their history and culture as well as their beliefs, values, family relations, and individual perceptions of QoL.

The foremost factors associated with lower QoL in our study sample were more severe symptoms of depression, NPI-Affective symptoms, and poorer physical health for the whole population, while low functional abilities were only associated with low QoL for persons with dementia. Efforts aiming at preventing low or decreasing QoL at any stage of dementia should, therefore, target these factors as well as keeping a person-centered approach open to the individual perceptions of QoL.

Conflicts of interest

None.

Description of authors' roles

A. E. Ydstebø designed the study and wrote the paper. S. Bergh organized the data collection and supervised the development of the paper. G. Selbæk organized the data collection and supervised the development of the paper. J. Šaltytė Benth was responsible for the statistical design of the study and for carrying out the statistical analysis. K. Brønnick supervised the development of the paper. C. Vossius supervised the design of the study and the development of the paper.

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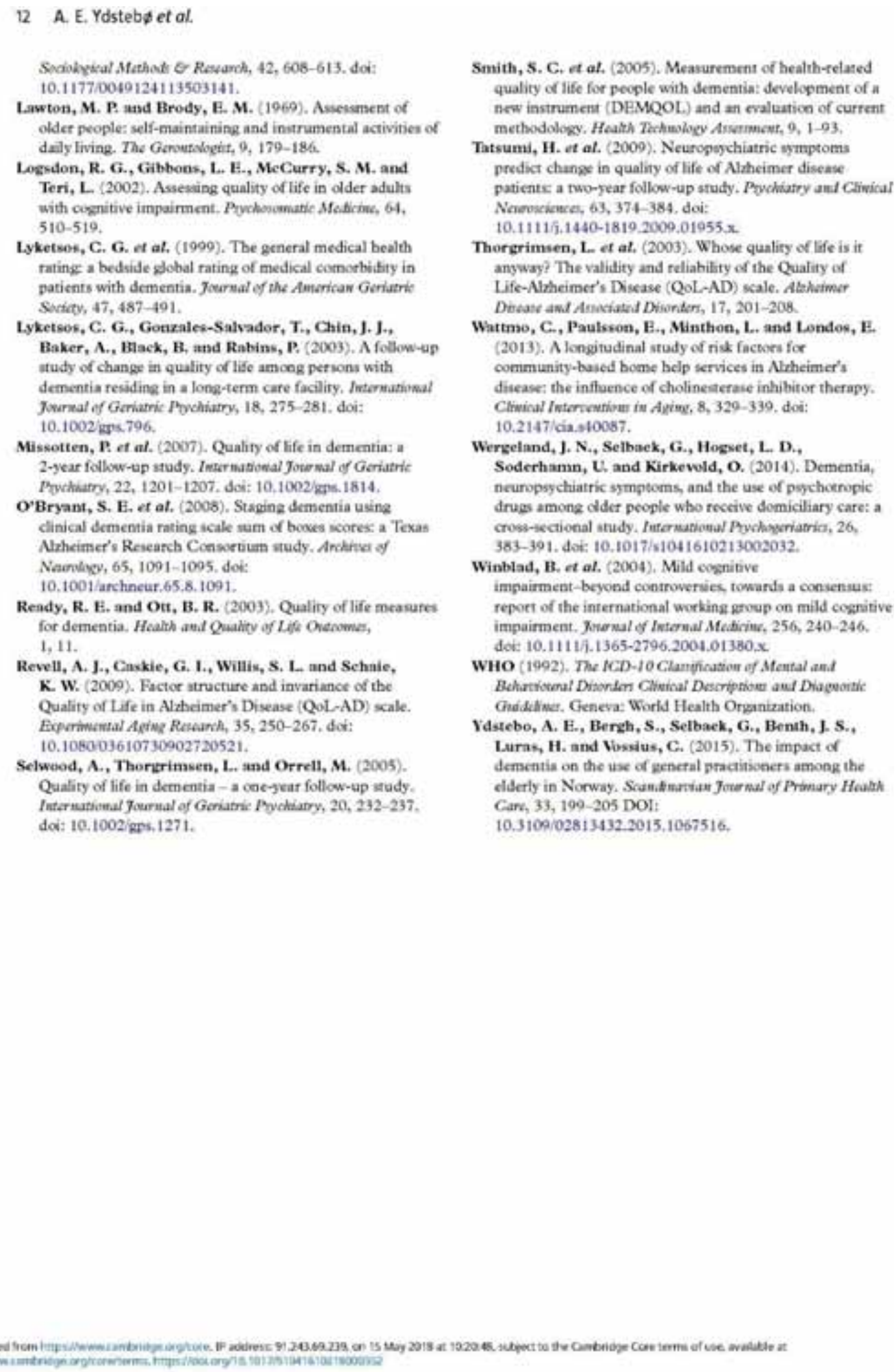

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Appendix 4 – Paper III

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BMC Geriatrics

RESEARCH ARTICLE Open Access

Informal and formal care among persons with dementia immediately before nursing home admission

Arnt Egil Ydstebø[1,2,3*], Jurate Šaltytė Benth[3,4,5], Sverre Bergh[3,6], Geir Selbæk[3,6,7] and Corinna Vossius[1,2]

Abstract

Background: Dementia is a care intensive disease, especially in the later stages, implying in many cases a substantial carer burden. This study assesses the use of formal and informal care resources among persons with dementia during the last month before nursing home admission. It also describes main providers of informal care and assesses the extent of informal care rendered by the extended social network.

Methods: In this cross-sectional study, we collected data about persons with dementia that were newly admitted to a nursing home in Norway. Information about the amount of formal and informal care during the last 4 weeks preceding nursing home admission was collected from the primary caregivers. Clinical data were collected by examining the patients, while sociodemographic data was collected from the patients' files.

