

Awareness and its relationships with neuropsychiatric symptoms in people with Korsakoff syndrome or other alcohol-related cognitive disorders living in specialized nursing homes

Ineke J. Gerridzen^{1,2}  | Karlijn J. Joling¹  | Marja F. Depla¹ | Ruth B. Veenhuizen¹ | Els M.L. Verschuur³ | Jos W.R. Twisk⁴ | Cees M.P.M. Hertogh¹

¹Department of General Practice and Elderly Care Medicine, Amsterdam Public Health research institute, VU University Medical Center, Amsterdam, The Netherlands

²Nursing home Markenhof, Atlant, Beekbergen, The Netherlands

³HAN University of Applied Sciences, Nijmegen, The Netherlands

⁴Department of Epidemiology and Biostatistics, Amsterdam Public Health Research Institute, VU University Medical Center, Amsterdam, The Netherlands

Correspondence

Ineke J. Gerridzen, Department of General Practice and Elderly Care Medicine, Amsterdam Public Health research institute, VU University Medical Center, MF room C-383, PO Box 7057, 1007 MB Amsterdam, The Netherlands.

Email: i.gerridzen@vumc.nl

Funding information

Atlant; Netherlands Organization for Health Research and Development; Pieter van Foreest Stichting; Stichting Vermogensbeheer Hoogeland Zorg

Objectives: Impaired awareness of functional deficits is often observed in people with Korsakoff syndrome (KS) and may result in refusal of care, although this area has been understudied. This study aimed to investigate levels of impaired awareness and their relationships with neuropsychiatric symptoms (NPS) in people with KS residing in specialized nursing homes.

Methods: A cross-sectional, observational study was conducted among 215 residents with KS or other alcohol-related cognitive disorders. Awareness was measured with the Patient Competency Rating Scale (PCRS). NPS and subsyndromes were measured with the Neuropsychiatric Inventory-Questionnaire (NPI-Q). Adjusted multi-level regression analyses were performed to examine the relationships between the level of awareness and NPS.

Results: The mean level of impaired awareness was 39.3 (SD = 19.9) indicating moderate impairment. Twenty-nine percent of the residents had no or mildly impaired awareness; 37% were moderately impaired, and 34% were severely impaired. Residents with moderately impaired awareness showed more severe apathy than residents with no or mildly impaired awareness (difference 1.23; 95% CI 1.02-1.48; $p = 0.03$). No associations were found between the level of awareness and other NPI outcomes. Cognitive functioning seems to have the strongest impact on the association between level of awareness and NPS in KS residents.

Conclusions: Impaired awareness of functional deficits is highly common in KS residents; however, apart from apathy, is not significantly related with NPS. Additional research should further examine, which interventions are effective in dealing with impaired awareness in these people, particularly when apathy is present.

KEYWORDS

alcohol-related cognitive disorder, awareness, Korsakoff syndrome, neuropsychiatric symptoms, long-term care

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2019 The Authors. *International Journal of Geriatric Psychiatry* Published by John Wiley & Sons Ltd.

1 | INTRODUCTION

The neuropsychiatric disorder Korsakoff syndrome (KS) is caused by thiamine deficiency, which is most commonly because of concomitant alcohol abuse. This disorder is considered to lie on a spectrum with other alcohol-related cognitive disorders because of the heterogeneity of these disorders.^{1,2} KS is characterized by cognitive impairments accompanied by confabulations. Specifically, episodic memory is severely affected,³ with executive dysfunctioning being another prominent characteristic.^{4,5} Besides cognitive impairments, neuropsychiatric symptoms (NPS) are also highly prevalent.⁶

There are clinical reports,⁷⁻⁹ which state that people with KS also have difficulties in recognizing their deficits: "The patient believes that nothing is wrong with him," as Egger et al stated.¹⁰ Moreover, experiences in daily clinical practice of care staff in nursing homes (NHs) suggest that residents with KS do not recognize their own care needs and are therefore reluctant to receive care.¹¹ This lack of insight into their deficits may have a negative impact on resident's participation in daily life activities, ranging from basic self-care activities to occupational and recreational therapies, and may subsequently hinder their health and well-being. Consequently, care staff are faced with challenges in dealing with this lack of insight, which may in turn lead to stress and care burden. Combined with common challenging NPS, such as agitation and disinhibition, a lack of insight may lead to the inappropriate prescribing of psychotropic drugs.¹²

A lack of insight has been extensively studied in people with traumatic brain injury and dementia. Furthermore, it may also be observed in other neuropsychiatric disorders such as stroke, frontotemporal dementia, Huntington's disease and schizophrenia.¹³ There is no clear definition of this clinical phenomenon, and besides "lack of insight," multiple terms are used interchangeably such as "anosognosia" and "denial."^{14,15}

The term "impaired awareness" is used in people with traumatic brain injury to refer to someone's "unrealistic self-appraisal" or "disturbance in insight to a variety of behavioral limitations and their impact on daily life activities."¹⁶ In the context of dementia, Clare et al defined "awareness" as "an accurate appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications, which may be expressed explicitly or implicitly."¹⁷ Since awareness is a complex concept, Clare et al acknowledged "the influence of both cognitive, psychosocial, and environmental factors on awareness (biopsychosocial model)" within a theoretical framework.¹⁷ Furthermore, studies on people with dementia have also revealed that awareness is related to a specific "object" or "domain," such as memory functioning, daily life functioning, or socio-emotional functioning.^{15,18}

Additionally, associations have been found between the level of awareness and NPS in people with dementia.¹⁴

Only a few observational, case-control studies have investigated awareness in people with KS.^{10,19,20} However, these studies were limited by small sample sizes and were conducted on people who had been temporarily admitted to a specialized psychiatric admission ward. We therefore assume that these studies are not

Key points

- Most residents with Korsakoff syndrome living in specialized nursing homes overestimate their functional capacities, which could hinder their self-care and participation in daily activities.
- Apathy is significantly related with impaired awareness of functional deficits.
- Additional research should be conducted to further examine which clinical approaches and (psychosocial) interventions are effective to deal with impaired awareness of functional deficits in these residents.

representative of the overall population of people with KS residing in specialized NHs.

