

Dementia, neuropsychiatric symptoms, and the use of psychotropic drugs among older people who receive domiciliary care: a cross-sectional study

Jon N. Wergeland,^{1,2} Geir Selbæk,^{3,4} Lisbeth D. Høgset,³ Ulrika Söderhamn²
and Øyvind Kirkevold^{1,3,5}

¹Norwegian Centre for Research, Education and Service Development, Vestfold Hospital Trust, Tønsberg, Norway

²Faculty of Health and Sport Sciences, University of Agder, Kristiansand, Norway

³Centre for Old Age Psychiatric Research, Inlandet Hospital Trust, Ottestad, Norway

⁴Akershus University Hospital, Lørenskog, Norway

⁵Faculty of Health, Care and Nursing, Gjøvik University College, Gjøvik, Norway

ABSTRACT

Background: The objective of this study was to (a) determine the prevalence of cognitive impairment, dementia, and neuropsychiatric symptoms (NPSs) among home-dwelling people, 70 years and older (70+ years), who receive domiciliary care, and (b) describe their use of psychotropic drugs. Few studies have investigated dementia among people receiving in-home care.

Methods: A sample ($N = 1,000$) representative of people aged 70+ years receiving domiciliary care was randomly recruited for participation. A standardized interview with the participants and their next of kin were performed using well-established assessment scales. Two clinical experts independently diagnosed dementia according to ICD-10 criteria.

Results: Of the 415 participants (41.5%) with dementia according to ICD-10 criteria, 19.5% had a dementia diagnosis known to the patient themselves, their caregiver, or health workers in the domiciliary care service. In the previous month, 72.1% exhibited NPSs (21.1% rated as clinically significant), with depression (47.5%), apathy (33.7%), anxiety (33.0%), and irritability (31.1%) being the most common. Psychotropic drugs were regularly used by 40.1% of the sample. Antidepressants ($p = 0.001$) and cognitive enhancers ($p < 0.001$) were more often given to people with dementia than to those without dementia.

Conclusions: Dementia and NPSs are highly prevalent among people who receive domiciliary care, and diagnostic disclosure is low. People with dementia constitute a distinct group with respect to NPSs and psychotropic drug use. Early detection and correct diagnosis might increase the understanding of their everyday challenges and enable families to alleviate consequences of dementia and NPSs.

Keywords: BPSD, cognitive impairment, community dwelling, domiciliary care, medication, older people

Introduction

Dementia is common in older populations and it is challenging to provide sufficient healthcare to those living in their own homes. In the general population, the prevalence of dementia increases exponentially with age. In Western Europe, the prevalence is estimated to increase from 4.3% in the age group 70–74 years to 43.1% among people aged 90+ years (Prince *et al.*, 2013). In 2010, 35.6 million people worldwide were estimated to be living with

dementia, and most people with dementia live in developing countries (Prince *et al.*, 2013). The numbers affected will double every 20 years to 81.1 million by 2040 (Ferri *et al.*, 2005).

In Norway, the public sector plays an important role in offering health services and social care. The increase of the older population put a heavy strain on the provision of domiciliary care in the community. Among Norwegians over 66 years old, 16.9% receive some kind of domiciliary care (Otnes, 2010). Two main policies are universally accepted: to enable older people to stay in private homes as long as possible and to support family caregivers (Luppa *et al.*, 2008).

Dementia is found in 80.5% of nursing home residents and neuropsychiatric symptoms (NPSs)

Correspondence should be addressed to: Jon N. Wergeland, PhD, University of Agder, Serviceboks 422, 4604 Kristiansand, Norway. Phone: +4793216030; Fax: +4738141301. Email: jon.wergeland@uia.no. Received 1 Aug 2013; revision requested 6 Sep 2013; revised version received 9 Oct 2013; accepted 18 Oct 2013. First published online 20 November 2013.

are present in more than 80% of residents with dementia (Selbaek *et al.*, 2007; Zuidema *et al.*, 2007). Over a five-year period, NPSs have been shown to occur in 97.0% of people with dementia living in the community. The most prevalent symptoms are depression, apathy, anxiety, and irritability (Steinberg *et al.*, 2008). Prevalence of NPSs is associated with both, the type (Martinez *et al.*, 2008) and severity of the dementia (Lyketsos *et al.*, 2002). The psychosocial environment and the amount of psychotropic drugs predict NPSs among nursing home residents. People with NPSs are given more psychoactive drugs and are more often physically restrained than those without symptoms (Zuidema *et al.*, 2007).

NPSs predict a poorer quality of life, increased disability (Okura *et al.*, 2010), and are as opposed to exposure of antipsychotics associated with time to institutionalization and death (Lopez *et al.*, 2013). NPSs can be challenging and cause harm to both, the person with dementia and the family caregiver.