Results: A total of 395 persons with dementia were included. The amount of informal care provided by the family caregiver was 141.9 h per month SD = 227.4. Co-resident patients received five times more informal care than non-co-residents. Informal care from the extended social network was provided to 212 patients (53.7%) with a mean of 5.6 (SD = 11.2) hours per month and represented 3.8% of the total informal care rendered to the patients. Formal care was provided to 52.7% of the patients with a mean of 18.0 (SD = 50.1) hours per month. Co-residency was significantly associated with more informal care, and the associations varied with respect to age, relation to the caregiver, and the caregiver's working situation. Good/excellent general health was associated with less formal care.

Conclusion: Persons with dementia on the verge of admission to a nursing home are mainly supported by the family caregiver, and the use of informal care is particularly high among co-residents. In order to delay nursing home admission, future research should explore the unrealized care potential in extended social networks, as well as the potential for increasing the number of recipients of formal care services.

Keywords: Dementia, Informal care, Formal care, Resource use, Living situation, Social network

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* Correspondence: arnt.egil.ydstebo@stavanger.kommune.no
[1] Centre for Age-related Medicine, Stavanger University Hospital, Stavanger, Norway
[2] Centre for Development of Institutional and Home Care Services Rogaland, Stavanger, Norway
Full list of author information is available at the end of the article

Background

The number of people living with dementia worldwide was estimated as 35.6 million in 2010, and the numbers are expected to double over the next 20 years [1]. Strategies are needed to secure sufficient support for people living with dementia as well as their informal and professional caregivers without financially overstraining health and welfare systems. Health economic evaluations show that nursing home placement is the most significant factor driving costs in dementia care and that the interval from diagnosis to institutionalization is about 30–40 months [2–5]. A considerable amount of informal care is provided in the patient's home, and the burden of care is one of the main important factors associated with nursing home admission (NHA) [6–11]. Several studies report that a considerable amount of informal care is provided in the home environment from 30 up to 100 h per week in their respective populations [7, 10, 12–16]. Factors associated with increased informal care are dementia severity, severe neuropsychiatric symptoms, and increased functional impairment [7, 8, 12, 17–19]. The influence of co-residency between the primary caregiver and the person with dementia is of particular interest. Previous studies have found associations between co-residency and increased informal care, while more formal care was associated with persons with dementia living alone [12, 15, 17, 20].

Expecting an increasing number of persons with dementia, The Norwegian Ministry of Health published the first national Dementia Strategy in 2007 to better meet the needs of patients, family caregivers, and the health care system. This strategy was updated in 2015. One of the main goals of the Norwegian Dementia Strategy 2020 [21] is to enhance the support to the family caregivers and better the cooperation with voluntary services to empower persons with dementia to participate more actively in society and to live longer in their own homes. A study performed in eight European countries found that informal care from family and friends, in addition to the primary caregiver, were available to less than half of the carers in the study and suggested that provision of informal support to the carer may act as a protective factor for the perceived carer burden [14]. However, knowledge about the extent of informal care in Norway delivered during the period before NHA, and the providers of informal care, not only including primary caregivers but also the extended social network, is scarce. Better insight to the extent of care provided in patients' homes, who provides the care, and what factors are related to the amount of care in the period before NHA may assist the development of new services aiming to prolong time to nursing home admission.

The aim of this study was to assess the resource use in formal and informal care among persons with dementia during the last month before NHA, and to assess clinical and sociodemographic factors associated with the use of care. We aimed as well as to describe the main providers of informal care, and to assess the amount of informal care rendered by the extended social network.

Methods

Setting

This is a cross-sectional study assessing baseline data in a sample drawn from the Resource Use and Disease Course in Dementia – Nursing Home (REDIC-NH) project.

Study population

The study population was a sub-sample of participants in the- REDIC-NH project. The REDIC-NH study is a longitudinal observational study that includes newly admitted patients from 47 small and large nursing homes in four Norwegian counties and follows them from admission to the NH over a course of 5 years or until death [22]. Patients older than 65 years, or younger than 65 years but with established dementia, were included. In addition, the expected stay in the NH had to be more than 4 weeks. Patients with a life expectancy shorter than 6 weeks were not eligible. The study included a convenience sample of 695 persons, and recruitment took place between January 2012 and August 2014.

To increase homogeneity and describe the resource use in a dementia population exclusively, patients without dementia, or not permanently admitted to NH where excluded from the present study, as were participants without complete Resource Utilization in Dementia (RUD) questionnaire.

To be admitted to a long-term NH stay in Norway, the person must apply to the municipality. The application is evaluated based on a needs' assessment, and available places are allocated based on urgency. If there are no available places, the applicant usually is placed on a waiting list, with a waiting period from a few days up to several weeks.

Ethical considerations

The patients' capacity to consent was assessed by the nursing home staff, including a physician. Written informed consent was obtained from patients with the capacity to consent or from the family caregivers on behalf of the patients in cases of reduced capacity to consent. The study was approved by the Regional Committee for Medical and Health Research Ethics (2011/1738).

Data collection

Data were collected by healthcare workers at the nursing home, under the supervision of 10 research nurses. The research nurses completed 5 days of training prior to the start of the study, and the data collectors completed 2 days of training. Data were collected through cognitive and physical tests and structured interviews with the

patients, their family caregivers defined as a next of kin who looked after the patient at least once a week, and the health workers.

Measures

Demographic data included the patients' age and gender and were collected by reviewing the patients' files kept at the NHs. A diagnosis of dementia according to the ICD-criteria [23] was independently established by two of the authors (SB and GS) based on all available information about the patients. Both SB and GS are specialists in psychiatry and experienced in geriatric psychiatry and research. If no consensus was reached, a third psychiatrist was consulted.

