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Original Study

Neuropsychiatric Symptoms in People With Korsakoff Syndrome and Other Alcohol-Related Cognitive Disorders Living in Specialized Long-Term Care Facilities: Prevalence, Severity, and Associated Caregiver Distress

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A B S T R A C T

Keywords:

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alcohol-related cognitive disorder
neuropsychiatric symptoms
long-term care

Objectives: Caring for people with Korsakoff syndrome (KS) residing in specialized long-term care facilities (LTCFs) can be distressing because of challenging neuropsychiatric symptoms (NPS). However, good-quality studies on NPS in this under-researched population are lacking. This study examined the prevalence and severity of NPS in people with KS living in specialized LTCFs and the associated caregiver distress.

Design: Cross-sectional, observational study. Data were obtained using structured interviews with care staff, elderly care physicians, and residents.

Setting: Nine specialized LTCFs in the Netherlands.

Participants: KS residents admitted for at least 3 months.

Measurements: The prevalence and severity of NPS were measured with the Neuropsychiatric Inventory–Questionnaire (NPI-Q). The associated caregiver distress was assessed with the NPI Distress Scale (NPI-D) according to the nurse or nurse assistant.

Results: Almost all of the 281 residents (96.4%) showed at least 1 NPS and 45.8% showed 5 or more symptoms. Irritability/lability (68.3%), agitation/aggression (58.7%), and disinhibition (52.7%) were most prevalent. Although the mean level of severity for all NPS was relatively low, half of the residents (49.1%) had at least 1 severe NPS. Care staff experienced low levels of distress associated with NPS.

Conclusion: NPS are highly prevalent in KS residents. Unexpectedly, these did not have any severe impact on residents and care staff. Acquiring more insight into the persistence and course of NPS, and its associations, among KS residents is important to better understand and reduce these symptoms and, ultimately, improve the quality of care for these residents.

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The neuropsychiatric disorder Korsakoff syndrome (KS) is the chronic phase of a preceding acute Wernicke encephalopathy, also called Wernicke-Korsakoff syndrome, and is caused by severe thiamine deficiency. In particular, alcoholics are at increased risk of

developing KS due to malnutrition. Post-mortem studies have shown a prevalence of Wernicke encephalopathy varying from 0% to 2% in the general population¹ and 12.5% in alcoholics.²

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) (American Psychiatric Association, 2000) refers to KS as “alcohol-induced persisting amnesic disorder.” However, established diagnostic criteria are lacking and KS is increasingly considered to exist on a spectrum with other alcohol-related cognitive disorders, such as alcohol-related dementia and alcohol-related brain damage, which merge into each other and often overlap.^{3,4} The DSM-5 (American Psychiatric Association,

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2013) provides a clearer description of neurocognitive dysfunction and designates KS as “alcohol-induced major neurocognitive disorder, amnesic confabulatory type.”⁵

Severe deficits in long-term explicit memory are a key feature in KS and are often associated with confabulation.⁶ Executive functioning is also commonly impaired.⁷ Lack of insight into the disease is another typical characteristic in people with KS, besides cognitive deficits.^{8–10}

Because of the severe cognitive deficits, approximately 25% of those affected by the acute WE do not recover and will require long-term institutionalization.¹¹ In the Netherlands, the majority of people with KS depending on long-term care reside in nursing home wards specialized in the care for this population. There are indications that residents with KS in these specialized long-term care facilities (LTCFs) exhibit a variety of neuropsychiatric symptoms (NPS), in particular agitation and irritability, but also symptoms such as apathy.^{12–15} Care staff might experience some NPS as challenging, and a retrospective review of medical records in KS residents suggested that these symptoms are often treated with psychotropic drugs.¹⁴ Furthermore, KS residents are often reluctant to receive care because of a denial of having any problem.^{16,17} This could make it even more challenging for care staff to deal with residents and might lead to a burden of care.

