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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

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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, amnestic 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 amnestic 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

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