The clinical measures dementia severity and severity of physical health were obtained using the following instruments: The General Medical Health Rating (GMHR) [24], a four-category, reliable, and valid global bedside assessment tool for rating the severity of physical health. The score is based on an overall assessment by health care workers. The Clinical Dementia Rating Scale (CDR) assesses the severity of dementia as no dementia, possible dementia, and mild, moderate, or severe dementia. CDR comprises six items (memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care). A score is calculated according to an algorithm where the memory item is given more weight. For statistical purposes, we calculated the CDR sum of boxes (CDR-SOB), which offers an extended range of values and is calculated by adding the item scores (range 0–18). Higher scores indicate more severe dementia [25].

The extent of formal care and the extent and providers of informal care during the last 4 weeks preceding NHA were recorded by the RUD questionnaire, that is answered by the primary caregiver and includes the following information about the primary caregiver [26]: Age, gender, relation to the patient, co-residential status, work status, hours worked last month, and lost work hours due to care tasks in the last month. Information about the extended social network included: Relation to patient and hours of provided informal care last month. The extent of informal care provided by the family caregiver last month was recorded in regard to the following three aspects: 1) the time used to help the patients with personal activities of daily living (PADL), 2) the time used on instrumental ADL (IADL), 3) and the time used on supervision, like helping the patient with orientation or preventing behavior that is distressing to the patient. We calculated the total informal care time by summarizing the amounts of time for these three types of care. If this sum exceeded 24 h per day, a total informal care time of 24 h per day was set. Formal care was equalled to the time provided by professional home care services, while services like home help, meal delivery, day care centres, or respite care were not included due to insufficient data.

Statistical analysis

Data are described by the means and standard deviations (SD) or frequencies and percentages. Differences between groups were assessed by Independent Samples t-test for continuous variables and the χ^2-test for categorical variables. Associations between predefined covariates (gender, age, caregiver gender, caregiver relation to patient, caregiver in paid work, co-residency with family caregiver, GMHR, and CDR) and the three outcome variables (informal care by the primary caregiver, informal care by the extended social network and formal care) were assessed by estimating bivariate and multiple linear mixed models. Random effects for nursing homes were included in the models to adjust the estimates for possible within-nursing-home correlations. Stratification by living with or without a caregiver was performed by including interactions between the dichotomous variable (co-residency with or without caregiver) and all covariates. Interactions with $p < 0.1$ were kept in the model. Missing values in variables co-resident, carer relation, and carer in work were imputed by logical rules whenever possible. The analyses were performed using IBM SPSS Statistics for Windows version 25.0 (Armonk, NY: IBM Corp.) and SAS v 9.4. Results with p-values less than 0.05 were considered statistically significant.

Results

Study population

The REDIC-NH cohort consists of 696 patients, among which 445 had dementia and were permanently admitted to a nursing home. However, 50 patients had to be excluded due to missing or incomplete RUD questionnaires. Thus, the study included 395 patients with a mean age of 84.4 (SD = 7.5) years, and 265 (67.1%) patients were female. According to the CDR, 277 (73.9%) had moderate or severe dementia. There were no differences regarding demographic or clinical characteristics between patients who completed the RUD questionnaire and those who did not.

The extent of formal and informal care is presented in Table 1.

The extent of informal care

The mean care time provided by the family caregiver was 141.9 (SD = 227.4) hours per month, while the total contribution of the patients' extended social network, including family members, was 5.6 (SD = 11.2) hours per month.

The extent of formal care

Formal care was provided to 208 (52.7%) of the patients with a mean of 34.2 (SD = 64.9) hours per month among

Table 1 Formal and informal care during the last month before NHA (*N* = 395)

Variable	
Formal care	
Recipients, n (%)	208 (52.7)
Mean hours of formal care, recipients of formal care, last month (SD)	34.2 (64.9)
Mean hours of formal care, whole sample last month (SD)	18.0 (50.1)
Informal care by the primary carer, mean hours last month (SD)	
PADL	74.8 (170.5)
IADL	65.9 (142.1)
Supervision	55.9 (158.9)
Total informal care by the primary carer	141.9 (227.4)
Informal care by wider social network, mean hours last month (SD)	
Family	3.8 (10.2)
Relatives	0.4 (3.0)
Friends	0.1 (0.8)
Neighbours	0.2 (1.0)
Others	0.9 (4.0)
Total informal care by the extended social network	5.6 (11.2)

NHA Nursing Home Admission, SD Standard Deviation

those receiving formal care. For the whole sample, the mean amount of formal care per month was 18.0 (SD = 50.1) hours.

Informal care – characteristics of the family caregiver

Characteristics of the family caregivers and the extended social networks are presented in Table 2. Of the 395 patients, 379 (95.9%) had a family caregiver, of whom 228 (60.2%) were females, 255 (67.3%) were the patients' children, while 81 (21.4%) were spouses. The mean age was 57.4 (SD = 8.9) years for family caregivers who were the patients' children and 77.7 (SD = 7.6) years for family caregivers who were the patients' spouses. Co-resident caregivers accounted for 105 (26.6%) of the sample. A total of 194 (54.2%) caregivers were doing paid work, and they worked 34.9 (SD = 10.3) hours per week. Of the caregivers in paid work, 60 (30.8%) reported a mean loss of 11.2 (SD = 9.6) working hours per week due to care tasks.

