**ORIGINAL PAPER** 

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# Non-cognitive symptoms of dementia in nursing homes: frequency, course and consequences

Accepted: 6 May 2003

Abstract Background Since most studies concerning the frequency of non-cognitive symptoms of dementia are based on samples of psychiatric services, the results of these studies may be influenced by their selection procedure. For this reason, we investigated the frequency of non-cognitive dementia symptoms based on an epidemiological nursing home study. Methods The sample consisted of 249 nursing home residents in Austria who were interviewed with the Clinical Interview Schedule within 2 weeks after admission (T1) and again 6 months later (T2). For the analyses of the non-cognitive symptoms among the demented, only manifest clinical abnormalities observed during the interview were included. Further, mobility and impaired self-care were assessed. *Results* At admission, dementia was found in 63.9% of the sample. At T1, 38%, and at T2, 36.1% of the demented suffered from any non-cognitive symptoms. Flattened or incongruous affect, suspiciousness or aggressiveness, and anxiety were found most frequently. Multiple regression analyses showed that non-cognitive symptoms increase the risk for impaired self-care. Discussion Despite the fact that the frequency of several non-cognitive symptoms found in our survey is lower than reported from studies based on psychiatric samples, a high proportion of the demented in nursing homes suffer from such symptoms. Non-cognitive symptoms of dementia increase the risk for an impaired self-care, which supports the assumption that they raise the costs of caring.

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# Introduction

Several authors (e.g., Holroyd 2000; Burns et al. 1990) reported that non-cognitive symptoms such as depression, hallucinations or delusions are very frequent among dementia sufferers. Some others (Malone et al. 1993; Wragg and Jeste 1989) mentioned that non-cognitive symptoms increase the risk for referral to psychiatric services. Since most studies concerning the frequency of non-cognitive symptoms are based on samples of psychiatric services or dementia research centers (Ballard et al. 2001), the results of these studies may be biased by their selection procedure. For this reason, Haupt (1996) stated that as yet the prevalence of non-cognitive symptoms is unclear and suggested investigating this topic not only in psychiatric patients.

Only a small number of analyses based on prevalence studies have been performed in nursing home samples. Studies in nursing homes investigating aggressive behaviors or agitation reported that these symptoms are common and that they are frequently associated with cognitive decline or with dementia, but did not report frequencies among the demented (Zimmer et al. 1984; Cohen-Mansfield et al. 1990). Among nursing home residents, only one study investigating the prevalence of dementia analyzed the frequency of uncooperative behavior (Rovner et al. 1992).

Further, most studies are cross-sectional, leaving it uncertain whether these symptoms are continuous or resolve quickly (Levy et al. 1996). Until now, there have been no studies investigating the course of non-cognitive symptoms of dementia in nursing homes, while several authors have investigated this question among psychiatric patients (Ballard et al. 1996, 1997; Devanand et al. 1997; Starkstein et al. 1997).

Several studies have shown that the presence of noncognitive symptoms decreases the patient's ability to complete everyday tasks (Haupt et al. 1995; Pearson et al. 1989). All studies but one investigated this question among patients of psychiatric services. Only Rovner et al. (1990) studying nursing home residents reported that those suffering from "complicated dementia" (i. e., being classified as DSM-III subtype of dementia "with delusions", "with delirium" or "with depression") needed more time for nursing care than residents suffering from "uncomplicated dementia". However, Zubenko and colleagues (1992) reported that also persons who have an "uncomplicated dementia" often suffer from non-cognitive symptoms. Therefore, for elderly people living in nursing homes there is only weak evidence that non-cognitive symptoms of dementia decrease the ability to perform activities of daily living.

Usually, studies investigating non-cognitive symptoms among nursing home residents relied on reports from the nursing staff, but, we must not forget that several other studies (e.g., Kafonek et al. 1989) reported that the ability of the nursing staff to accurately identify psychiatric morbidity is often low. Frequently, the staff of nursing homes has never had a psychiatric training. Therefore, the assessment of psychiatric symptoms based on nurses' reports might be of limited validity. We assume that an investigation of these symptoms by trained psychiatrists using a research interview is the best method to yield a high validity.