Epidemiological studies indicate high rates of antidepressant and antipsychotic drugs in the general population. Their use is more prevalent among women than among men, in older rather than in younger age groups (Barbui and Percudani, 2006), and there is more use in institutional care (Ruths *et al.*, 2001). People with anxiety and dementia are more frequently reported to use antipsychotic agents than people with schizophrenia and bi-polar disorder (Jano *et al.*, 2008). It is important to consider potential risks when prescribing psychotropic drugs to people with dementia and take into account possible adverse reactions.

Prior to nursing home admission most people in Norway receive domiciliary care. Norwegian legislation makes domiciliary care a mandatory service in all municipalities. The service offered can be of medical and/or of practical nature like nursing, social care, community-based mental health, day-care, safety alarm, support person, and short-term stay in a nursing home.

To our knowledge, neither prevalence of neuropsychiatric symptoms (NPSs) nor dementia has been investigated in either Norwegian or international studies among older people receiving domiciliary care. The objective of this study was to (a) determine the prevalence of cognitive impairment, dementia, and NPSs among home-dwelling people, 70 years and older (70+ years), who receive domiciliary care and (b) describe their use of psychotropic drugs. We hypothesized that prevalence of cognitive impairment, dementia, and NPSs among older people receiving domiciliary care is higher than in general populations and lower than in nursing home populations.

Materials and methods

This is a descriptive study with a cross-sectional design.

Sample

A sample, representative of people, 70+ years receiving domiciliary care was recruited from 19 municipalities in five counties in the eastern part of Norway. Both rural and urban municipalities of various sizes were invited to collaborate in the study. People aged 70+ years, receiving some kind of domiciliary care and having a next of kin who saw them at least once a week, were eligible for inclusion. A random selection of recipients of domiciliary care was made, regardless of the amount and kind of service received. Of 1,795 eligible people, 795 refused to participate. Among those who rejected participation, the proportion of women (73.0% vs. 68.1%, $p = 0.004$) was higher and their mean age (85.0 SD 6.2 vs. 83.4 SD 5.7, $p < 0.001$) was higher than that of those who were included in the study. The final sample comprised 1,000 people aged 70+ years who were receiving domiciliary care.

Data collection

Data were collected between August 2008 and December 2010. A research nurse coordinated the project and cooperated with health workers, who were assessors in the municipalities. Altogether 134 assessors, mostly nurses, physiotherapists, and occupational therapists, in the 19 municipalities interviewed participants and their next of kin. The group of assessors went through a two-day course with training in how to use the assessment scales. Interviews with each participant and their next of kin were performed simultaneously in their own homes by two separate assessors. Written informed consent was collected from both the participant and their next of kin before the interviews were carried out. Due to practical considerations 67 (6.7%) next of kin had to be interviewed by phone within a fortnight from the participant interview.

Cognitive functioning and the severity of the dementia were measured by Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975), Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE; Jorm, 2004), Clock Drawing Test (CDT; Shulman, 2000) and Clinical Dementia Rating Scale (CDR; Hughes *et al.*, 1982).

MMSE is a valid, reliable, and widely used screening instrument (Engedal *et al.*, 1988) for cognitive impairment and dementia. The items are added to give a sum score between 0 and 30, and lower scores indicate poorer cognitive

functioning. The IQ-CODE is an interview with the closest proxy, which assesses observed change from ten years earlier. “No change” is scored 3 on a scale ranging 0–5. Values <3 indicate improvement and values >3 indicate deterioration. The CDT is rated to a score of 5 for a “perfect” clock; visuo-spatial errors from minor to severe is given a score from 4 to 1; and inability to make any reasonable representation of a clock is given a zero score. The CDR assesses the level of dementia. The CDR is scored by the assessor based on all available information, both from the participant and their next of kin. Based on an algorithm giving precedence to memory, a CDR score is generated with scores 0, 0.5, 1, 2, and 3, indicating no, possible, mild, moderate, and severe dementia, respectively.

Two physicians with wide experience in old age psychiatry independently made a diagnosis of dementia according to the ICD-10 (World Health Organization, 2013b) and mild cognitive impairment (MCI) according to the Winblad criteria (Winblad *et al.*, 2004) using available information. Where they disagreed a third clinical expert was consulted and a consensus was reached.

NPSs were assessed with the Neuropsychiatric Inventory ten-item version (NPI-10). It collects information on symptoms in ten domains – delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, and aberrant motor behaviors. The ratings were based on symptoms occurring over the previous four weeks reported by the next of kin (Cummings *et al.*, 1994). Each item was rated by frequency (four-point scale), severity (three-point scale), and perceived caregiver distress (six-point scale). Frequency multiplied with severity gave the item score (1–12). In line with previous research scores, ≥ 4 and ≥ 9 on an individual item was taken to signify clinically significant and severe symptoms, respectively (Steinberg *et al.*, 2004; Selbaek *et al.*, 2007). All item scores were added to give an NPI sum-score (0–120).