Informal care - characteristics of the extended social network

In our study sample, 212 (53.7%) patients received support from at least one member of their social network, whereas 183 (46.3%) had no additional carers beside the family caregiver. Of the 212 patients that received help from their extended social network, 154 (72.6%) received help from family members, while 29 (13.7%) received help from more distant relatives, 15 (7.1%) received help from friends, 22 (10.4%) received help from neighbours, and 44 (20.8%) received help from others (Table 2).

The impact of sociodemographic and clinical factors on the use of care

Male patients received more informal care than female patients (187.1 versus 120.3 h per month, $p = 0.016$). There was no statistical difference between genders regarding formal care. Co-resident patients received more informal care (343.1 versus 67.4 h per month, $p < 0.001$) and less formal care than patients living alone (9.1 versus 21.2 h per month, $p = 0.001$), while there was no statistical difference in the extent of informal care by the extended social network between co-residents and non-co-residents (Fig. 1). The ratios of informal to formal care were 37.7:1 for co-resident patients and 3.2:1 for patients living alone. Family caregivers who did paid work provided less informal care than those who were not working (74.2 versus 228.7 h per month, $p < 0.001$). There were no statistical differences in formal care between patients with working and non-working family caregivers.

According to the bivariate linear mixed models presented in Table 3, more hours of *informal care by the family caregiver* was significantly associated with the patient being of lower age, having male gender, having a family caregiver not doing paid work, having a spouse as a family caregiver as opposed to a child, having more severe dementia, and having a co-resident caregiver. Having a family caregiver doing paid work was associated with more *informal care from the social network*. Having a spouse as the family caregiver as opposed to a child, good/excellent GMHR, and co-residency were associated with less *formal care*.

Table 2 Description of the family caregivers (*n* = 379) and the patient's extended social network

Family caregiver's relation to patient, n (%)	
- spouse	81 (21.4)
- child	255 (67.3)
- others	43 (11.3)
Age, mean (SD)	
- spouse-carers	77.7 (7.6)
- child-carers	57.4 (8.9)
Gender, n (%) *female*	228 (60.2)
Co-resident, n (%) *yes*	105 (26.6)
Employed, n (%) *yes*	194 (54.2)
Hours worked per week if in paid work, mean (SD)	34.9 (10.3)
Carers that lost working hours due to care tasks, n (%)	60 (30.8)
Mean hours lost per week, if reporting lost hours (SD)	11.2 (9.6)
Care benefit as part of paid work, n (%) *yes*	8 (4.0)
Mean hours care benefit per week, if receiving care benefit, mean (SD)	7.6 (5.6)
Number of additional care providers, n (%)	
- 0	183 (46.3)
- 1	172 (43.5)
- 2	28 (7.1)
- 3	12 (3.7)
Additional care providers' relation to patients, n (%)	
- family	154 (72.6)
- relatives	29 (13.7)
- friends	15 (7.1)
- neighbours	22 (10.4)
- others	44 (20.8)

SD Standard Deviation

In the multiple model, female gender of caregiver was significantly associated with more hours of informal care by the family caregiver. Several interactions with co-residency were present in the model. Co-resident patients had significantly more hours of informal care than non-co-resident patients with differences varying between strata. There were no differences between male and female patients. Differences in provided informal care between spouses and children caregivers were significantly larger among non-co-resident patients than co-resident patients, Differences in received informal care from working and non-working caregivers were significantly higher among co-resident patients than non-co-resident patients. Higher age was associated with fewer hours of informal care, and there was a significantly stronger reduction among co-resident patients than non-co-resident patients. Less formal care was only associated with good/excellent GMHR.

Discussion

This study assessed the use of formal and informal care among home-dwelling persons with dementia during the last month before permanent admission to a nursing home. For the two-thirds of the patients living alone, their closest caregiver was mainly one of their children, while for the patients living in co-residency, the caregiver was most frequently the spouse. Half of the sample received formal care in the form of home care services. The extent of informal care was substantially larger than the extent of formal care, and the majority of the informal care was delivered by the family caregiver, while the extended social network only contributed 3.8%. Half of the primary caregivers even reported to have no additional help at all, including the majority of spouses living with the patient. Only a small portion of 10% received care from two or more persons in their extended social network; however, the low hourly contribution suggests that the help was somewhat sporadic.

Care contributions from the extended social network have seldom been investigated or discussed in previous studies. In the US, The National Study of Caregiving found that 73–78% of caregivers to persons with dementia had additional helpers [27]. In Norway, the REDIC project found that 50 to 70% of caregivers had additional helpers, however, our findings show that the hourly contribution was low. We can only suggest possible reasons for the low contribution. Norway has high employment rates among both genders, possibly reducing the opportunity to support relatives [28]. Another explanation could be the increasing urbanization causing longer geographical distance between relatives [29]. The massive expansion of the public care services during the last 50 years might also lead to a perception that the provision of care to elderly relatives is a state- rather than a family-responsibility [30]. As more then 95% of all informal care was rendered by the main caregiver, there seems to exist unexhausted resources in involving the extended social network in order to relief the burden experienced by primary caregivers. However, the research community has yet to explore how to access these resources and the barriers that might exist in both rendering care but as well accepting it.