Thus, in order to analyze the frequency, the course and the consequences of non-cognitive symptoms among demented nursing home residents, we used the data of an epidemiological study based on research interviews performed by trained psychiatrists (Wancata et al. 1998).

# Subjects and methods

#### Subjects

This study was undertaken in three nursing homes in Vienna, and seven nursing homes in two rural districts in Tyrol, Austria. Originally, it was intended to include about equal numbers (130 consecutive admissions) in each of the two catchment areas. For the present analyses, only residents aged 60 years or more were included. Residents were interviewed by research psychiatrists within 2 weeks after admission to the nursing home [Time 1 (T1)] and re-interviewed 6 months (plus/minus 2 weeks) later [Time 2 (T2)]. More details of the sampling procedure can be found in Wancata et al. (1998).

#### Methods

Psychiatric case identification was carried out by means of the Clinical Interview Schedule (CIS) (Goldberg et al. 1970) in a modification for use with old people (Cooper and Schwarz 1982). This semi-structured interview was developed to study psychiatric morbidity in nonpsychiatric and community settings. It includes a section with a list of 11 "reported symptoms" and a section with 12 "clinical abnormalities" observed at interview (23 5-point scales). Furthermore, the rater has to make a rating of the overall clinical severity on a 5-point scale. For diagnosis, we used the third revised version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) (APA 1987). As has been done in other epidemiological studies (e. g., Fichter 1990), a psychiatric "case" was defined by two criteria: the presence of a DSM- diagnosis and the presence of an overall clinical severity of at least 2 on a 5-point rating. The interviews were carried out by three research psychiatrists trained in the use of the CIS. Residents were interviewed in a quiet area of the nursing home with as much privacy as possible.

For the analyses of the non-cognitive symptoms of dementia only manifest clinical abnormalities observed by psychiatrists during the CIS interview (excluding "cognitive impairment") were used. Because of the obvious problems in getting valid information from patients suffering from severe cognitive impairment, all subjectively reported symptoms were excluded from our analyses. For our calculations of clinical abnormalities, we used a cut-off of 2/3 according to the CIS (Goldberg et al. 1970): 2 = moderate severity/3 = marked severity.

Data on age, sex and marital status were obtained from the case notes. Additional information was gathered from relatives and from nursing home staff. We used previous occupation as a decisive social class criterion according to the system of Kleining and Moore (1968). In our data analysis, the two upper-class categories were combined, as has been done in other epidemiological studies because of the small numbers involved (Fichter 1990). Mobility and impaired self-care were assessed using instruments developed for epidemiological surveys in non-psychiatric and community settings (Bickel 1990). This assessment of self-care covers eight areas of daily living which are also important in nursing homes (e.g., washing hands and face, using the toilet, putting on stockings and shoes, having a shower, eating). For our analysis of self-care, we used the sum score of the eight 3-point scales (0 = not impaired, 1 = slightly impaired, 2 = cannot do without help).

Before starting the investigation, we carried out a pilot study on 20 residents to test for interrater reliability. The reliability for caseidentification between the three pairs of raters was between 0.79 and 1.00 (weighted kappa). The interrater agreement for manifest clinical abnormalities observed during the interview (cut-off 2/3) was between 90% and 100%. Interviewees and their relatives were informed that the purpose of the study was to investigate psychiatric morbidity, and were assured that any information obtained would be treated as confidential.

#### Statistics

Data were analyzed using the Superior Performing Software System (SPSS Inc.). For pairwise comparisons, chi-square statistics, Kendall's Tau C correlations and Mann-Whitney U-tests were used. For these analyses, we considered a critical alpha of 0.05 as significant. Due to the problem of multiple comparisons, we used alpha-adjustment [Bonferoni (Bortz 1989)]. In order to identify predictors for impaired self-care, multiple regression analyses (forward procedure) with self-care as the dependent variable were performed at T1 and at T2. Because of a skewed distribution of impaired self-care, we used the natural logarithm for multiple regressions.