The presence of NPS, such as agitation and apathy, in people with KS were mentioned in the earliest reports by S.S. Korsakoff in 1889.¹⁸ Recently, a systematic review identified 15 studies reporting on the prevalence or severity of behavioral symptoms in people with KS and other alcohol-related cognitive disorders.¹⁹ These studies indicated that agitation and aggression (median 27%) and depressive symptoms and disorders (median 27%) were most prevalent. Lower prevalence rates were found for psychotic symptoms and disorders (median 10%) and for anxiety and anxiety disorders (median 6%). However, because of serious methodological limitations and heterogeneity of the included studies, these estimates must be interpreted with caution. Moreover, the included studies were not primarily designed to assess behavior, and most prevalence rates were obtained clinically. To conclude, good-quality studies on the prevalence and severity of NPS and associated caregiver distress in this patient group are lacking. Therefore, the aim of this study was to examine the prevalence and severity of NPS in people with KS and other alcohol-related cognitive disorders living in specialized LTCFs, and the associated caregiver distress. In the remainder of the article, we use the term KS as an umbrella term.

Methods

Study Design

A cross-sectional, observational design was used to study the prevalence and severity of NPS in KS residents living in specialized LTCFs in the Netherlands, and to examine the caregiver distress associated with these symptoms.

Selection and Setting

Participants were recruited between September 2014 and February 2016 from 9 LTCFs providing specialized care to KS residents living in the Netherlands. They were all participating in the “Dutch Korsakoff Knowledge Centre,” an association of LTCFs and psychiatric hospitals that aims to share knowledge and expertise about KS and KS care. The participating LTCFs were located in the Northern, Middle, and Western part of the Netherlands and included both urban and rural areas. These LTCFs had an estimated total of 624 places for KS residents, varying from 20 to 140 per LTCF.

In the Netherlands, KS residents living in specialized LTCFs underwent an extended neuropsychological assessment and are already diagnosed with KS or another alcohol-related cognitive disorder by specialists in psychiatry or neurology before admission. Incidentally, residents with other neurocognitive disorders with a comparable neuropsychiatric profile, such as traumatic brain injury, also reside in these wards.

Care staff of the KS wards were informed about the study at the start of the project. Subsequently, elderly care physicians who delivered medical care to the KS residents were asked to select residents according to the following inclusion criteria:

1. A primary diagnosis of KS, Wernicke encephalopathy, Wernicke-Korsakoff syndrome, or alcohol-induced persisting amnesic disorder as reported in the medical record. Given the diagnostic uncertainties and overlap between KS and other alcohol-related cognitive disorders, residents with alcohol-induced persisting dementia, alcohol-related dementia, alcoholic dementia, and alcohol-related persistent cognitive impairment were also eligible. In the remainder of the article, we have referred to these diagnoses as KS.
2. Being admitted to a specialized LTCF for at least 3 months. This period was chosen as certain alcohol-related cognitive impairment can be reversible after an alcohol abstinence period.²⁰
3. Availability of a legal representative to give informed consent.

Eligible participants were included in the study after written informed consent of the legal representative was obtained. Residents who underwent an interview were also asked to give written consent. The institutional review board of the VU University Medical Center Amsterdam approved the research protocol and considered it not to be subject to the Dutch Medical Research Involving Human Subjects Act.

Measurements

Neuropsychiatric Symptoms

The prevalence of NPS was measured with the Neuropsychiatric Inventory–Questionnaire (NPI-Q).²¹ The NPI-Q is a brief questionnaire form of the NPI that was originally developed for the assessment of 12 domains on behavioral and psychological symptoms that are common in dementia.²² The Dutch translation used in this study has been demonstrated to be reliable and valid.²³ The primary responsible nurse or nurse assistant of the resident completed the NPI-Q. For each symptom, the frequency was assessed with the general screening question: “Has the symptom been present in the last month (‘yes’ = present, ‘no’ = absent)?”

The severity of NPS was measured with the NPI-Q severity subscale. When a symptom had been present in the last month, the primary nurse or nurse assistant rated the severity of the NPI-Q on a 3-point scale ranging from 1 (mild) to 3 (severe). Multiplying frequency and severity yields a symptom severity score ranging from 0 (symptom was absent) to 3 (severe). The NPI-Q total severity score is the sum of the symptom scores and ranges from 0 to 36.