As good quality studies are lacking on awareness in institutionalized people with KS, the present study aimed to examine the level of awareness across multiple functional domains in this population and to explore the relationship between the level of awareness and NPS. Based on experiences in Dutch clinical practice, we hypothesized that awareness in residents with KS is impaired in all domains of daily functioning and that impaired awareness is associated with NPS. In this paper, we use the term awareness, which refers to someone's awareness of functional deficits.

2 | METHODS

2.1 | Study design and participants

We performed a cross-sectional, observational study on people with KS and other alcohol-related cognitive disorders living in specialized NHs from September 2014 to February 2016. Residents in these facilities underwent an extended neuropsychological assessment and were already diagnosed with KS or another alcohol-related cognitive disorder before admission to the NH. Because of the nosological uncertainties in the diagnosis of KS, it is highly probable that this group of residents do have diagnoses on the whole spectrum of alcohol-related cognitive disorders, varying from KS to alcohol-related dementia and alcohol-related brain damage. Participants were eligible when the following criteria had been fulfilled, as judged by the resident's elderly care physician:

1. A primary diagnosis of KS or other alcohol-related cognitive disorder as reported in the medical chart. In the remainder of this paper, we have used the term KS as an umbrella term for both KS and other alcohol-related cognitive disorders;
2. having been admitted to a specialized NH for at least 3 months; and
3. the availability of a legal representative to provide informed consent.

After written informed consent of the legal representative of eligible participants had been obtained, the resident himself/herself was asked to give informed consent to undergo an interview. The Medical Ethics Committee of the VU University Medical Center Amsterdam approved the study.

2.2 | Measurements

Awareness of functional deficits was assessed with the Patient Competency Rating Scale (PCRS). This instrument was originally developed to assess awareness of deficits after traumatic brain injury, but it has also been used in stroke, Alzheimer's disease, and other neurodegenerative diseases.²¹⁻²⁵ The PCRS has good validity, reliability, and feasibility in people with traumatic brain injury.^{16,26,27}

The PCRS consists of 30 items that measure competency in everyday tasks and includes both a self-rating ("patient's form") and an informant rating ("clinician's form," ie, significant other). Both questionnaires are identical and constitute 30 pairs of PCRS items. We considered the primary responsible nurse or nurse assistant as the best person to complete the "significant other form." For each item, the resident and nurse were asked to judge how easy or difficult it is for the resident to perform a task using a 5-point Likert scale (1 = "cannot do it," 2 = "very difficult to do it," 3 = "can do it with some difficulty," 4 = "fairly easy to do it," 5 = "can do it with ease"). The total PCRS score is the sum of the score of each item ranging from 30 to 150, with higher ratings indicating higher levels of competency. Awareness is defined as the discrepancy score between the patient's rating and the nurse's rating (range = -120 to 120). The larger the positive score, the more the resident overestimates his/her competences. The PCRS discrepancy scores were categorized into "no or mildly impaired awareness" (score < 28), "moderately impaired awareness" (score = 28-51) and "severe impaired awareness" (score > 51).²⁸ Furthermore, based on factor analysis of the PCRS items, three functional domains can be identified: a cognitive domain (8 items), an interpersonal/emotional domain (8 items), and a physical domain (12 items).²⁹

Neuropsychiatric symptoms (NPS) were assessed with the Neuropsychiatric Inventory-Questionnaire (NPI-Q),³⁰ a brief form of the NPI, which is a widely used validated and reliable questionnaire to measure NPS in dementia and other neuropsychiatric disorders.^{31,32} The NPI-Q provides information on 12 behavioral and psychological symptom domains. After the screening question to determine whether the symptom had been "absent" (score = 0) or "present" (score = 1) in the last month, severity was scored on a 3-point scale ranging from 1 = "mild" to 3 = "severe." The NPI-Q total severity score is the sum of the severity scores for each symptom ranging from 0 to 36, with higher scores indicating more severe NPS.

Following previous research, the NPI-Q symptoms were grouped into subsyndromes: "agitation," "affective symptoms," and "psychosis".³³ The total score of each subsyndrome score is the sum of the score of the included NPI-Q symptoms. Because the symptom "apathy/indifference" was not grouped into one of the subsyndromes, it was analyzed as a separate symptom.³³

Sociodemographic and clinical characteristics on age, gender, level of education, marital status, length of stay, and use of psychotropic drugs were collected through medical records review. Psychotropic drugs were categorized into antipsychotics, antidepressants, and benzodiazepines.