We found that the family caregiver provided a mean of 142 h per month of informal care. In contrast, a health economic analysis performed on several cohorts of persons with dementia concluded that a mean of 60 to 85 h per months of informal help were rendered at

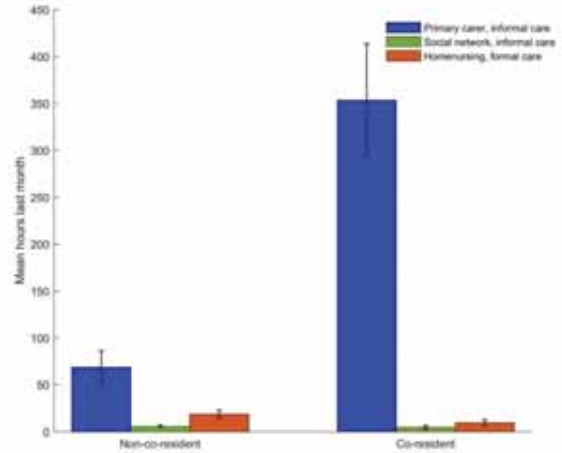

Fig. 1 Time used to care for patients during the last month before nursing home admission

the point of diagnosis, thus, indicating a considerable increase in the need for care in the period leading up to NHA [31]. A previous study conducted in eight European countries with a cohort similar to the REDIC cohort reported 360 h of informal care per month, while studies observing cohorts with younger patients in earlier stages of dementia reported a range of 82 to 160 h per month [12, 14–16]. These differences might be owed to varying shares of co-residing family caregivers. In addition, cultural differences regarding the experienced obligation to care for elder family members as well as the accessibility and costs of formal care might impact the extent of informal care.

Co-residency was a main predictor for the extent of informal care rendered. This might be an indication of "supply creates its own demand", as co-resident caregivers (the spouse in most cases) might be more involved than needed when assisting the patients with daily tasks and supervision [32]. It could as well lead to an overestimation of care time, as it might be difficult to distinguish shared household activities from care activities. On the other hand, more severe dementia was associated with more informal care, suggesting that the amount of informal care is adjusted to the severity of dementia.

Only about half of the sample received formal care and our finding of 4.5 h of formal care per week is considerably lower than the findings in a comparable study that reported 7.5 h [15]. Another analysis of care resources to Norwegian home-dwelling persons with and without dementia found that 3.2 h of formal care was provided to a sub-population with dementia [31]. Thus, indicating a progressive increase in formal care provision. In recent years Norwegian Dementia Strategies have asked for more differentiated care services and a more individualized approach toward persons with dementia and their family caregivers. Consequently, we would expect a higher amount of informal care time and dementia-specific clinical measures to be associated with the extent of formal care, but we found that only somatic health was related to it. A possible explanation could be that Norwegian home care services mainly cover help with tasks related to ADL dependencies and, to a lesser degree, with tasks related to IADL dependencies and supervision of the patients [33].

Our finding that co-resident patients received less formal care and more informal care than patients living alone is consistent with previous studies [12, 15–17]. It indicates a substitutive rather than complimentary relationship between formal and informal care use and are in line with a recently published study in six Western-European countries [34]. This might as well apply to the contributions from the extended social network as more support was provided from the extended social network in cases with non-co-residency and when the primary carer was holding a job.

The low use of formal care substituted by a high use of informal care might be due to a lack of perceived capacity or skill in the primary care services to offer specialized and individualized dementia care, especially care and support directed towards co-resident caregivers. A cross-European study found that the formal services available to persons with dementia were non-specific and not tailored to the patient group or the specific