Caregiver distress associated with NPS was measured with the NPI Distress Scale (NPI-D). This is a subscale of the NPI-Q and provides a reliable and valid measure of subjective caregiver distress in relation to NPS.²⁴ After rating the frequency and severity of each symptom on the NPI-Q, the nurse or nurse assistant rated the level of distress experienced in relation to that symptom on a 6-point scale ranging from 0 (not distressing at all) to 5 (severely or very severely distressing). The NPI-D total distress score is calculated by summing the distress scores of the individual symptoms and ranges from 0 to 60. The caregiver distress scores of each symptom were categorized into low (score 0–1), medium (score 2–3), and high (score 4–5).²⁴

Background and Clinical Characteristics

Sociodemographic and clinical data on age, gender, marital status, educational level, ethnicity, admission date to the LTCF, somatic and psychiatric comorbidity, and use of psychotropic drugs were collected by the elderly care physicians from residents' medical records. Comorbid disorders were classified according to the section "disease diagnoses" of the Resident Assessment Instrument (RAI) for LTCF 2.0, version 9.1 (www.interrai.org). Psychotropic drugs were categorized into antipsychotics, antidepressants, and benzodiazepines.

Functional status was assessed with the Activities of Daily Living Hierarchy Scale of the interRAI-LTCF and the Instrumental Activities of Daily Living Performance Scale of the interRAI-Home Care (www.interrai.nl).²⁵ The Activities of Daily Living Hierarchy Scale measures performance on 4 self-care tasks. The Instrumental Activities of Daily Living Performance Scale measures performance on 8 instrumental activities of daily living. In this study, we used the items "ordinary housework" and "managing finances," because the other Instrumental Activities of Daily Living Performance Scale tasks were either completed by the care staff (eg, managing medications) or did not apply (eg, there were no stairs in the LTCF).

Cognitive functioning was assessed with the interRAI Cognitive Performance Scale.²⁶ The Cognitive Performance Scale measures residents' everyday cognitive performance.

Social functioning was assessed with the interRAI Revised Index for Social Engagement, which measures residents' involvement in social activities in the LTCF.^{27,28}

Awareness of functional deficits was assessed with the Patient Competency Rating Scale.^{29,30} The resident rated his or her ability to perform a variety of everyday tasks and functions, and these scores were compared with the ratings of the primary responsible nurse or nurse assistant. The discrepancy between the resident's and the nurse's ratings represents the level of impaired self-awareness (range –120 to 120). A greater discrepancy indicates greater impairment in self-awareness (ie, the resident overestimates or underestimates his or her abilities compared to the nurse).

Data Collection

Research interviewers and a research assistant, all trained by the researcher (I.G.), administered the questionnaires to the primary responsible nurse or nurse assistant and, when possible, the resident during a structured interview. The elderly care physician completed a survey to obtain the medical information.

Statistical Analysis

Similarity in the characteristics (ie, gender) of participants and nonparticipants, and significant differences in nonresponse between LTCFs were explored with the chi-squared test ($P < .05$). Descriptive statistics were applied to calculate numbers, percentages, means, and standard deviations. The Statistical Package for Social Sciences (SPSS), version 22.0, was used for the statistical analysis.

Results

Study Sample

From the estimated 624 residents living in the participating LTCFs, a total of 483 residents were selected by the elderly care physicians to be eligible to participate in the study (Figure 1). After written informed consent was received from 298 legal representatives (response rate = 61.7%), 8 residents died and 5 were discharged from the LTCF before the data collection. Furthermore, 4 residents were excluded because outcome data of the NPI were missing. As a result,

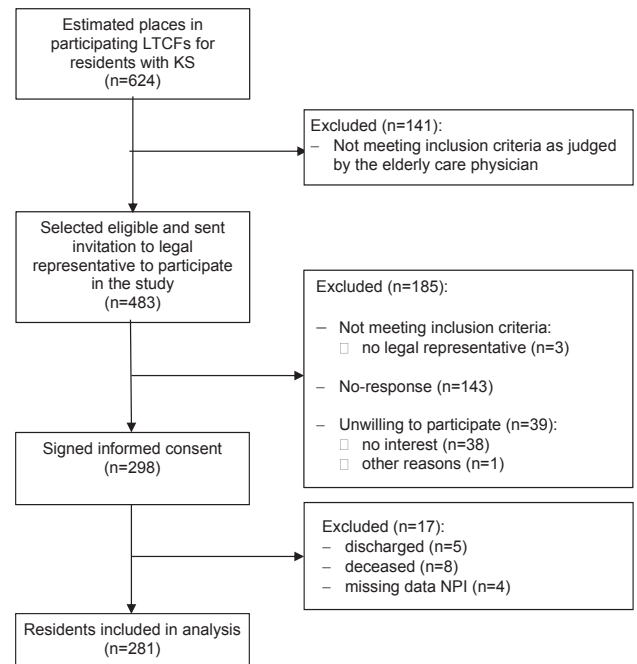


Fig. 1. Flowchart of the selection process.

the study sample consisted of 281 residents, ranging from 7 to 82 participants per LTCF. Of the invited representatives, 143 did not respond and 39 refused to participate (Figure 1).