The data on prescriptions and use of medical drugs were collected directly from the chart records of the domiciliary care services. The Anatomical Therapeutic Chemical (ATC) (World Health Organization, 2013a) classification system was used in order to identify five groups of psychotropic drugs: antipsychotics (N05A), anxiolytics (N05B), hypnotics (N05C), antidepressants (N06A), and cognitive enhancers (N06D).

Statistical analysis

Data were analyzed using IBM SPSS statistics Windows version 20 (IBM Corporation, Armonk,

NY, USA). The frequencies of NPSs and use of psychotropic drugs were compared between participants with and without dementia, using the Pearson chi-square test. The same test was used to compare the prevalence of dementia between sexes in each age group. Associations between clinically significant NPSs (≥ 4) and prescription of psychotropic drugs were analyzed using Mantel-Haenszel Common Odds Ratio (OR) with a 95% Confidence Interval (CI). The number of cases on each individual NPS varies from that of the complete sample, because some cases lacked data on either frequency or severity of a symptom. In order to report the prevalence of any NPS in the sample, the value “not applicable” was changed to “not present” on the ten items (13–22 cases). In order to adjust for multiple comparisons, we used two-tailed significance at the 0.01 level.

Ethical considerations

All participants and their next of kin had prior to participation been given written and oral information about the project and signed an informed consent to their participation in the project. In the case of those lacking capacity for consent, their closest family proxy gave their informed consent on behalf of their next of kin. The project is approved by the Regional Committee for Medical and Health Research Ethics; Committee A, Eastern Norway (S-08111b), the Norwegian Social Science Data Services (NSD) (07–2008SI), and the Directorate for Health and Social Affairs (08/2984).

Results

Demographic characteristics

The mean age was 83.4 years (SD 5.7), 68.1% were female and 60.4% were widowed. Social care without nursing was received by 323 persons (32.5%), whereas 670 persons (67.5%) received domiciliary nursing and social care. Also, 547 persons (54.7%) reported good or very good physical health, and 665 persons (67.7%) were living alone.

Dementia

According to the Winblad criteria (Winblad *et al.*, 2004), 27.8% of the sample had MCI. In further analyses, MCI are analyzed as part of the group without dementia. Dementia according to the ICD-10 criteria was present in 415 persons (41.5%) of the sample. Of these, 81 persons (19.5%) had a diagnosis of dementia that was known to the participant, their next of kin or registered in the chart records of the domiciliary care services. Of

Table 1. The prevalence of dementia among older people who receive domiciliary care sorted by sex and age groups ($N = 1,000$)

AGE GROUPS	FEMALE: n^a/n^b (% ^c)	MALE: n^a/n^b (% ^c)	p^*	BOTH SEXES COMBINED: n^a/n^b (% ^c)
70–74 years	12/37 (32.4)	7/32 (21.9)	NS	19/69 (27.5)
75–79 years	39/132 (29.5)	24/50 (48.0)	NS	63/182 (34.6)
80–84 years	70/209 (33.5)	43/111 (38.7)	NS	113/320 (35.3)
85–89 years	96/200 (48.0)	56/102 (54.9)	NS	152/302 (50.3)
90+ years	56/104 (53.8)	12/23 (52.2)	NS	68/127 (53.5)
All	273/682 (40.0)	142/318 (44.7)	NS	415/1,000 (41.5)

^aNumber of participants in age group with dementia.

^bNumber of participants in age group.

^cProportion of participants in age group with dementia.

*Pearson chi-square test.

Table 2. The prevalence of neuropsychiatric symptoms (NPSs) at different levels of severity among older people who receive domiciliary care ($N = 1,000$)

NEUROPSYCHIATRIC SYMPTOMS	N^a	ANY SYMPTOM n (% ^b)	CLINICALLY SIGNIFICANT SYMPTOM (≥ 4) n (% ^b)	SEVERE SYMPTOM (≥ 9) n (% ^b)
Delusions	978	100 (10.2)	35 (3.6)	9 (0.9)
Hallucinations	979	58 (5.9)	18 (1.8)	5 (0.5)
Agitation/aggression	982	116 (11.8)	34 (3.5)	8 (0.8)
Depression	982	365 (37.2)	134 (13.6)	26 (2.7)
Anxiety	983	246 (25.0)	101 (10.3)	15 (1.5)
Euphoria	974	50 (5.1)	20 (2.1)	4 (0.4)
Apathy	978	181 (18.5)	98 (10.0)	24 (2.5)
Disinhibition	979	77 (7.9)	29 (3.0)	7 (0.7)
Irritability	983	207 (21.1)	62 (6.3)	14 (1.4)
Aberrant motor behavior	976	47 (4.8)	30 (3.1)	8 (0.8)
Any NPI-symptom	995	547 (55.0)	256 (25.7)	120 (12.1)

^aNumber of patients with complete data.