## Results

## Sample description at T1

Of a total of 270 residents 60 years or older admitted during the investigation period, 7.8% were too ill to be questioned, refused to take part in the study or dropped out for other reasons. Thus, our T1 sample consisted of 249 nursing home residents (92.2% of all admissions). The majority of the subjects were female (78.3%) and older than 80 years (69.9%). Only 12.4% of the residents were married, while 64.4% were widowed. Only 10.5% were able to walk more than 500 meters without help, and 43.1% were confined to bed. At admission to nursing home, about 90% had been suffering for more than 1 year from their somatic disorders. At admission (T1), 76.7 % of the sample suffered from any psychiatric disorder according to CIS case criteria (DSM diagnosis, degree of overall clinical severity  $\geq$  2). Dementia was the most frequent psychiatric diagnosis (63.9 %), followed by minor depression (16.9 %). All other diagnostic categories lay below 4 %. More details concerning psychiatric prevalence have been published separately (Wancata et al. 1998).

## Non-cognitive symptoms at T1

At T1, 5.7% of all demented (n = 159) suffered from any other psychiatric comorbidity (1.3% from psychoses and 4.4% from alcohol or drug abuse). Concerning the analyses of non-cognitive symptoms of dementia, residents with a secondary psychiatric disorder were excluded. Therefore, the sample for these analyses consisted of only 150 demented residents.

Of all demented at T1, 38% had one or more marked non-cognitive symptoms. To be "retarded in speech or movement" was found most frequently (14%), followed by "depressive thought content" (11.3%). Based on clinical considerations, non-cognitive symptoms were condensed into two groups (Table 1): 30% suffered from any "depressive" symptoms and 12.7% from any "aggressive-psychotic" symptoms.

# Outcome after 6 months

After 6 months, only 179 residents (71.9%) of the T1 sample were still living in the nursing homes (Table 2). In all, 20.1% had died during this period, and 4.8% had been referred to a hospital (4% to a general hospital and 0.8% to a psychiatric hospital). All those who had been referred to psychiatric hospitals suffered from dementia with aggressive-psychotic symptoms. A further 3.2% were discharged to their private households. The percentage of residents who had died during the 6 months was markedly higher among demented persons with non-cognitive symptoms than among non-cases (chi-square = 11.15; df = 1; p < 0.0042). No statistically significant differences were found concerning admission to hospitals or discharge to private households.

**Table 1** Frequency of non-cognitive psychiatric abnormalities observed at interview among demented at T1 (N = 150)

	T1 (%)	
Depressive symptoms:		
Retarded in speech/movement	14.0	
Depressed in mood	8.0	
Flattened or incongruous affect	10.7	
Depressive thought content	11.3	
Hypochondriasis	0.7	
Aggressive-psychotic symptoms:		
Suspicious/defensive/aggressive	6.0	
Histrionic	0.7	
Anxious/agitated/tense	6.7	
Elated/excited/euphoric	2.0	
Delusions/misinterpretations	3.3	
Hallucinations	1.3	
Any depressive symptoms	30.0	
Any aggressive-psychotic symptoms	12.7	
Any symptoms	38.0	

# Non-cognitive symptoms at T2

Six months after admission (T2), the prevalence of all psychiatric disorders was 70.3%. Again, dementia was found most frequently (59.4%). Additionally, 10.3% suffered from minor depression and 4% from major depression. All other categories lay below.

Of all those demented present in the nursing homes at T1 and at T2 (n = 104), 17.3% received a secondary psychiatric diagnosis at T1 or at T2 and were excluded from our analyses. Thus, the sample for the analyses of the course of non-cognitive symptoms consisted of only 86 persons.