Cognitive function was measured with the Cognitive Performance Scale (CPS), which measures resident's everyday cognitive.³⁴ The CPS is generated from five items of the Resident Assessment Instrument-Minimum Data Set (RAI-MDS) (www.interrai.org). These items include whether a resident is comatose, has intact short-term memory, has cognitive skills for daily decision making, is understood by others, and has independence in eating. The total CPS score is calculated by using a hierarchical scoring system and varies from 0 = "intact" to 6 = "very severe impairment". The CPS has good agreement with the MMSE.³⁴

2.3 | Data collection

Trained research interviewers collected data through a structured interview with the residents (PCRS-patient's form) and their primary nurses or nurse assistants (PCRS-clinician's form, NPI-Q, CPS). The elderly care physician was asked to complete an online survey to obtain the medical information.

2.4 | Statistical analysis

Descriptive statistics were used to calculate numbers, percentages, ranges, means and standard deviations of baseline characteristics, NPS, and the level of awareness. To examine possible selection bias, baseline differences between completers and noncompleters of the PCRS patient's form were tested with the chi-squared test for dichotomous or categorical variables and the independent samples *t* test for continuous variables. The Mann-Whitney *U* test was used when continuous variables were not normally distributed. In order to compare the scores of the items and the domains between both PCRS forms, the paired samples *t* test was used. For the analysis of relationships between the level of awareness and NPS, we first checked the assumptions of normality for the dependent variables by examining the distribution of the residuals with histograms. A log transformation of apathy was used due to right skewness, and the affective and psychosis subsyndromes were dichotomized into absent (score = 0) versus present (score = 1).

Next, the relationships between the level of awareness and the normally distributed continuous dependent variables (severity of NPS, agitation, and apathy) were analyzed with linear mixed models in which an adjustment was made for the correlated observations within the participating NHs (multilevel modeling). Logistic generalized estimating equations (GEEs) were used for the dichotomous dependent variables (affective symptoms and psychosis subsyndrome). Level of awareness was coded as a categorical variable with the no/mildly impaired awareness group as the reference category.

Subsequently, unadjusted analyses were performed to assess the relationships between level of awareness and NPS. In the next step, adjusted models were constructed to investigate the impact of sociodemographic characteristics (gender, age, and level of education), clinical characteristics (length of stay and cognitive functioning), and psychotropic drugs on the relationships between level of awareness and NPS. The first model was adjusted for sociodemographics. In the second model, the analyses were repeated, including clinical characteristics (length of stay and cognitive functioning) as covariates. To investigate whether psychotropic drugs modified the relationship between level of awareness and apathy, these medications were added in the third model.

In a last step, interaction terms (cognitive functioning * level of awareness) were entered in the adjusted models to examine possible effect modification of cognitive functioning.

The level of significance was set at two-tailed $p < 0.05$. All analyses were conducted with the Statistical Package for Social Sciences (SPSS), version 22.0.

3 | RESULTS

3.1 | Recruitment process and flow of participants

Written informed consent was obtained from 298 residents' representatives (Figure 1). Of these, 75 residents did not undergo an interview. Eight residents died, and five were discharged from the NH before the interview took place. Twenty-six residents were not willing, or not able according to the nurse, to complete the PCRS-patient's form. For 36 residents, the reason for not participating was not listed. One

interview was ended because the resident became agitated. Finally, seven residents were excluded from the analysis because data on the NPI-Q ($n = 4$) or the PCRS-patient's form ($n = 3$) were missing. A total of 281 nurses completed the PCRS about the resident, and 215 residents completed the PCRS themselves; therefore, 215 pairs of PCRS forms were available for analysis and included in the study sample.

3.2 | Baseline characteristics

The mean age of the residents was 63.2 years ($SD = 7.9$), and the majority (77.2%) were single men (Table 1). The mean length of stay was 6.7 years ($SD = 5.6$). Cognitive functioning was moderately impaired (mean = 2.6, $SD = 1.6$). The mean NPI-Q total severity score was 8.0 ($SD = 5.6$, range = 0-36). Two-thirds of residents used at least one psychotropic drug (63.7%), of which antipsychotics were prescribed most frequently (47.9%). Psychotropic drugs were most frequently prescribed to residents with moderately impaired awareness.

3.3 | Differences between completers and noncompleters of PCRS-patient's form

Residents who had not completed the PCRS themselves ($n = 66$) had more severe NPS (NPI-Q total severity score 11.0 vs 8.0, $t = 3.605$, $df = 279$, $p < 0.001$). They also demonstrated more difficulties in performing everyday tasks as judged by the nurse with the PCRS (PCRS-clinician's form total score 77.7 vs 86.4, $t = 3.954$, $df = 279$, $p < 0.001$). These differences were present on all domains: physical domain (PCRS-clinician's form domain score 2.44 vs 2.77,