^bPercentage among patients with complete data.

those participants who received nursing and social care and of those who received only social care, the prevalence of dementia was respectively 51.8% and 20.4% ($\chi^2 = 88.213$, $p < 0.001$). The mean MMSE score was 24.5 (SD 4.8), mean IQ-CODE score was 3.5 (SD 0.6), 28.0% had CDR ≥ 1 . Table 1 demonstrates that the prevalence of dementia was independent of sex, and increased with age. In the youngest group (aged 70–74 years) 27.5% had dementia, whereas 53.5% in the oldest group (aged 90+ years) had dementia.

Neuropsychiatric symptoms

At least one NPS was present in 55.0% of the total sample, 72.1% and 42.9% in people with and without dementia, respectively ($\chi^2 = 83.188$, $p < 0.001$). The highest NPI sum score in the sample was 75 and 448 persons had no NPSs. Depression (37.2%), anxiety (25.0%), and irritability (21.1%) were the most frequent NPSs. One or more clinically significant symptom defined as an NPI score ≥ 4 on a single item was exhibited by 25.7%.

One or more severe symptoms (defined as a score ≥ 9 on a single NPI item) were exhibited by 12.1% of the sample (Table 2). All the individual NPSs were more frequent in participants with dementia than in those without dementia (Table 3).

Use of psychotropic drugs

The use of psychotropic drugs is presented in Table 4. Of the participants, 40.1% were prescribed psychotropic drugs on a regular basis. The participants were prescribed up to five different types of psychotropic drugs. A larger proportion of those with dementia than those without dementia (49.9% vs. 33.2%, $\chi^2 = 28.246$, $p < 0.001$) were prescribed psychotropic drugs. Antidepressants and antipsychotic drugs were more often given to people with dementia than to those without dementia.

Table 5 shows associations between the different NPSs and the use of psychotropic drugs. The use of antipsychotics was associated with delusions, anxiolytics with hallucination, depression, and anxiety. The use of hypnotics was not associated

Table 3. The prevalence of neuropsychiatric symptoms among older people with and without dementia who receive domiciliary care ($N = 1,000$)

NEUROPSYCHIATRIC SYMPTOM	N ^a	ANY SYMPTOM n (% ^b)			CLINICALLY SIGNIFICANT SYMPTOMS (≥ 4) n (% ^b)		
		NO DEMENTIA	DEMENTIA	p^c	NO DEMENTIA	DEMENTIA	p^c
Delusions	978	21 (3.7)	79 (19.4)	<0.001	3 (0.5)	32 (7.8)	<0.001
Hallucinations	979	13 (2.3)	45 (11.1)	<0.001	3 (0.5)	15 (3.7)	<0.001
Agitation/ Aggression	982	32 (5.6)	84 (20.6)	<0.001	6 (1.0)	28 (6.9)	<0.001
Depression	982	172 (29.9)	193 (47.5)	<0.001	50 (8.7)	84 (20.7)	<0.001
Anxiety	983	111 (19.3)	135 (33.0)	<0.001	34 (5.9)	67 (16.4)	<0.001
Euphoria	974	17 (3.0)	33 (8.2)	<0.001	7 (1.2)	13 (3.2)	NS
Apathy	978	45 (7.8)	136 (33.7)	<0.001	22 (3.8)	76 (18.8)	<0.001
Disinhibition	979	20 (3.5)	57 (14.0)	<0.001	8 (1.4)	21 (5.2)	0.001
Irritability	983	80 (13.9)	127 (31.1)	<0.001	20 (3.5)	42 (10.3)	<0.001
Aberrant motor behavior	976	15 (2.6)	32 (7.9)	<0.001	10 (1.7)	20 (5.0)	0.004
Any symptom	995	250 (42.9)	297 (72.1)	<0.001	23 (3.9)	87 (21.1)	<0.001

^aNumber of patients with complete data.

^bPercentage among patients with and without dementia.

^cPearson chi-square test.

Table 4. The use of psychotropic drugs in older people with and without dementia who receive domiciliary care ($N = 1,000$)

ANATOMICAL CHEMICAL GROUPS (ATC-CODE)	TOTAL GROUP: N (%)	NO DEMENTIA: $N = 585$ (%)	DEMENTIA: $N = 415$ (%)	p -VALUE*
Antipsychotics (N05A)	36 (3.6)	14 (2.4)	22 (5.3)	NS
Anxiolytics (N05B)	86 (8.6)	43 (7.4)	43 (10.4)	NS
Hypnotics (N05C)	218 (21.8)	117 (20.0)	101 (24.3)	NS
Antidepressants (N06A)	154 (15.4)	72 (12.3)	82 (19.8)	0.001
Cognitive enhancers (N06D)	56 (5.6)	4 (0.7)	52 (12.5)	<0.001
Any psychotropic drug	401 (40.1)	194 (33.2)	207 (49.9)	<0.001

*Pearson chi-square test.

with any NPS, while cognitive enhancers were associated with all the NPSs except euphoria. The use of antidepressants was associated with delusions, depression, anxiety, and apathy.