Among demented residents who participated in the survey at both times (n = 86), one or more marked noncognitive symptoms were found among nearly half of all demented either at T1 or at T2 (47.7%; Table 3). At T1, 33.7%, and at T2, 36.1% suffered from non-cognitive symptoms. Among those having non-cognitive symptoms at T1, about one-third remitted from these symptoms between T1 and T2 (11.6%), while two-thirds (22.1%) suffered from these symptoms at both T1 and at T2 (= "Chronic" course). Of all demented, 14% developed non-cognitive symptoms in the intervening 6 months (= Incidence).

 
 Table 2
 Outcome after 6 months: comparison of psychiatrically ill with psychiatric non-cases (the critical alpha after Bonferoni adjustment was 0.0042)

	Non-cases	Non-demented cases	Dementia without non-cognitive symptoms	Dementia with non-cognitive symptoms
Drop-outs during 6 months	15.5	21.9	26.9	45.6
Admitted to hospital	1.7	3.1	4.3	10.5
Death	6.9	18.8	20.4	31.6*
Discharged to private household	6.9	0.0	2.2	3.5
Present at T2	84.5	78.1	73.1	54.4

\* Chi-square statistics; p < 0.0042

lable 3	Prevalence and course	of non-cognitive p	sychiatric abnormali	ties observed at interview amon	g demented residents	present at T1 and T2 ( $N = 86$ )
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	Present at T1 (%)	Remission (%)	Chronic (%)	Incidence (%)	Present at T2 (%)	Present at T1 or T2 (%)
Depressive symptoms:						
Retarded in speech/movement	9.3	3.5	5.8	5.8	11.6	15.1
Depressed in mood	5.9	4.7	1.2	3.5	4.7	9.3
Flattened or incongruous affect	7.0	2.3	4.7	8.1	12.8	15.1
Depressive thought content	7.0	3.5	3.5	4.7	8.2	11.6
Hypochondriasis	1.2	1.2	0.0	1.2	1.2	2.3
Aggressive-psychotic symptoms:						
Suspicious/defensive/aggressive	7.0	2.3	4.7	7.0	11.7	14.0
Histrionic	0.0	0.0	0.0	2.3	2.3	2.3
Anxious/agitated/tense	9.4	4.7	4.7	3.5	8.2	12.8
Elated/excited/euphoric	1.2	1.2	0.0	0.0	0.0	1.2
Delusions/misinterpretations	4.6	2.3	2.3	4.7	7.0	9.3
Hallucinations	2.4	1.2	1.2	0.0	1.2	2.4
Any depressive symptoms	22.1	8.1	14.0	10.5	24.5	32.6
Any aggressive-psychotic symptoms	17.5	4.7	12.8	9.3	22.1	26.7
Any symptoms	33.7	11.6	22.1	14.0	36.1	47.7

Concerning individual non-cognitive symptoms, incidence was highest for "flattened or incongruous affect" (8.1%) and for "suspicious, defensive and aggressive" symptoms (7%). Remission was highest for "depressed mood" (4.7%) and for "anxiety, agitation and tension" (4.7%). At T2, "flattened or incongruous affect" was found most frequently (12.8%), followed by "suspicious, defensive and aggressive" symptoms (11.7%) and by "retardation in speech or movement" (11.6%).

#### Impaired self-care

Both at T1 and at T2, impairment of self-care was significantly higher among those suffering from dementia with non-cognitive symptoms than among the mentally well (Mann-Whitney U-test, Table 4). In contrast, we could not find such an association for dementia without non-cognitive symptoms and non-demented psychiatric disorders (e.g., depression or substance abuse disorders), either at T1 or at T2.

Further, we used multiple regression analyses to identify predictors of impaired self-care. The independent variables included age, sex, social class, marital status, dementia with non-cognitive symptoms, dementia without non-cognitive symptoms, non-demented psychiatric caseness (according to CIS), duration of the somatic illness, and mobility. Impaired self-care at T1 was predicted by the presence of dementia with non-cognitive symptoms and by diminished mobility (Table 5). Similarly, at T2, impaired self-care was significantly associated with dementia with non-cognitive symptoms, with a longer duration of somatic illnesses, and with reduced mobility.