Flowchart of selection process

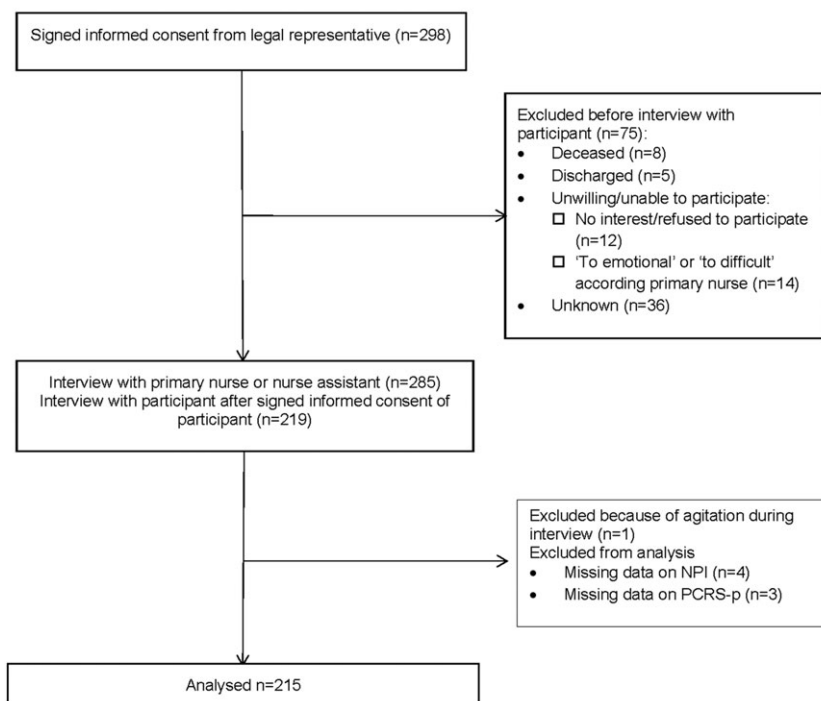


FIGURE 1 Flowchart of the selection process

TABLE 1 Baseline characteristics of the study sample, presented by level of awareness group (N = 215)

	Level of Impaired Awareness			Total N = 215
	No/mild (score < 28) n = 62 (28.8%)	Moderate (score = 28-51) n = 80 (37.2%)	Severe (score > 51) n = 73 (34.0%)	
Age (years) mean (SD)	62.9 (7.5)	62.7 (8.4)	63.9 (7.8)	63.2 (7.9)
Male; n, %	50 (23.3)	57 (26.5)	59 (27.4)	166 (77.2)
Education; n, %				
Elementary, lower	36 (16.7)	46 (21.4)	42 (19.5)	124 (57.7)
Secondary	8 (3.7)	17(7.9)	18 (8.4)	43 (20.0)
Higher/university	9 (4.2)	6 (2.8)	2 (0.9)	17 (7.9)
Unknown				31 (14.4)
Marital status; n, %				
Single, divorced, or widowed	57 (26.5)	73 (34.0)	58 (27.0)	188 (87.4)
Married or partner	4 (1.9)	5 (2.3)	8 (3.7)	17 (7.9)
Unknown				10 (4.7)
Length of stay in specialized NH (years), mean (SD)	6.6 (5.1)	7.6 (6.2)	5.9 (5.2)	6.7 (5.6)
PCRS discrepancy score ^a (-120 to 120), mean (SD)	14.2 (9.7)	40.2 (6.7)	61.1 (8.1)	39.3 (19.9)
CPS score (<u>0-6</u>), mean (SD)	1.9 (1.5)	2.5 (1.5)	3.2 (1.6)	2.6 (1.6)
NPI-Q total severity score (<u>0-36</u>), mean (SD)	6.7 (5.2)	8.6 (5.9)	8.5 (5.6)	8.0 (5.6)
Apathy symptom (<u>0-3</u>)	0.5 (0.8)	0.9 (1.1)	1.0 (1.1)	0.8 (1.0)
Agitation subsyndrome (<u>0-9</u>)	2.8 (2.4)	3.4 (2.5)	3.5 (2.8)	3.2 (2.6)
Affective symptoms subsyndrome (<u>0-6</u>)	1.0 (1.4)	1.6 (1.8)	1.3 (1.6)	1.3 (1.7)
Psychosis subsyndrome (<u>0-6</u>)	0.7 (1.5)	0.9 (1.5)	0.9 (1.4)	0.9 (1.5)
Use of psychotropic drugs; n, %				
Any psychotropic drug	40 (18.6)	53 (24.7)	44 (20.5)	137 (63.7)
Antipsychotic	28 (13.0)	42 (19.5)	33 (15.4)	103 (47.9)
Antidepressant	22 (10.2)	33 (15.4)	24 (11.2)	79 (36.7)
Benzodiazepine	14 (6.5)	33 (15.4)	19 (8.8)	66 (30.7)

Abbreviations: CPS, Cognitive Performance Scale; NPI-D, Neuropsychiatric Inventory-Distress Scale; NPI-Q, Neuropsychiatric Inventory-Questionnaire; PCRS, Patient Competency Rating Scale. The underlined scores indicate the more positive outcome.

^aPatient rating minus nurse rating.

$t = -3.267$, $df = 279$, $p = 0.001$), cognitive domain (2.19 vs 2.50, $t = -2.908$, $df = 279$, $p = 0.004$), and interpersonal/emotional domain (2.83 vs 3.08, $t = -3.073$, $df = 279$, $p = 0.002$).

3.4 | Level of awareness

The mean level of awareness was 39.3 (SD = 19.9), which indicates moderate impairment. A total of 28.8% of the residents were not or mildly impaired; 37.2% showed moderately impaired awareness, and 34.0% were severely impaired (Table 1).