Discussion

This is the first Norwegian community-based study to systematically investigate the prevalence of dementia and NPSs among older people receiving domiciliary care. Few international studies have studied this group, which probably represents the majority of future nursing-home placements. In order to link findings to previous research, the results are compared to prevalence rates in the general population and in the nursing home population. When interpreting the findings, it is important to keep in mind that this sample receives some kind of domiciliary care.

The results show, as expected, that the prevalence of dementia increases with age. Participants aged 70–74 years have six times higher prevalence,

participants aged 80–84 years show almost three times higher prevalence, while the oldest group (90+ years) shows a 10% higher prevalence compared to results reported in a recent systematic review (Prince *et al.*, 2013). This review estimates dementia to be present in 7.2% of the general population above 60 years in Europe and report ten times higher prevalence rates (43.1% vs. 4.3%) in the oldest group (90+ years) compared to the group aged 70–74 years (Prince *et al.*, 2013). In the present sample, the prevalence of dementia is almost twice as high (53.5% vs. 27.5%) in the oldest group. This suggests that people of 70–74 years with a decline in cognitive functioning are more likely to be in need of domiciliary care and people of 90+ years are offered nursing-home placements rather than domiciliary care. In the oldest age group, a bigger proportion of the general population also needs some kind of help, which might explain the reduced gap in prevalence above 90 years.

Selbaek *et al.* (2007) found that 80.5% of residents in nursing homes had dementia, which is

Table 5. The use of psychotropic drugs among older people who receive domiciliary care with clinically significant (≥ 4) neuropsychiatric symptoms (NPSs). In all comparisons, symptom absence is set as reference group

PSYCHOTROPIC DRUGS	ANTIPSYCHOTICS (%)	ANXIOLYTICS (%)	HYPNOTICS (%)	ANTIDEPRESSANTS (%)	COGNITIVE ENHANCERS (%)
Delusions (<i>n</i>)					
Present (35)	17	17	17	34	31
Absent (943)	3	8	22	15	5
OR (95% CI)**	6.4 (2.5–16.6)*	2.3(0.9–5.7)	0.7 (0.3–1.8)	3.0 (1.5–6.2)*	9.3 (4.3–20.2)*
Hallucinations (<i>n</i>)					
Present (18)	0	28	11	28	22
Absent (961)	4	8	22	15	5
OR (95% CI)**	NA	4.3 (1.5–12.3)*	0.4 (0.1–1.9)	2.2 (0.8–6.1)	5.1 (1.6–16.0)*
Agitation/aggression (<i>n</i>)					
Present (34)	9	15	18	18	24
Absent (948)	3	8	22	15	5
OR (95% CI)**	2.7 (0.8–9.4)	1.9 (0.7–5.0)	0.8 (0.3–1.9)	1.2 (0.5–2.9)	5.8 (2.5–13.6)*
Depression (<i>n</i>)					
Present 134)	5	15	28	32	15
Absent (848)	3	8	21	13	4
OR (95% CI)**	1.6 (0.7–3.7)	2.1 (1.2–3.6)*	1.4 (1.0–2.2)	3.2 (2.1–4.9)*	4.0 (2.3–7.2)*
Anxiety (<i>n</i>)					
Present (101)	3	20	23	30	14
Absent (882)	4	7	22	14	5
OR (95% CI)**	0.8 (0.2–2.7)	3.1 (1.8–5.4)*	1.1 (0.7–1.7)	2.7 (1.7–4.2)*	3.3 (1.7–6.2)*
Euphoria (<i>n</i>)					
Present (20)	5	10	40	5	15
Absent (954)	4	9	21	16	5
OR (95% CI)**	1.4 (0.2–10.9)	1.2 (0.3–5.2)	2.4 (1.0–6.1)	0.3 (0–2.2)	3.1 (0.9–10.8)
Apathy (<i>n</i>)					
Present (98)	7	9	20	25	13
Absent (880)	3	9	22	15	5
OR (95% CI)**	2.3 (1.0–5.4)	1.1 (0.5–2.2)	0.9 (0.5–1.5)	1.9 (1.2–3.2)*	3.1 (1.6–5.9)*
Disinhibition (<i>n</i>)					
Present (29)	3	14	31	31	21
Absent (950)	4	9	22	15	5
OR (95% CI)**	1.0 (0.1–7.2)	1.7 (0.6–5.1)	1.6 (0.7–3.6)	2.6 (1.1–5.7)	4.8 (1.9–12.3)*
Irritability (<i>n</i>)					
Present (62)	5	8	21	21	27
Absent (921)	4	9	22	15	4
OR (95% CI)**	1.4 (0.4–4.7)	0.9 (0.4–2.4)	1.0 (0.5–1.8)	1.5 (0.8–2.8)	8.7 (4.6–16.5)*
Aberrant motor behavior (<i>n</i>)					
Present (30)	3	7	20	17	23
Absent (946)	4	9	22	15	5
OR (95% CI)**	0.9 (0.1–6.9)	0.8 (0.2–3.2)	0.9 (0.4–2.2)	1.1 (0.4–2.9)	5.7 (2.3–13.9)*