There was no significant difference in gender between participants and nonparticipants (78% vs 75%, $\chi^2 = 0.55$, $df = 1$, $P = .46$). Furthermore, there was no significant difference in the number of residents who did not respond or refused to participate between the LTCFs ($\chi^2 = 10.7$, $df = 8$, $P = .22$).

Sociodemographic and Clinical Characteristics

The mean age was 63.2 years [standard deviation (SD) 7.9] (Table 1). Most residents were male (77.9%) and had no partner (85.8%). More than half of the residents (55.9%) were poorly educated. The mean length of stay was 6.5 years (SD 5.3). Cardiovascular diseases (38.8%), chronic obstructive pulmonary disease (28.5%), and mood disorders (30.6%) were the most frequent comorbid disorders. Psychotropic drugs were prescribed in two-thirds of residents (66.9%), and mostly included antipsychotics (46.9%) and antidepressants (38.1%). Of the residents, 25.6% used 2 types of psychotropic drugs, and 15.3% used 3 types. Most residents had mild to moderate cognitive impairment (75.8%), and were independent or needed only supervision in activities of daily living (74.4%). More help was required for instrumental activities of daily living tasks. More than half of the residents (54.4%) showed low to moderate social engagement. They overestimated their abilities (PCRS discrepancy score = 39.3), indicating moderate impaired self-awareness in performing everyday tasks and functions.

Prevalence of Neuropsychiatric Symptoms

Table 2 shows that irritability/lability (68.3%), agitation/aggression (58.7%), and disinhibition (52.7%) were most prevalent. Apathy/indifference was present in nearly half of the residents (49.5%). Hallucinations were least prevalent (8.9%). As shown in Figure 2, almost all residents (96.4%) had at least 1 NPS, 89.3% had 2 or more NPS, and 45.8% had 5 or more NPS. On average, the residents presented 4.5 NPS (SD 2.5).

Table 1
Sociodemographic and Clinical Characteristics of Residents With KS Living in Specialized LTCFs (N = 281)

Characteristic	n	%
Age, mean (years)	63.2 (SD 7.9, range 40.9-84.5)	
<55	39	13.9
55-65	129	45.9
>65	113	40.2
Gender (male)	219	77.9
Education		
Elementary, lower	157	55.9
Secondary	62	22.1
Higher/university	24	8.5
Unknown	38	13.5
Marital status		
Divorced	143	50.9
Single	76	27.0
Widowed	22	7.8
Married or partner	26	9.3
Unknown	14	5.0
Ethnicity		
Dutch	258	91.8
Other	20	7.1
Unknown	3	1.1
Length of stay in specialized LTCF (years)	6.5 (SD 5.3, range 0-29)	
Somatic disorder		
Cardiovascular diseases [*]	109	38.8
COPD	80	28.5
Neurological diseases [†]	78	27.8
Diabetes mellitus	46	16.4
Hypertension	37	13.2
Malignancy	33	11.7
Psychiatric disorder		
Mood disorder	86	30.6
Psychotic disorder	62	22.1
Personality disorder	34	12.1
Obsessive compulsive disorder [‡]	33	11.7
Anxiety disorder	26	9.3
Use of psychotropic drugs		
Any psychotropic drug	188	66.9
Antipsychotic	132	46.9
Antidepressant	107	38.1
Benzodiazepine	101	35.9
Two types of psychotropic drugs	72	25.6
Three types of psychotropic drugs	43	15.3
ADLH mean score (range 0-6)	1.2 (SD 1.2)	
Independent or supervision	209	74.4
Impaired	72	25.6
Instrumental ADL dependency		
Ordinary housework [§]		
Independent, setup only, supervision	64	22.8
Impaired	214	76.2
Managing finances		
Independent, setup only, supervision	4	1.4
Impaired	270	96.1
CPS mean score (range 0-6)	2.7 (SD 1.6)	
No or mild impairment (CPS 0-1)	89	31.7
Moderate impairment (CPS 2-4)	124	44.1
Severe impairment (CPS 5-6)	68	24.2
RISE mean score (range 0-6)	4.1 (SD 1.8)	
Low engagement (RISE 0-2)	56	19.9
Moderate engagement (RISE 3-4)	97	34.5
High engagement (RISE 5-6)	128	45.6
PCRS discrepancy score [¶] (mean difference)	39.3 (SD 19.9)	
No or mild impairment (score <28)	57	30.2
Moderate impairment (score 28-51)	73	38.6
Severe impairment (score >51)	59	31.2