Among demented residents, those with non-cognitive symptoms showed a significantly higher cognitive impairment than those without non-cognitive symptoms (Kendall's Tau C at T1: R = 0.23 p = 0.0038; at T2: R = 0.33 p = 0.0006). Due to the problem of multicollinearity, we had excluded "cognitive impairment" from our regression analyses of the total sample. Therefore, to identify predictors for impaired self-care exclusively among the demented, we performed separate multiple regression analyses with age, sex, social class, marital status, severity of cognitive impairment (based on the CIS), presence of non-cognitive symptoms, duration of the somatic illness, and mobility as the independent variables (Table 6). Again, we used the natural logarithms of impaired self-care for these calculations. Decreased ability of self-care among the demented at T1 was predicted by cognitive impairment, the presence of non-cognitive symptoms, and reduced mobility. At T2,

Table 4	Impaired	self-care	at T1	and	at 1	Γ2:	de-
mented	and other	psychiatri	cally i	ll com	ipare	ed v	vith
non-case	s (the criti	ical alpha	after l	Bonfe	roni	adj	ust-
ment wa	s 0.01)						

	11			12	12	
	Mean	Median	SD	Mean	Median	SD
Total sample	9.3	10.0	4.6	9.9	11.0	4.4
Non-cases	7.8	8.0	4.1	8.5	9.0	3.7
Non-demented psychiatric cases	8.8	8.0	4.7	9.4	10.0	4.2
Dementia – without non-cognitive symptoms	9.3	10.0	4.2	9.4	11.0	4.5
Dementia – with any non-cognitive symptoms	12.8	14.0	3.8*	13.4	15.0	3.5*
Dementia – with depressive symptoms	14.0	15.0	2.9*	12.9	15.0	2.5*
Dementia – with aggressive-psychotic symptoms	11.0	11.0	4.6*	14.0	15.0	3.9*

\* Mann-Whitney U-test; p < 0.01

 
 Table 5
 Predictors for impaired self-care at T1 and at T2 among all nursing home residents (results from multiple regression analyses)

	T1 B (95 % CI)	T2 B (95% CI)
Sex	n. s.	n. s.
Age	n. s.	n. s.
Marital status	n. s.	n. s.
Social class	n. s.	n. s.
Non-demented psychiatric cases	n. s.	n. s.
Dementia without non-cognitive symptoms	n. s.	n. s.
Dementia with non-cognitive symptoms	0.226 (0.017–0.435)	0.405 (0.137–0.673)
Duration of somatic illness	n. s.	0.943 (0.146–1.740)
Mobility (walk without help)	0.638 (0.456–0.820)	0.278 (0.059–0.497)

 Table 6
 Predictors for impaired self-care at T1 and at T2 among the demented (results from multiple regression analyses)

	T1 B (95% CI)	T2 B (95 % CI)
Sex	n. s.	n. s.
Age	n. s.	n. s.
Marital status	n. s.	n. s.
Social class	n. s.	n. s.
Cognitive impairment	0.175 (0.042–0.308)	n. s.
Any non-cognitive symptoms	0.626 (0.025–1.227)	0.444 (0.150–0.738)
Duration of somatic illness	n. s.	n. s.
Mobility (walk without help)	0.770 (0.482–1.058)	n. s.

we found a significant association only with the presence of non-cognitive symptoms.

# Discussion

In general, the frequency of several non-cognitive symptoms (e.g., delusions, hallucinations, aggression) found in this survey is lower than reported from other studies (Ballard et al. 1997; Devanand et al. 1997). The present study differs from others in several aspects. The present study was based on a sample of an epidemiological survey, while many other studies are based on persons attending a psychiatric research center or on those being referred to specialist psychiatric services because of the severity of their symptoms (Wragg and Jeste 1989). In addition, in our analysis, we included only persons with marked or severe non-cognitive symptoms, while many other studies do not report on the severity of symptoms. If we include in our survey symptoms with moderate severity, in addition to those with marked or severe severity, the frequency of those suffering from non-cognitive symptoms either at T1 or at T2 would rise from 47.7 % to 96.5 % (88.3 % at T1, and 94.1 % at T2). Further, persons suffering from any psychiatric co-morbidity were excluded from our analyses.