* $p \leq 0.01$, Pearson chi-square test, $df = 1$.

**Mantel-Haenszel Common Odds Ratio (OR).

Note: NA = not applicable.

twice as high as the prevalence of dementia in the present sample. The present results are in line with earlier research (Luppa *et al.*, 2008; Okura *et al.*, 2011; Lopez *et al.*, 2013), which define cognitive impairment, type, and severity of dementia and NPSs to be important predictors for nursing-home placement.

The results of the present study demonstrate that dementia and NPSs are common among people who receive domiciliary care. A dementia prevalence rate of 41.5% suggests that municipalities in Norway already offer domiciliary care to many people suffering different stages of dementia. Dementia and NPSs are still not the main reason

for offering a service, as it is mostly devoted to the care of physical disabilities, practical assistance or medical treatment (Finnvold, 1997). Frailty, polypharmacy, NPSs (Monastero *et al.*, 2007), and functional limitations (Okura *et al.*, 2010) are all associated with cognitive impairment and dementia. Cognitive function and NPSs are not assessed with the same thoroughness in domiciliary care (Selbaek and Høgset, 2010). Clinicians should be aware of the impact dementia and NPSs have, on decisions in everyday life and what support families need in order to continue co-living with their affected family member.

The low disclosure and diagnosis of dementia in this sample (19.5%) compared to the nursing home population (55.0%) (Selbaek *et al.*, 2007) indicates that general practitioners (GPs) have either avoided diagnosing their patient's cognitive impairment or omitted to communicate a diagnosis to the patient's family or partners in the health service. Where GPs have made a diagnosis, it is important that this is imparted to those affected by it. This enables family and health workers to agree upon decision making when it comes to how to meet NPSs in everyday life, evaluate the use and effects of psychotropic treatment, and tailor the domiciliary care offered to older people with dementia. Mutual decisions on such challenges might reduce caregiver's distress and enhance cognitive and psychological well-being of the older person.

In contrast to reports of dementia being more prevalent among females (Juncos-Rabadan *et al.*, 2012), results from the present study show no difference between the sexes. Selection effects are likely to explain the findings.

The findings confirm NPSs to be highly related to dementia and show all the NPSs to appear more frequently among people with dementia. Depression (37.2%), anxiety (25.0%), irritability (21.1%), and apathy (18.5%) are in line with the international literature (Lyketsos *et al.*, 2002; Selbaek *et al.*, 2007; Geda *et al.*, 2008; Steinberg *et al.*, 2008), the most common symptoms. Frequencies of any symptom (55.0%), clinically significant (≥ 4) symptoms (25.7%) and severe (≥ 9) symptoms (12.1%) are lower than frequencies reported in Norwegian nursing-home patients (73.8%, 65.2% and 29.2% respectively; Selbaek *et al.*, 2007).

Despite some methodological differences, the results are comparable to several other studies (Lyketsos *et al.*, 2002; Geda *et al.*, 2008; Okura *et al.*, 2010) that show NPSs to be less frequent in people without dementia than in people with cognitive impairment/dementia. This raises the question of whether cognitive deficits, dementia, and NPSs are sufficiently

prioritized and systematically addressed when older people and their families consult the domiciliary care service. In order to reduce and treat neuropsychiatric symptoms, early detection, diagnosis, and knowledge about consequences of both the disease and the use of psychotropic drugs are important and feasible measures in community healthcare. High psychotropic prescriptions and low disclosures of dementia in this study actualize to what degree the older person is able to give informed consent about treatment with psychotropic drugs and to what extent GPs should include family on decision making in such decisions. Organizing health services, which systematically address such issues, is a first important step to understanding, managing, and intervening in the psychopathology of dementia, regardless of etiological or comorbid explanations. Such an approach could strengthen support for family caregivers and enable the person with dementia to stay at home as long as possible.