ADLH, Activities of Daily Living Hierarchy Scale; COPD, chronic obstructive pulmonary disease; CPS, Cognitive Performance Scale; PCRS, Patient Competency Rating Scale; RISE, Revised Index for Social Engagement.

The underlined scores indicate the more positive outcome.

^{*}Including cerebrovascular accident (n = 35), coronary heart disease (n = 33), chronic heart failure (n = 9), peripheral artery disease (n = 19), cardiac arrhythmia (n = 13), and valvular heart disease (n = 4).

[†]Including traumatic brain injury (n = 21), Parkinson disease (n = 1), multiple sclerosis (n = 1), epilepsy (n = 43), Alzheimer disease (n = 1), dementia with vascular component (n = 11), and other dementia (n = 7).

[‡]Including hoarding (n = 14).

[§]Activity did not occur n = 3.

^{||}Activity did not occur n = 7.

[¶]n = 189.

Table 2
NPI-Q Symptom Scores for Frequency and Severity Among KS Residents (N = 281)

	Frequency		Severity						
	n	%	(0-3)	Mild (Score = 1)		Moderate (Score = 2)		Severe (Score = 3)	
			Mean (SD)	n	%	n	%	n	%
Irritability/lability	192	68.3	1.4 (1.1)	51	18.1	94	33.5	47	16.7
Agitation/aggression	165	58.7	1.2 (1.1)	49	17.4	70	24.9	46	16.4
Disinhibition	148	52.7	1.0 (1.1)	54	19.2	51	18.1	43	15.3
Apathy/indifference	139	49.5	0.9 (1.1)	56	19.9	52	18.5	31	11.0
Dysphoria/depression	122	43.4	0.9 (1.1)	33	11.7	53	18.9	36	12.8
Appetite/eating abnormalities	93	32.6	0.6 (0.9)	47	16.7	28	10.0	18	6.4
Delusions	90	32.0	0.7 (1.1)	21	7.5	29	10.3	40	14.2
Nighttime behavior disturbance	86	30.6	0.5 (0.9)	44	15.7	23	8.2	19	6.8
Anxiety	70	24.9	0.6 (1.0)	15	5.3	26	9.3	29	10.3
Euphoria/elation	70	24.9	0.4 (0.8)	31	11.0	31	11.0	8	2.8
Aberrant motor behavior	63	22.4	0.5 (0.9)	19	6.8	25	8.9	19	6.8
Hallucinations	25	8.9	0.2 (0.7)	8	2.8	6	2.1	11	3.9
NPI-Q total severity score (0-36)			8.7 (5.9)						

NPI-Q, Neuropsychiatric Inventory–Questionnaire.
The underlined scores indicate the more positive outcome.

Severity of Neuropsychiatric Symptoms

The mean NPI-Q total severity score was 8.7 (SD 5.9) (Table 2). Overall, the mean severity score of all symptoms was low, ranging from 0.2 to 1.4. Irritability/lability (1.4), agitation/aggression (1.2), and disinhibition (1.0) were the most severe symptoms. When considered in detail, most symptoms, if present, were mild to moderately severe. As presented in Figure 2, nearly half of the residents (49.1%) had at least 1 severe NPS (severity score = 3).