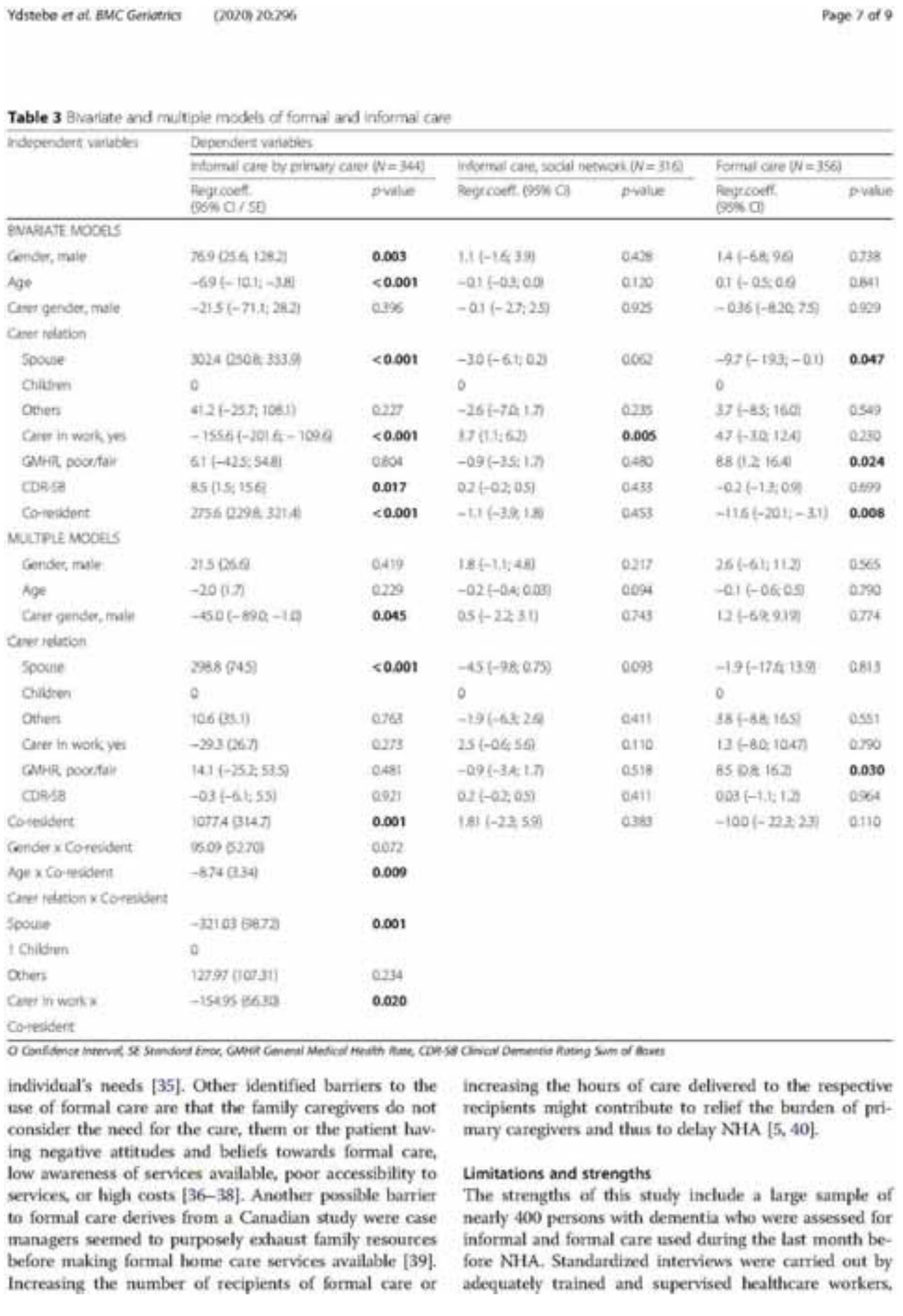

Table 3 Bivariate and multiple models of formal and informal care

Independent variables	Dependent variables					
	Informal care by primary carer (*N* = 344)		Informal care, social network (*N* = 316)		Formal care (*N* = 356)	
	Regr.coeff. (95% CI / SE)	*p*-value	Regr.coeff. (95% CI)	*p*-value	Regr.coeff. (95% CI)	*p*-value
BIVARIATE MODELS						
Gender, male	76.9 (25.6; 128.2)	**0.003**	1.1 (−1.6; 3.9)	0.428	1.4 (−6.8; 9.6)	0.738
Age	−6.9 (− 10.1; −3.8)	**<0.001**	−0.1 (−0.3; 0.0)	0.120	0.1 (− 0.5; 0.6)	0.841
Carer gender, male	−21.5 (−71.1; 28.2)	0.396	− 0.1 (− 2.7; 2.5)	0.925	− 0.36 (−8.20; 7.5)	0.929
Carer relation						
Spouse	302.4 (250.8; 353.9)	**<0.001**	−3.0 (− 6.1; 0.2)	0.062	−9.7 (− 19.3; − 0.1)	**0.047**
Children	0		0		0	
Others	41.2 (−25.7; 108.1)	0.227	−2.6 (−7.0; 1.7)	0.235	3.7 (−8.5; 16.0)	0.549
Carer in work, yes	− 155.6 (−201.6; − 109.6)	**<0.001**	3.7 (1.1; 6.2)	**0.005**	4.7 (−3.0; 12.4)	0.230
GMHR, poor/fair	6.1 (−42.5; 54.8)	0.804	−0.9 (−3.5; 1.7)	0.480	8.8 (1.2; 16.4)	**0.024**
CDR-SB	8.5 (1.5; 15.6)	**0.017**	0.2 (−0.2; 0.5)	0.433	−0.2 (−1.3; 0.9)	0.699
Co-resident	275.6 (229.8; 321.4)	**<0.001**	−1.1 (−3.9; 1.8)	0.453	−11.6 (−20.1; − 3.1)	**0.008**
MULTIPLE MODELS						
Gender, male	21.5 (26.6)	0.419	1.8 (−1.1; 4.8)	0.217	2.6 (−6.1; 11.2)	0.565
Age	−2.0 (1.7)	0.229	−0.2 (−0.4; 0.03)	0.094	−0.1 (− 0.6; 0.5)	0.790
Carer gender, male	−45.0 (− 89.0; −1.0)	**0.045**	0.5 (− 2.2; 3.1)	0.743	1.2 (−6.9; 9.19)	0.774
Carer relation						
Spouse	298.8 (74.5)	**<0.001**	−4.5 (−9.8; 0.75)	0.093	−1.9 (−17.6; 13.9)	0.813
Children	0		0		0	
Others	10.6 (35.1)	0.763	−1.9 (−6.3; 2.6)	0.411	3.8 (−8.8; 16.5)	0.551
Carer in work, yes	−29.3 (26.7)	0.273	2.5 (−0.6; 5.6)	0.110	1.3 (−8.0; 10.47)	0.790
GMHR, poor/fair	14.1 (−25.2; 53.5)	0.481	−0.9 (−3.4; 1.7)	0.518	8.5 (0.8; 16.2)	**0.030**
CDR-SB	−0.3 (−6.1; 5.5)	0.921	0.2 (−0.2; 0.5)	0.411	0.03 (−1.1; 1.2)	0.964
Co-resident	1077.4 (314.7)	**0.001**	1.81 (−2.3; 5.9)	0.383	−10.0 (− 22.3; 2.3)	0.110
Gender x Co-resident	95.09 (52.70)	0.072				
Age x Co-resident	−8.74 (3.34)	**0.009**				
Carer relation x Co-resident						
Spouse	−321.03 (98.72)	**0.001**				
1 Children	0					
Others	127.97 (107.31)	0.234				
Carer in work x Co-resident	−154.95 (66.30)	**0.020**				

CI Confidence Interval, SE Standard Error, GMHR General Medical Health Rate, CDR-SB Clinical Dementia Rating Sum of Boxes

individual's needs [35]. Other identified barriers to the use of formal care are that the family caregivers do not consider the need for the care, them or the patient having negative attitudes and beliefs towards formal care, low awareness of services available, poor accessibility to services, or high costs [36–38]. Another possible barrier to formal care derives from a Canadian study were case managers seemed to purposely exhaust family resources before making formal home care services available [39]. Increasing the number of recipients of formal care or increasing the hours of care delivered to the respective recipients might contribute to relief the burden of primary caregivers and thus to delay NHA [5, 40].