It is encouraging to report close associations between the presence of NPSs and the prescription of different psychotropic drugs dispensed for the symptom, even though it is difficult to interpret such associations in an analysis based on cross-sectional data. The prescriptions of anxiolytics (8.6%), antidepressants (15.4%), and antipsychotics (3.6%) were considerably lower than prescriptions of the same drugs in nursing homes (21.9%, 50.9% and 23.4%, respectively; Ruths *et al.*, 2013). Recent studies show that NPSs is associated with time to institutionalization and death (Lopez *et al.*, 2013) and that discontinuation of antipsychotics has negative effects on quality of life (Devanand *et al.*, 2011). This might make older people and their families prefer to have NPSs medicated at home in order to postpone institutionalization as long as possible. These findings must however be weighed against data showing uncertain efficacy as well as increased risk of serious adverse events associated with antipsychotic drug use (Ballard *et al.*, 2009). The difference in the prevalence of dementia, NPSs, and prescription rates of psychotropic drugs in nursing homes compared to the present sample raises the question of whether dementia and the presence of NPSs are important predictors of nursing-home placements or whether dementia and NPSs are getting worse as a consequence of institutionalization. More research is needed into these questions.

The results of this study confirmed the supposition that prevalence of cognitive impairment, dementia, and NPSs among older people receiving domiciliary care is higher than in the general population and lower than in the nursing-home population. The study's strengths includes a randomly selected, large number of study

participants from different counties in Norway, ensuring a sample representative of persons aged 70+ years receiving domiciliary care. The use of well-established assessment scales in an authentic clinical environment in the municipality enables comparisons. The structured face-to-face interviews with the participants and their next of kin simultaneously strengthen the information that was collected.

Limitations that should be considered are the fact that many assessors with different experience in using screening instruments were engaged in order to collect data from many municipalities. However, all the assessors completed comprehensive and standardized training prior to the data collection and all of the assessors were familiar with observing and cooperating with older people and their families in their homes. Participants in the study were selected on the basis of receiving a service from the municipality, so this clinical sample may not be representative of the general population aged 70+, but the findings is generalizable to people aged 70+ who receive domiciliary care.

Conclusion

Dementia is highly prevalent among older people receiving domiciliary care. However, only a minority of the people with dementia have a dementia diagnosis known to themselves, their relatives, or the domiciliary care services. People with dementia constitute a distinct group in terms of NPSs and psychotropic drug use, and municipalities offer important domiciliary care services to people suffering different stages of dementia. Early detection and correct diagnosis might increase the understanding of the family's everyday challenges and enable them to alleviate consequences of dementia and NPSs.

Conflict of interest

GS has given lectures at conferences sponsored by pharmaceutical companies. JNW, ØK, US, and LDH declare no conflict of interest.

Description of authors' roles

GS, JNW, and ØK conceived the project and designed the overall study plan; GS, LDH, ØK, and JNW prepared the dataset and analyzed data; JNW wrote the paper and ØK, GS, and US were supervisors. All authors read and approved the final paper.

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References

- Ballard, C. G. et al.** (2009). Management of agitation and aggression associated with Alzheimer disease. *Nature Reviews Neurology*, 5, 245–255.
- Barbui, C. and Percudani, M.** (2006). Epidemiological impact of antidepressant and antipsychotic drugs on the general population. *Current Opinion in Psychiatry*, 19, 405–410.
- Cummings, J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A. and Gornbein, J.** (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology*, 44, 2308–2314.
- Devanand, D. P., Pelton, G. H., Cunqueiro, K., Sackeim, H. A. and Marder, K.** (2011). A 6-month, randomized, double-blind, placebo-controlled pilot discontinuation trial following response to haloperidol treatment of psychosis and agitation in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 26, 937–943.
- Engedal, K., Haugen, P., Gilje, K. and Laake, P.** (1988). Efficacy of short mental tests in the detection of mental impairment in old age. *Comprehensive Gerontology A*, 2, 87–93.
- Ferri, C. P. et al.** (2005). Global prevalence of dementia: a Delphi consensus study. *Lancet*, 366, 2112–2117.
- Finnvold, J.** (1997). Receive assistance, but misses social contact (Norwegian). Available at: http://www.ssb.no/helse/artikler-og-publikasjoner/_attachment/69940?_ts=137db1ae938.
- Folstein, M. F., Folstein, S. E. and Mchugh, P. R.** (1975). "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198.
- Geda, Y. E. et al.** (2008). Prevalence of neuropsychiatric symptoms in mild cognitive impairment and normal cognitive aging: population-based study. *Archives of General Psychiatry*, 65, 1193–1198.
- Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A. and Martin, R. L.** (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140, 566–572.
- Jano, E., Johnson, M., Chen, H. and Aparasu, R. R.** (2008). Determinants of atypical antipsychotic use among antipsychotic users in community-dwelling elderly, 1996–2004. *Current Medical Research and Opinion*, 24, 709–716.