Caregiver Distress Associated With Neuropsychiatric Symptoms

Table 3 shows that the mean NPI-D total distress score was 6.0 (SD 6.9). Overall, all NPS were associated with low caregiver distress, with mean scores ranging from 0.1 to 1.0. Irritability/lability (1.0) and agitation/aggression (0.9) were associated with the highest levels of distress. When considered in detail, irritability/lability and agitation/aggression were, in particular, most associated with moderate distress. As presented in Figure 2, 10.7% of the residents had at least 1 NPS that was associated with high distress (distress score >3).

Discussion

This study is the first to investigate the prevalence, severity, and associated caregiver distress of NPS in a relatively large sample of residents with KS and other alcohol-related cognitive disorders living in specialized LTCFs. The results indicated that NPS are highly prevalent, and often occur with multiple concomitant symptoms. Although half of the residents presented with at least 1 severe symptom;

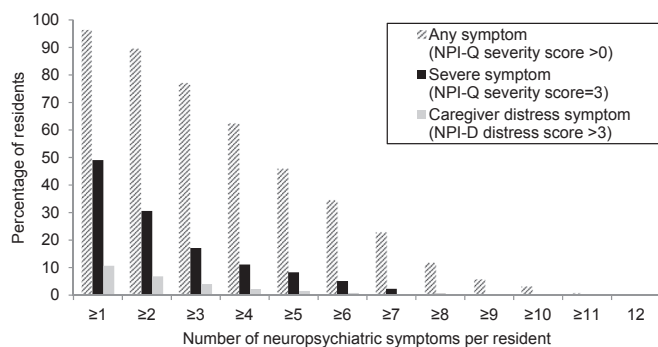


Fig. 2. Frequency distribution of the number of NPS, the most severe and the most distressing NPS among KS residents (n = 281).

overall, mean severity estimates of NPS were low and caregivers experienced little associated distress.

Prevalence of Neuropsychiatric Symptoms

We found that almost all residents had at least 1 NPS. Irritability/lability, agitation/aggression, and disinhibition were the most common symptoms followed by apathy/indifference and dysphoria/depression, whereas hallucinations were relatively rare. These findings support the experiences from care staff who frequently encounter NPS in residents with KS. NPS in this group of residents were more prevalent compared with estimates from the aforementioned systematic review on NPS in KS (ranging from 6% to 27%).¹⁹

NPS have been studied more extensively in nursing home residents with dementia. These studies reported prevalence rates varying from 79% to 90% in residents with any type of dementia.^{31–34} Prevalence rates in these studies were expressed as the presence of clinically relevant NPS (frequency × severity score ≥ 4 on the NPI), which makes a comparison with our results quite difficult. Nevertheless, our study indicated that NPS are also highly prevalent in nursing home residents with KS. In order to get an insight in how the estimates of our study relate to studies on nursing home residents with dementia, we will now further discuss our findings in relation to the findings that were reported in the latter studies as much as possible.

Apathy has been found as the most prevalent NPS in nursing home residents with dementia,³¹ and also in specific subgroups, such as residents with young-onset dementia and frontotemporal dementia.^{33,34} In addition to this, apathy has been found to be more prevalent in residents with alcohol-related dementia than in Alzheimer disease.³³ Although we identified apathy as a highly common symptom in residents with KS (with almost half of the sample presenting this symptom), our findings indicated that irritability/lability, agitation/aggression, and disinhibition were more prevalent in KS residents (with respectively about two-thirds and more than half of residents presenting irritability/lability and disinhibition). Furthermore, disinhibition seems to be much more common in KS residents than in residents with dementia and young-onset dementia.^{31,33} Disinhibition also occurs frequently in residents with frontotemporal dementia.³⁴

As in people with dementia,³⁵ it can be argued that some NPS, such as apathy and disinhibition, in people with KS reflect a deficit in executive functioning. Executive functioning plays an important role in the regulation of behavior in people with KS,³⁶ and impairment of executive functioning is associated with frontal brain damage caused

Table 3
NPI-D Symptom Scores for Caregiver Distress Among KS Residents (N = 281)