Limitations and strengths

The strengths of this study include a large sample of nearly 400 persons with dementia who were assessed for informal and formal care used during the last month before NHA. Standardized interviews were carried out by adequately trained and supervised healthcare workers, thus securing high-quality data. Private entities rarely provide health care service in the municipalities in Norway. Thus, the municipalities are almost exclusively responsible for the provision of care services and provide a homogenous environment for health service research with similar criteria for NHA.

A major limitation is that our sample might not be representative of the general population of persons with dementia in this stage in Norway as only patients that completed the BL examination were included, and the mean time from admission to BL was 10.5 weeks [22]. As a confounding factor we might thus have excluded patients who were eligible for the study but who died shortly after admission to a nursing home, or eligible persons that did not have a family caregiver. Furthermore, the physical and cognitive tests were first performed at the BL examination and could be sensitive to changes during this time period or due to the event of admission. However, the GMHR and CDR have shown to be stable over time [41–43]. Moreover, caregiver-reported data from the RUD questionnaire may have yielded inaccuracies in the extent of formal and informal care.

We equated formal care with home care services without taking into account other forms of services, such as meal delivery, day care centres, or respite care due to insufficient or lacking data. This might have resulted in an underestimation of the extent of formal care. However, we consider home care services as the most relevant type of formal care in Norway, and as well when comparing different health care systems.

This study was performed in Norway, and the findings might not be transferrable to other countries with different health systems. In Scandinavia, public health services provide the majority of care, and it is rendered free of charge for relatively small fees to the patients. Thus, the extent of formal care, the point of time for NHA and the extent of informal care might differ substantially in other health care systems and cultural settings.

Conclusion

We found that persons with dementia on the verge of admission to a nursing home are mostly supported by informal care provided by one primary carer, while the amount of care provided by the patients' extended social network and the provision of formal care was low. Future research should explore the unrealized care potential in the extended social networks and the possibilities in more diverse formal care services directed to persons with dementia and their caregivers.

Abbreviations

NHA: Nursing home admission; REDIC-NH: Resource Use and Disease Course in Dementia-Nursing Home; RUD: Resource utilization in dementia; P-ADL: Personal activity of daily living; IADL: Instrumental activity of daily living; GMHR: General medical health rating; CDR: Clinical dementia rating; SD: Standard deviation

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Authors' contributions

CV, GS, SB, JSB, and AEY developed the concept, study design and research questions. AEY and CV processed the data, performed descriptive analysis and prepared the manuscript. JSB, SB, and GS critically reviewed and added comments to the manuscript at all phases. JSB provided expert advice on the statistical analysis and performed the bivariate and multiple linear mixed models. All authors took part in revising the paper and approved the final version.

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Availability of data and materials

The datasets generated and/or analysed during the current study are available for researchers in cooperation with the data owner, the Research Centre for Age-related Functional decline and Disease – Innlandet Hospital Trust. Information is available on the following page link: https://sykehuset-innlandet.no/avdelinger/alderspsykiatrisk-forskningssenter

Ethics approval and consent to participate

The patients' capacity to consent was assessed by the nursing home staff, including a physician. Written informed consent was obtained from patients with the capacity to consent or from the legal guardians on behalf of the patients in cases of reduced capacity to consent. The study with reference number 2011/1738 was approved by the Regional Committee for Medical and Health Research Ethics South-east Norway, University of Oslo.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details
[1]Centre for Age-related Medicine, Stavanger University Hospital, Stavanger, Norway. [2]Centre for Development of Institutional and Home Care Services Rogaland, Stavanger, Norway. [3]Research centre for Age-related Functional decline and Disease, Innlandet Hospital Trust, Postboks 68, N-2312 Ottestad, Norway. [4]Institute of Clinical Medicine, University of Oslo, Oslo, Norway. [5]Health Services Research Unit, Akershus University Hospital, Akershus, Norway. [6]Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway. [7]Institute of Health and Society, University of Oslo, Oslo, Norway.

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Publisher's Note

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Appendix 5 – Paper II - corrected Table 3

Table 3: Results from bivariate and multiple nominal regression of trajectories for **patient- and proxy-rated** QOL-AD. Multiple models were reduced by AIC, odds ratios are presented for persons with and without dementia for variables which were a part of interaction with dementia diagnosis.