Statistically significant differences between patients' and clinicians' ratings were found for all items except for the item "controlling laughter" and for all domains (Table 2). Awareness was most severely impaired for the items "taking care of finances" (2.80) "driving a car" (2.33), and "scheduling daily activities" (2.15) and the least severely impaired for the items controlling laughter (0.28), "controlling crying" (0.30) and "dressing self" (0.51). In addition, the items "taking care of

finances" (93.0%), "scheduling daily activities" (87.4%), and "taking care of personal hygiene" (84.7%) were most frequently overestimated by residents ($P > C$). Items with highest agreement between resident and nurse ($P = C$) included dressing self (50.7%) and controlling crying (52.1%). With regard to the PCRS domains, awareness was most severely impaired for the cognitive domain (1.77) and the least impaired for the interpersonal/emotional domain (1.08).

3.5 | Relationship between levels of awareness and NPS

Unadjusted analyses showed that NPS (total severity score) and apathy were significantly more severe in residents with both moderately and severely impaired awareness than in residents who were not or mildly impaired. Furthermore, affective symptoms were less common in residents with moderately impaired awareness, and psychotic symptoms were less common in residents with severely impaired

TABLE 2 Paired-samples *t* test between patients' ratings and clinicians' ratings of the PCRS (N = 215)

No.	PCRS Item ("How much of a problem do I have/do they have in...")	P < C n, %	P = C n, %	P > C n, %	Patient Rating Mean, SD	Clinician Rating Mean, SD	Mean Difference (range = -4 - 4) ^a	95% CI
Physical domain								
1	Preparing meals	10 (4.7)	27 (12.6)	178 (82.8)	4.12 (1.24)	2.27 (1.17)	1.85	1.65-2.04
2	Dressing self	14 (6.6)	109 (50.7)	92 (42.8)	4.68 (0.76)	4.17 (0.95)	0.51	0.39-0.64
3	Personal hygiene	8 (3.8)	25 (11.6)	182 (84.7)	4.62 (0.83)	2.91 (1.15)	1.71	1.54-1.88
4	Washing dishes	10 (4.6)	61 (28.5)	143 (66.9)	4.56 (0.93)	3.32 (1.36)	1.24	1.06-1.42
5	Doing laundry	5 (2.4)	38 (18.0)	168 (79.6)	4.16 (1.28)	2.48 (1.27)	1.68	1.50-1.85
9	Staying involved	15 (7.1)	43 (20.3)	154 (72.6)	3.95 (1.16)	2.47 (0.97)	1.48	1.29-1.67
11	Remembering names	33 (15.4)	48 (22.4)	133 (62.2)	4.15 (1.18)	3.21 (1.20)	0.94	0.74-1.15
14	Driving a car if had to	6 (2.8)	37 (17.4)	170 (79.8)	3.70 (1.60)	1.38 (0.71)	2.33	2.11-2.55
	Mean item per domain				4.24 (0.69)	2.77 (0.74)	1.47 (0.63-3.25)	1.37-1.57
Cognitive domain								
6	Taking care of finances	2 (0.9)	13 (6.1)	198 (93.0)	4.25 (1.11)	1.46 (0.71)	2.80	2.62-2.98
7	Keeping appointments	9 (4.3)	26 (12.1)	179 (83.7)	4.50 (0.86)	2.69 (1.03)	1.80	1.63-1.98
10	Remembering dinner	15 (7.0)	38 (17.8)	161 (75.2)	3.68 (1.34)	2.01 (1.14)	1.67	1.46-1.88
12	Remembering schedule	20 (9.4)	29 (13.6)	164 (77.0)	4.28 (1.07)	2.83 (1.17)	1.45	1.26-1.64
13	Remembering things to do	14 (6.5)	39 (18.1)	162 (75.4)	4.17 (1.06)	2.59 (1.10)	1.58	1.39-1.77
24	Scheduling activities	3 (1.4)	24 (11.2)	187 (87.4)	4.47 (0.93)	2.33 (1.12)	2.15	1.97-2.32
25	Understanding new instructions	15 (7.0)	38 (17.8)	161 (75.2)	4.27 (1.00)	2.88 (0.92)	1.38	1.21-1.56
26	Meeting responsibilities	13 (6.1)	34 (16.0)	166 (77.9)	4.54 (0.84)	3.17 (0.98)	1.36	1.20-1.53
	Mean item per domain				4.27 (0.70)	2.50 (0.77)	1.77 (0.88-3.50)	1.65-1.90
Interpersonal/emotional domain								
15	Getting help when confused	20 (9.4)	37 (17.5)	155 (73.1)	4.06 (1.15)	2.57 (1.11)	1.49	1.27-1.70
16	Adjusting to changes	13 (6.1)	33 (15.5)	167 (78.4)	4.03 (1.07)	2.48 (0.90)	1.55	1.38-1.73
17	Handling arguments	19 (8.9)	42 (19.6)	153 (71.5)	3.82 (1.18)	2.50 (0.86)	1.32	1.13-1.51
18	Accepting criticism	27 (12.6)	43 (20.0)	145 (67.4)	3.80 (1.20)	2.54 (0.90)	1.26	1.06-1.46
19	Controlling crying	31 (14.6)	111 (52.1)	71 (33.3)	4.52 (0.88)	4.22 (1.02)	0.30	0.16-0.44
20	Acting appropriately	21 (9.9)	46 (21.6)	146 (68.6)	4.62 (0.77)	3.49 (1.08)	1.13	0.95-1.31
21	Showing affection	21 (9.9)	38 (17.8)	154 (72.3)	4.45 (0.82)	3.30 (1.10)	1.15	0.98-1.33
22	Participating in group activities	33 (15.5)	49 (23.0)	131 (61.5)	4.08 (1.19)	3.23 (1.15)	0.85	0.66-1.04
23	Recognizing upsetting someone ^b	31 (14.9)	37 (17.8)	140 (67.3)	3.99 (1.13)	2.80 (1.06)	1.19	0.97-1.41
27	Controlling temper	39 (18.4)	48 (22.6)	125 (59.0)	4.04 (1.09)	3.20 (1.01)	0.84	0.64-1.05
28	Keeping from being depressed	26 (12.1)	66 (30.7)	123 (57.2)	4.20 (1.04)	3.40 (1.10)	0.80	0.62-0.98
29	Controlling emotions	28 (13.2)	49 (23.0)	136 (63.9)	4.28 (1.00)	3.21 (1.13)	1.08	0.88-1.27
	Mean item per domain				4.16 (0.60)	3.08 (0.56)	1.08 (0.88-2.92)	0.98-1.19
Items not grouped								
8	Starting conversation	59 (27.4)	47 (21.9)	109 (50.7)	3.82 (1.19)	3.26 (1.14)	0.56	0.36-0.77
30	Controlling laughter	49 (23.0)	63 (29.6)	101 (47.4)	4.17 (1.15)	3.89 (1.00)	0.28	0.09-0.48
	Total score (range = 30-150)				125.7(16.5)	86.4 (15.6)		