	Caregiver Distress (0–5)	Caregiver Distress Categories					
		Low Distress (Score = 0 or 1)		Medium Distress (Score = 2 or 3)		High Distress (Score = 4 or 5)	
		Mean (SD)	n	%	n	%	n
Irritability/lability	1.0 (1.3)	200	71.2	71	25.3	10	3.6
Agitation/aggression	0.9 (1.3)	205	73.0	60	21.4	16	5.7
Disinhibition	0.7 (1.2)	223	79.4	47	16.7	11	3.9
Apathy/indifference	0.6 (1.0)	232	82.6	46	16.4	3	1.1
Dysphoria/depression	0.7 (1.1)	225	80.1	47	16.7	9	3.2
Appetite/eating abnormalities	0.4 (1.0)	250	89.0	27	9.6	4	1.4
Delusions	0.4 (0.9)	248	88.3	28	10.0	5	1.8
Nighttime behavior disturbance	0.3 (0.9)	253	90.0	25	8.9	3	1.1
Anxiety	0.4 (0.9)	254	90.4	21	7.5	6	2.1
Euphoria/elation	0.3 (0.8)	257	91.5	22	7.8	2	0.7
Aberrant motor behavior	0.3 (0.8)	258	91.8	20	7.1	3	1.1
Hallucinations	0.1 (0.5)	272	96.8	7	2.5	2	0.7
NPI-D total distress score (0–60)	6.0 (6.9)						

The underlined scores indicate the more positive outcome.

by alcohol neurotoxicity.^{7,36} Previous studies have revealed that people with KS perform poorly on executive functioning, including shifting, updating, and inhibition tasks.⁷ Inhibition, in particular, seems to be impaired.³⁷ Furthermore, apathy can also be a side effect of psychotropic drugs, which were extensively prescribed in our study sample (in two-thirds of residents).

Affective symptoms were, in addition, common in our study sample. Dysphoria/depression, especially, seem to occur often in KS residents (nearly half of the residents presenting this symptom). It is known that alcohol dependence frequently co-occurs with other psychiatric conditions (ie, dual diagnosis). Mood and anxiety disorders are, in particular, common.³⁸ It is unclear what the effect of these comorbid disorders is on the expression of NPS in KS.

In line with studies among residents with dementia,³¹ and specific subgroups,^{33,34} lower prevalence rates were found for delusions and hallucinations in the present study on KS residents. Furthermore, delusions were also much more prevalent than hallucinations (32% vs 9%). We hypothesize that the relatively high prevalence of delusions in KS residents could partly be attributed to a disturbance of reality monitoring.³⁹ As a consequence, people with KS might exhibit an impaired perception of reality and tend to misidentify imagined events as real. This might lead to delusion-like ideas. Therefore, it could be possible that care staff misinterpreted this behavior in residents and rated it as a delusion.

Severity of Neuropsychiatric Symptoms

Although NPS were highly prevalent, the overall severity of all symptoms was low according to the care staff who completed the NPI-Q. Irritability/lability, agitation/aggression, and disinhibition were the most severe symptoms, followed by apathy/indifference and dysphoria/depression. When exploring the proportion of residents with a severe symptom, nearly half of the residents suffered from at least 1 severe NPS, which again included irritability/lability, agitation/aggression, and dysphoria/depression. This discrepancy with the rather low mean symptom scores can probably be explained by the wide range in estimates.

In the previously mentioned systematic review on behavioral symptoms in people with KS,¹⁹ 6 studies reported on the severity of NPS in KS. None of the reported severity estimates in this review met pathologic thresholds, and relatively high severity estimates were found for apathy. The low severity estimates found in this review are in line with the findings from the present study. However, as explained before, serious methodologic limitations

and heterogeneity of the included studies in the review limited drawing conclusions about the results. Research on nursing home residents with dementia revealed also low severity estimates.^{32,40,41}

Associated Caregiver Distress of Neuropsychiatric Symptoms

In contrast with indications from clinical practice, the results of this study showed low levels of caregiver distress associated with NPS. Only a small proportion of residents (10.7%) showed at least 1 NPS that was associated with high distress. Irritability/lability and agitation/aggression were the most distressing symptoms.

As far as we know, no quantitative studies reported on caregiver distress of NPS in nursing home residents with KS. A study among nursing home residents with dementia living in special care units found somewhat higher distress levels and identified the presence of NPS as a strong predictor of distress in care staff.³² In this study, agitation/aggression was also the most distressing symptom.