Variables	Patient-rated QoL						Proxy-rated QoL					
	Bivariate models		Multiple models				Bivariate models		Multiple models			
			No-dementia		Dementia				No-dementia		Dementia	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
DEMENTIA												
Group-1 – ref.	1						1	-				
Group-2	1.02 (0.57; 1.77)	0.993					0.29 (0.18; 0.47)	**<0.001**				
Group-3	0.34 (0.16; 0.71)	**0.005**					0.09 (0.03; 0.23)	**<0.001**				
AGE[1]												
Group-1 – ref.	1	-					1	-	1	-	1	-
Group-2	1.01 (0.96;1.06)	0.763					1.05 (1.01;1.10)	**0.027**	1.14 (1.06;1.23)	**0.001**	1.03 (0.96;1.11)	0.443
Group-3	1.04 (0.97;1.10)	0.289					1.01 (0.94;1.07)	0.881	1.07 (0.96;1.18)	0.214	1.34 (1.06;1.69)	**0.014**
LIVING ALONE												
Group-1 – ref.	1	-					1	-				
Group-2	0.76 (0.43;1.35)	0.342					1.46 (0.91;2.32)	0.113				
Group-3	1.48 (0.72;3.02)	0.285					2.41 (1.15;5.06)	**0.020**				
MMSE[1]												
Group-1 – ref.	1	-					1	-				
Group-2	1.01 (0.96;1.05)	0.806					1.09 (1.04;1.14)	**<0.001**				
Group-3	1.11 (1.04;1.19)	**0.003**					1.32 (1.18;1.47)	**<0.001**				
GMHR												
Poor /fair												
Group-1 – ref.	1	-	1	-	1	-	1	-				
Group-2	0.48 (0.27;0.86)	**0.014**	0.69 (0.30;1.59)	0.387	0.30 (0.09;0.93)	**0.037**	0.45 (0.28;0.71)	**0.001**				
Group-3	0.08 (0.03;0.17)	**<0.001**	0.24 (0.08;0.74)	**0.013**	0.01 (0.00;0.11)	**<0.001**	0.19 (0.09;0.41)	**<0.001**				
Good/excellent – ref.	1	-	1	-	1	-		-				
CDR-SOB[1]												
Group-1 – ref.	1	-	1	-	1	-	1	-	1	-	1	-
Group-2	0.99 (0.93; 1.05)	0.670	0.89 (0.64;1.22)	0.452	1.06 (0.90;1.25)	0.509	0.83 (0.78; 0.89)	**<0.001**	0.70 (0.55;0.90)	**0.005**	0.94 (0.86;1.04)	0.248
Group-3	0.81 (0.73; 0.90)	**<0.001**	0.38 (0.21;0.30)	**0.002**	1.19 (0.88;0.26)	0.259	0.40 (0.27; 0.59)	**<0.001**	0.22 (0.10;0.49)	**<0.001**	0.72 (0.51;1.02)	0.062
IADL[1]												
Group-1 – ref.	1	-	1	-	1	-	1					
Group-2	1.15 (0.46; 2.92)	0.763	1.08 (0.82;1.42)	0.578	0.73 (0.56;0.96)	**0.022**	11.8 (4.9; 28.1)	**<0.001**				
Group-3	12.8 (3.45; 47.5)	**<0.001**	1.03 (0.72;1.49)	0.861	0.63 (0.39;1.04)	0.069	1274 (132;12295)	**<0.001**				
PSMS[1]												
Group-1 – ref.	1		1	-	1	-	1	-				
Group-2	0.66 (0.45; 0.97)	**0.034**	1.02 (0.92;1.12)	0.754	0.88 (0.81;0.96)	**0.005**	0.39 (0.26; 0.57)	**<0.001**				
Group-3	0.17 (0.08; 0.36)	**<0.001**	0.97 (0.80;1.17)	0.749	0.79 (0.66;0.94)	**0.008**	0.06 (0.02; 0.19)	**<0.001**				
CSDD[1,2]												

Group-1 – ref.	1		1	-			1	-	1			-
Group-2	0.92 (0.87; 0.97)	**0.003**	0.91 (0.84; 0.99)	**0.026**			0.83 (0.77; 0.88)	**<0.001**	0.92 (0.85; 1.00)			**0.042**
Group-3	0.81 (0.74; 0.89)	**<0.001**	0.92 (0.82; 1.04)	0.178			0.51 (0.40; 0.65)	**<0.001**	0.77 (0.61; 0.98)			**0.037**
NPI-AGITATION[1]												
Group-1 – ref.	1		1	-	1	-	1	-				
Group-2	1.00 (0.95; 1.06)	0.967	1.05 (0.88;1.25)	0.616	1.04 (0.96;1.13)	0.304	0.93 (0.88; 0.98)	**0.006**				
Group-3	0.91 (0.83; 1.00)	0.062	1.32 (1.04;1.68)	**0.021**	0.96 (0.81;1.15)	0.679	0.67 (0.50; 0.90)	**0.008**				
NPI-PSYCHOSIS[1]												
Group-1 – ref.	1						1	-				
Group-2	1.03 (0.90; 1.17)	0.707					0.81 (0.70; 0.93)	**0.004**				
Group-3	0.82 (0.62; 1.07)	0.139					0.23 (0.02; 2.45)	0.221				
NPI-AFFECTIVE[1,3]												
Group-1 – ref.	1		1	-			1	-	1	-	1	-
Group-2	0.97 (0.92; 1.01)	0.154	0.98 (0.92; 1.06)	0.655			0.85 (0.80; 0.91)	**<0.001**	0.85 (0.76;0.95)	**0.004**	0.96 (0.88;1.05)	0.329
Group-3	0.82 (0.74; 0.92)	**0.001**	0.86 (0.75; 0.99)	**0.045**			0.38 (0.21; 0.67)	**0.001**	0.41 (0.19;0.91)	**0.029**	1.01 (0.61;1.68)	0.963

QoL = Quality of Life, OR = Odds Ratio, CI = Confidence Interval, Coeff. = coefficient, SE = Standard Error, ref = reference value, MMSE = Mini Mental Status Examination, GMHR = General Medical Health Rating, CDR SOB= Clinical Dementia Rating sum of boxes, IADL = Instrumental Activity of Daily living, PSMS=Physical Self Maintenance Scale, CSDD = Cornell Scale for Depression in Dementia, NPI = Neuropsychiatric Symptoms, NPI-Agitation = agitation/aggression, euphoria, disinhibition, aberrant motor behavior and irritability, NPI-Psychosis = delusions and hallucinations, NPI-Affective = depression, anxiety and apathy.

[1] *Odds for one-unit change*

[2] *No interaction between dementia diagnosis and CSDD present, i.e. odds are the same for those without and with dementia*

[3] *No interaction between dementia diagnosis and NPI-Affective among patients present, i.e. odds are the same for those without and with dementia*