Abbreviations: C, clinician rating; 95% CI, 95% confidence interval; P, patient rating; PCRS, Patient Competency Rating Scale.

^aAll differences were statistically significant with $p < 0.001$, except item 30 which was significant at $p \leq 0.005$.

^bseven missings.

awareness (Table 3). After adjusting for sociodemographics (model 1), the relationships between the level of awareness and NPS (total severity score) and apathy remained significant. Subsequent analyses

adjusting for length of stay and cognitive functioning (model 2) showed that only apathy remained significantly associated with the level of awareness: apathy was more severe in residents with

TABLE 3 Multilevel regression analyses of associations between levels of awareness and neuropsychiatric outcomes (N = 215)

Mixed Model	Unadjusted			Adjusted for Sociodemographic Covariates (gender, age, and level of education)			Adjusted for Sociodemographic Covariates, Length of Stay, and Cognitive Functioning			Adjusted for Sociodemographic Covariates, Length of Stay, Cognitive Functioning, and Psychotropic Drugs (≥ 1)					
	Mean ^b	B	95% CI	p	B	95% CI	p	Mean ^b	B	95% CI	p	B	95% CI	p	
NPI-Q total severity (mean) (0–60)															
No/mild (score < 28)	6.66							6.66							
Moderate (score 28–51)	8.60	1.94	0.09–3.79	0.04	2.09	0.09–4.10	0.04	8.60	1.74	-0.27–3.75	0.09	1.91	-0.06–3.88	0.06	
Severe (score > 51)	8.51	1.94	0.04–3.85	0.05	1.68	-0.41–3.77	0.12	8.51	1.07	-1.10–3.23	0.33	1.53	-0.61–3.66	0.16	
Apathy (mean) (0–3)															
No/mild (score < 28)	0.52							0.52							
Moderate (score 28–51)	0.90	1.20	1.01–1.43	0.04	1.29	1.07–1.56	0.01	0.90	1.23	1.02–1.48	0.03	0.22	0.03–0.40	0.02	
Severe (score > 51)	0.96	1.25	1.05–1.49	0.01	1.26	1.03–1.53	0.02	0.96	1.16	-1.05–1.42	0.14	0.18	-0.03–0.38	0.09	
Agitation subsyndrome (mean) (0–9)															
No/mild (score < 28)	2.76							2.76							
Moderate (score 28–51)	3.35	0.59	-0.27–1.45	0.18	0.65	-0.30–1.61	0.18	3.35	0.71	-0.26–1.68	0.15	0.78	-0.19–1.74	0.11	
Severe (score > 51)	3.47	0.71	-0.17–1.59	0.11	0.48	-0.51–1.47	0.34	3.47	0.52	-0.53–1.56	0.33	0.70	-0.34–1.74	0.19	
Generalized estimating equations															
		n (%)	OR	95% CI	p	OR	95% CI	p	n (%)	OR	95% CI	p	OR	95% CI	p
Affective symptoms subsyndrome (yes/no)															
No/mild (score < 28)		109 (50.7)							109 (50.7)						
Moderate (score 28–51)		26 (23.9)	0.49	0.25–0.96	0.04	0.60	0.31–1.16	0.13	26 (23.9)	0.64	0.32–1.26	0.19	0.60	0.32–1.16	0.13
Severe (score > 51)		36 (33.0)	0.66	0.37–1.17	0.15	0.84	0.31–2.25	0.72	36 (33.0)	0.85	0.32–2.22	0.73	0.74	0.28–2.01	0.56
Psychosis subsyndrome (yes/no)															
No/mild (score < 28)		70 (32.6)							70 (32.6)						
Moderate (score 28–51)		16 (22.9)	0.60	0.32–1.13	0.11	0.66	0.29–1.51	0.33	16 (22.9)	0.69	0.30–1.63	0.40	0.64	0.28–1.45	0.28
Severe (score > 51)		26 (37.1)	0.56	0.35–0.90	0.02	0.49	0.25–1.00	0.04	26 (37.1)	0.56	0.25–1.27	0.16	0.46	0.22–0.93	0.03

Abbreviations: 95% CI, 95% confidence interval; NPI-Q, Neuropsychiatric Inventory-Questionnaire. No/mildly impaired awareness is reference category. Bold represents the values with $p < 0.05$. The underlined scores indicate the more positive outcome.