Various reasons might explain the relatively low severity of NPS and associated caregiver distress found in the present study. First, residents in our study, mainly relatively young and single men, were receiving care in specialized Korsakoff wards with the care tailored to their needs. This specialized care is based on the provision of a person-centered multidisciplinary care program, combined with a fixed daily routine and structure. These wards feature specific memory aids, and use, for example, specific colors, agenda or diary training, name boards, information posters, route directions, photos of care staff, and pictograms. Furthermore, most Korsakoff wards are provided with a day-activity center in which a wide range of structured and individualized recreational and occupational activities are provided, including simple woodwork, garden work, packaging work, and similar activities. In practice, most KS residents experience these activities as meaningful and enjoy the social aspects. This may have decreased the impact of NPS on residents and care staff.

Another explanation could be that the extensively prescribed psychotropic drugs decreased the impact of NPS on residents and care staff. Clinically, it has been proven to be very difficult for care staff to deal with symptoms, such as agitation/aggression and the delusions-like ideas, without prescription of these drugs. Combined with a denial of having any problem, care staff are challenged daily by how to deal with residents who believe that “nothing is wrong with them.”⁸ This is in line with the findings of the present study showing that self-awareness was moderately to severely impaired in two-thirds of the KS residents. In dementia care, it is increasingly

controversial to treat challenging NPS with psychotropic drugs because of adverse effects and limited efficacy evidence.⁴² However, the effect of psychotropic drugs in the treatment of NPS in patients with KS has hardly been studied to date.

Lastly, care staff might be likely to accept challenging NPS as they are used to cope with these behaviors. Professional caregivers in Dutch Korsakoff wards are generally well educated and trained in providing individualized care to KS residents. Generally, they have years of experience in the care for residents with KS and experience in daily practice that an “empathic directive approach,” which is often used in KS wards,⁴³ has been most effective to prevent and manage challenging behavior.

The discrepancy between the overall experiences from clinical practice that KS residents often exhibit challenging behavior, and the low severity and distress estimates found in the present study could probably be explained by a substantial proportion of residents with at least 1 moderate to severe symptom associated with moderate to high caregiver distress. These residents could have given the impression that KS residents present severe and distressing NPS.

Strengths and Limitations

To our knowledge, this is the largest study that examined NPS in people with KS residing in specialized LTCFs, and makes an important contribution to the literature in this field. Residents with all forms of alcohol-related cognitive disorders, varying from KS to alcohol-related dementia, participated in this study, thereby compromising the total population usually residing in Dutch Korsakoff wards. The broader term *alcohol-related brain damage* may cover this group, reflecting the heterogeneity of alcohol-related cognitive impairment in these residents.³ Furthermore, although not validated for specific subgroups of nursing home residents such as people with KS, NPS were measured with a brief version of the NPI, a widely used and well-established assessment instrument. Further research is recommended to validate the use of the NPI in nursing home care for people with KS.

There are also some limitations. About 40% of the invited residents did not participate in this study, mainly because their representatives did not respond. This could possibly limit generalization of our findings. However, we found no significance differences between participants and nonparticipants in gender and in nonresponse between the LTCFs. Furthermore, not all KS wards were actively invited to participate in this study. However, we believe that our study sample is likely to be representative for KS residents living in Dutch specialized LTCFs given the large sample size, including residents from small and large LTCFs all over the country. Moreover, all specialized LTCFs provided similar care for KS residents. The fact that the prevalence and severity of NPS were based on caregiver reports can be seen as another limitation. As discussed, the relatively specialized care staff could have underestimated the symptoms in their residents. Ratings might have been higher had they been derived from independent trained observers.

Conclusion and Implications

This study demonstrated a high prevalence of a wide variety of NPS in people with KS living in specialized LTCFs. However, NPS had no severe impact on residents and care staff. Irritability/lability, agitation/aggression, and disinhibition were predominant, and slightly more severe and more distressing for care staff.

The substantial prevalence of NPS we found supports the need for specialized care units with specifically trained care staff for people with KS, and multidisciplinary care tailored to their complex needs. The results of this study can provide guidance to further develop the skills of care staff for coping with the most prevalent and severe symptoms and develop guidelines regarding the treatment of NPS in

KS residents. This may improve the current, practice-based long-term care and can be a first step to better support the needs of this group of residents, thereby, ultimately, improving the quality of care. Future research should further explore the persistence and course of NPS and investigate which factors could influence NPS in residents with KS, and their relationship with, for instance, impaired self-awareness.

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