We assessed the presence of non-cognitive psychiatric symptoms at psychiatric interviews. Other surveys

(Hope et al. 1997) relied exclusively on reports from relatives and nursing staff. While an interview by an experienced psychiatrist increases the validity of symptom assessment, the assessment by family caregivers and nursing home staff permits the inclusion of symptoms that are absent during an interview, but were present at some time in the past. However, some authors (Cummings 1996) criticized that assessment by caregivers might be biased by the caregivers' mood and their educational level. On the one hand, the advantages of a research interview developed for epidemiological purposes (CIS) are obvious when investigating a total nursing home population, but on the other hand, it is difficult to make direct comparisons of frequencies with studies which were based on caregivers' assessment. For example, Hope and colleagues (1997) assessed the behavior over the preceding 4 weeks based on carer information and found that 72 % had been aggressive at some time. In contrast, in our survey, aggressiveness occurred in only 14%, either at T1 or at T2. It might be that assessments by nurses for a longer period of time would have resulted in higher rates.

Other authors (Hope et al. 1997; Ballard et al. 2001) reported behavioral changes (e.g., wandering, sexual exposure, hyperphagia) beside psychiatric symptoms and found that they occur frequently among demented. In our study, we did not assess these behaviors. For clinical purposes, some authors (e.g., Ballard et al. 2001) grouped the non-cognitive psychiatric symptoms into psychotic symptoms and depressive ones. Factor analysis of our data yielded several groups of symptoms too small for further analyses. Therefore, being aware of the methodological limitations, we decided to split the symptoms in our study only on the basis of clinical considerations into a group of "depressive" symptoms and a group of "aggressive-psychotic" symptoms.

While, at T1, 33.7% suffered from any marked or severe non-cognitive symptoms, 11.6% remitted from these symptoms within 6 months. Concerning the high rates of remission from marked symptoms between T1 and T2, it must be considered that, in our analysis, "remission" includes also symptoms which were present at T2 in a mild or moderate, but not in a marked or severe degree. Of some individual symptoms present at T1, about half remitted until T2. Other studies reported that of the symptoms remitted about one-quarter re-occur within several months (Ballard et al. 1996, 1997). This suggests that some non-cognitive symptoms are episodic and tend to recur in the same subgroup of patients after some time.

The question whether some of the non-cognitive symptoms present shortly after nursing home admission are triggered by the changing environment (i. e., admission to nursing home) has to be investigated in future surveys. A relatively small percentage of all demented with non-cognitive symptoms at T1 received antidepressants (13.8%) or high potential antipsychotics (37.9%) for more than 1 week. We assume that the intake of these psychotropics supported the remission from non-cognitive symptoms, but the sample size of our study is too small for detailed analyses.

Of our sample, 14% did not show marked or severe non-cognitive symptoms at T1, but developed such symptoms within 6 months. Starkstein et al. (1997) reported that about one-fifth of all demented develop comorbid depression within 1 year. This rate is a markedly higher rate than that found in our study. The slightly higher prevalence of non-cognitive symptoms at T2 could support the reports that the frequency of non-cognitive symptoms increases with the progression of dementia (Reisberg et al. 1989).

It is well known that persons suffering from dementia are often impaired in their ability to perform activities of daily living (Bickel 1990). Controlling for other potentially confounding variables, we found a significant relationship between disabled daily living tasks and dementia only for those having non-cognitive symptoms. Controlling for the severity of cognitive impairment among the demented, we could confirm that noncognitive symptoms play an important role in the ability to perform activities of daily living, both at T1 and at T2.

To our knowledge, this is the first study based on an epidemiological survey which investigated the frequency of non-cognitive symptoms of dementia. Taking all our results together, non-cognitive symptoms are frequent among the demented living in nursing homes. Further, non-cognitive symptoms seem to be associated with impaired self-care. This supports the idea that these symptoms increase the time and the costs of caring for nursing home residents.

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