^aPCRS discrepancy score

^bUncorrected

moderately impaired awareness than in residents who had no or mildly impaired awareness (difference 1.23; 95% CI 1.02-1.48; $df = 171$, $p = 0.03$). Adjustment for psychotropic drugs had no significant impact on the relationship between the level of awareness and apathy as found in model 3. No significant interaction effects were identified between cognitive functioning and level of awareness for any of the outcome measures.

4 | DISCUSSION

This study showed that most residents with KS living in specialized NHs (71.2%) demonstrated impaired awareness of functional deficits and that, on average, the level of awareness was moderately impaired. After adjustment, we found that residents with moderately impaired awareness had more severe apathy than residents who were not or mildly impaired. No significant associations were found with other NPI outcomes.

4.1 | Level of impaired awareness and its relationship with NPS

Our results confirm previous reports and support clinical experiences that awareness in people with KS is impaired.^{7,8,10,11,19,35} Furthermore, as determined by Walvoort et al who compared self-reported complaints and cognitive performance between people with KS and people with mild alcohol-related cognitive dysfunction (non-KS),¹⁹ we found that awareness was mostly impaired for the cognitive domain. Compared with Wester et al on people with KS who were temporally admitted to a specialized psychiatric admission ward (PCRS discrepancy score pretreatment and posttreatment 29.6 and 29.9, respectively),³⁵ we found that awareness was more impaired (discrepancy score = 39.3).

With regard to the studies on people with Alzheimer's disease by Shany-Ur et al (very mild/mild dementia) and Jacus et al (mild dementia),^{23,25} it appeared that awareness in our study sample was much more impaired (PCRS discrepancy score = 11.9 and 1.5, respectively). Furthermore, dementia research showed that impaired awareness becomes more frequent³⁶ and the level of impaired awareness increases¹⁴ as the severity of dementia progresses. This is in line with the findings of our study, which demonstrated that, based on the adjusted analyses, cognitive functioning seemed to have a strong impact on the relation between the level of awareness and NPS in residents with KS.

Furthermore, we found that moderately impaired awareness was significantly associated with more severe apathy. This is in contrast with the findings by Egger et al who suggested in their study that people with KS showing insight appeared to have more apathy, among other NPS, than people without this insight.¹⁰ These researchers were, however, cautious in interpreting their results due to the small sample size and the procedure that was followed to assess impaired awareness (clinical observation and evaluation). On the other hand and in line with our findings, several studies on people with dementia have also shown that lower levels of awareness seemed to be related to more severe apathy.^{25,36-38}

An explanation for the relationship between moderately impaired awareness and apathy that we found in our study sample could be a common neuropathological substrate, namely, frontal lobe pathology and lesions in fronto-subcortical circuit because of alcohol neurotoxicity.^{5,39,40} Furthermore, both impaired awareness and apathy are related to executive dysfunctioning.^{19,40,41} Accumulating evidence suggests that people with KS perform poorly on executive functioning, including shifting, updating, planning, and inhibition tasks because of frontal dysfunction.⁵ Another explanation may lie in the potential side effect of psychotropic drugs, which were extensively used by residents with KS. Care staff could have over asked in particular the residents with moderately impaired awareness, and this might be distressing to residents themselves and their environment resulting in agitated behavior and the prescription of psychotropic drugs. However, after adjustment for psychotropic drugs in the final model, the relationship between the level of awareness and apathy did not change significantly.

In contrast to research in people with dementia,^{25,36,42} we did not find a relationship between the level of awareness and the presence of depressive symptoms, although these symptoms were highly common in residents with KS (43.4%).⁶ In people with dementia, it is hypothesized that, in particular, dysthymia can be seen as an emotional reaction of people who are aware of their progressive cognitive decline, especially in the beginning of their disease process.⁴³ In line with dementia, it could be argued that impaired awareness in people with KS might protect them from becoming depressed due to the insight into their limitations, as they become indifferent to their disease. Further studies are recommended to examine this hypothesis.

Additionally, we did not find any associations between awareness and other NPS, such as agitation and psychosis. In contrast, several authors have found lower levels of awareness to be associated with more severe agitation, disinhibition and irritability in people with dementia.^{14,36}

4.2 | Strengths and limitations

This study adds to the literature as it is the first to examine the level of impaired awareness of functional deficits and its relationships with NPS in a large sample of people with KS or other alcohol-related cognitive disorders living in specialized NHs. The majority of the residents who participated in the study (response rate 75%) were able and willing to complete the PCRS themselves. Furthermore, awareness of functional deficits was measured with an assessment instrument, which is widely used in people with acquired brain injury. Although not specifically validated for the use in people with KS or other alcohol-related cognitive disorders, we supposed that the PCRS was the best available choice to use in these people group.

A limitation, however, could be that the nurses overestimated resident's competences as they could have become used to the functional deficits. Assessing residents' competences by an independent, significant other might result in more impaired levels of awareness. On the other hand, nurses ratings may be influenced by caregiver burden, which may have led to underestimation. Furthermore, residents may have

presented themselves better than they actually were when rating their functional competences because of a denial of their difficulties. As Clare et al described from a biopsychosocial perspective, "People may seek to minimize or deny their difficulties [...] Such processes may be especially evident when the individual is undergoing changes and challenges as a result of developing cognitive impairments".¹⁷ However, studies in people with traumatic brain injury have demonstrated good validity and reliability of the PCRS.²⁷ Future research is recommended to validate the use of the PCRS in people with KS.