- Jorm, A. F.** (2004). The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE): a review. *International Psychogeriatrics*, 16, 275–293.
- Juncos-Rabadan, O. et al.** (2012). Prevalence and correlates of cognitive impairment in adults with subjective memory complaints in primary care centres. *Dementia and Geriatric Cognitive Disorders*, 33, 226–232.
- Lopez, O. L. et al.** (2013). The long-term effects of conventional and atypical antipsychotics in patients with probable Alzheimer's disease. *American Journal of Psychiatry*, 170, 1051–1058.
- Luppa, M., Luck, T., Brahler, E., Konig, H. H. and Riedel-Heller, S. G.** (2008). Prediction of institutionalisation in dementia. A systematic review. *Dementia and Geriatric Cognitive Disorders*, 26, 65–78.
- Lyketsos, C. G., Lopez, O., Jones, B., Fitzpatrick, A. L., Breitner, J. and Dekosky, S.** (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: results from the cardiovascular health study. *JAMA*, 288, 1475–1483.
- Martinez, M. F., Flores, J. C., De Las Heras, S. P., Lekumberri, A. M., Menocal, M. G. and Imirizaldu, J. J. Z.** (2008). Prevalence of neuropsychiatric symptoms in elderly patients with dementia in Mungialde County (Basque country, Spain). *Dementia and Geriatric Cognitive Disorders*, 25, 103–108.
- Monastero, R., Palmer, K., Qiu, C., Winblad, B. and Fratiglioni, L.** (2007). Heterogeneity in risk factors for cognitive impairment, no dementia: population-based longitudinal study from the Kungsholmen Project. *American Journal of Geriatric Psychiatry*, 15, 60–69.
- Okura, T., Plassman, B. L., Steffens, D. C., Llewellyn, D. J., Potter, G. G. and Langa, K. M.** (2010). Prevalence of neuropsychiatric symptoms and their association with functional limitations in older adults in the United States: the aging, demographics, and memory study. *Journal of the American Geriatrics Society*, 58, 330–337.
- Okura, T., Plassman, B. L., Steffens, D. C., Llewellyn, D. J., Potter, G. G. and Langa, K. M.** (2011). Neuropsychiatric symptoms and the risk of institutionalization and death: the aging, demographics, and memory study. *Journal of the American Geriatrics Society*, 59, 473–481.
- Otnes, B.** (2010). *Homeservices at Nursing Home Level: Estimates from Statistics about National Reports on In-Home Care and Social Care 2008* (In Norwegian). Oslo: Statistisk sentralbyrå. (Documents, 2010/13).
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W. and Ferri, C. P.** (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia*, 9, 63–75 e2.
- Ruths, S., Straand, J. and Nygaard, H. A.** (2001). Psychotropic drug use in nursing homes: diagnostic indications and variations between institutions. *European Journal of Clinical Pharmacology*, 57, 523–528.
- Ruths, S. et al.** (2013). Trends in psychotropic drug prescribing in Norwegian nursing homes from 1997 to 2009: a comparison of six cohorts. *International Journal of Geriatric Psychiatry*, 28, 868–876.
- Selbaek, G. and Høgset, L. D.** (2010). *IPLOS and Assessment of the Need for Services among Home-Dwelling Elderly with Cognitive Impairment* (In Norwegian). Hamar, Norway: Sykehuset Innlandet HF, AFS.
- Selbaek, G., Kirkevold, O. and Engedal, K.** (2007). The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. *International Journal of Geriatric Psychiatry*, 22, 843–849.
- Shulman, K. I.** (2000). Clock-drawing: is it the ideal cognitive screening test? *International Journal of Geriatric Psychiatry*, 15, 548–561.
- Steinberg, M. et al.** (2004). The persistence of neuropsychiatric symptoms in dementia: the Cache County Study. *International Journal of Geriatric Psychiatry*, 19, 19–26.
- Steinberg, M. et al.** (2008). Point and 5-year period prevalence of neuropsychiatric symptoms in dementia: the Cache County Study. *International Journal of Geriatric Psychiatry*, 23, 170–177.
- Winblad, B. et al.** (2004). Mild cognitive impairment – beyond controversies, towards a consensus: report of the International Working Group on Mild Cognitive Impairment. *Journal of Internal Medicine*, 256, 240–246.
- World Health Organization, W.** (2013a). *The Anatomical Therapeutic Chemical Classification System* [Online]. Available at: <http://www.who.int/classifications/atcddd/en/>; last accessed 10 April 2012.
- World Health Organization, W.** (2013b). *ICD-10 International Statistical Classification of Diseases and Related Health Problems* [Online]. World Health Organization, WHO. Available at: <http://apps.who.int/classifications/icd10/browse/2010/en/>; last accessed 10 April 2013.
- Zuidema, S., Koopmans, R. and Verhey, F.** (2007). Prevalence and predictors of neuropsychiatric symptoms in cognitively impaired nursing home patients. *Journal of Geriatric Psychiatry and Neurology*, 20, 41–49.