Furthermore, the severity of NPS was found to be significantly higher in the group of residents who did not complete the PCRS themselves. Moreover, nurses judged that noncompleters were less competent to do everyday tasks than completers. As a consequence, level of awareness and the relationship with NPS in our sample could have been underestimated. On the other hand, completers and noncompleters were similar with regard to other baseline characteristics, and we therefore assume that this did not limit the generalizability of the present findings.

Finally, because of dichotomization of the affective and psychosis subsyndrome information might have been lost. Consequently, we were not able to compare the level of awareness with the severity of these subsyndromes. This may have limited the possibility to detect significant relationships.

5 | CONCLUSION AND IMPLICATIONS

The findings of the present study showed that most residents with KS overestimated their functional capacities, which could hinder their self-care and participation in daily activities. Apart from apathy, awareness is, however, not significantly related with NPS. These findings highlight the importance to recognize impaired awareness in the daily care of residents with KS, and to consider timely interventions, particularly when apathy is present.

Additional research should be conducted to further examine, which clinical approaches, such as an empathetic directive approach,⁴⁴ and (psychosocial) interventions are effective to deal with impaired awareness in these people. A better understanding of awareness in people with KS and how to optimally manage this in daily care may improve the quality of long-term care for these people and ultimately also their quality of life.

ACKNOWLEDGEMENTS

The authors would like to thank the management of the nursing homes for supporting the study and the residents and their caregivers for participating in this study.

SHORT INFORMATION

Approximately 25% of those affected by the neuropsychiatric disorder Korsakoff syndrome will require long-term institutionalization. Caring for people with Korsakoff syndrome can be distressing due to challenging behavior in many people. Impaired awareness (ie, a lack of insight

into their deficits) can make it even more challenging to provide good quality care. Although there are indications from daily clinical practice that awareness in people Korsakoff is often impaired, good quality studies are lacking. This study is the first to examine the level of impaired awareness of functional deficits and its relationships with neuropsychiatric symptoms in a large sample of people with Korsakoff syndrome or other alcohol-related cognitive disorders living in specialized nursing homes. We found that impaired awareness is highly common in these people; however, apart from apathy, it is not significantly related to neuropsychiatric symptoms. A better understanding of awareness in people with Korsakoff syndrome, and how to optimally manage this in daily care, may prevent them to withdraw their selves from self-care and participation in daily activities. This may improve the quality of long-term care for these people and ultimately also their quality of life.

FUNDING INFORMATION

This work was supported by the Netherlands Organization for Health Research and Development, Pieter van Foreest Stichting, Stichting Vermogensbeheer Hoogeland Zorg, and Atlant.

CONFLICTS OF INTEREST

Financial conflicts: Ineke J. Gerridzen received fees from Atlant as an employer. Personal conflicts: none

ORCID

Ineke J. Gerridzen  <https://orcid.org/0000-0003-0220-718X>

Karlijn J. Joling  <https://orcid.org/0000-0001-5301-6370>

REFERENCES

- Jauhar S, Smith ID. Alcohol-related brain damage: not a silent epidemic. *Br J Psychiatry*. 2009;194:287-288. author reply 288
- Lishman WA. *Organic Psychiatry: the psychological consequences of cerebral disorder*. 3rd ed. Oxford: Blackwell Science; 1998.
- Kopelman MD, Thomson AD, Guerrini I, Marshall EJ. The Korsakoff syndrome: clinical aspects, psychology and treatment. *Alcohol Alcohol*. 2009;44(2):148-154.
- Van Oort R, Kessels RP. Executive dysfunction in Korsakoff's syndrome: Time to revise the DSM criteria for alcohol-induced persisting amnesic disorder? *Int J Psychiatry Clin Pract*. 2009;13(1):78-81.
- Brion M, Pitel AL, Beaunieux H, Maurage P. Revisiting the continuum hypothesis: toward an in-depth exploration of executive functions in Korsakoff syndrome. *Front Hum Neurosci*. 2014;8:498.
- Gerridzen IJ, Hertogh CM, Depla MF, Veenhuizen RB, Verschuur EM, Joling KJ. 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. *J Am Med Dir Assoc*. 2018;19(3):240-247.
- Victor M, Adams RD, Collins GH. *The Wernicke Korsakoff syndrome and related neurological disorders due to alcoholism and malnutrition*. 2nd ed. Philadelphia PA: FA Davis; 1989.
- Blansjaar BA, Takens H, Zwinderman AH. The course of alcohol amnesic disorder: a three-year follow-up study of clinical signs and social disabilities. *Acta Psychiatr Scand*. 1992;86(3):240-246.

9. Thomson AD, Guerrini I, Marshall EJ. The evolution and treatment of Korsakoff's syndrome: out of sight, out of mind? *Neuropsychol Rev.* 2012;22(2):81-92.
10. Egger JI, Wester AJ, de Mey HR, Derksen JJ. Korsakoff's syndrome on the MMPI-2. *Acta Neuropsychiatr.* 2002;14(05):231-236.
11. Van den Hooff S, Buijsen M. Healthcare professionals' dilemmas: judging patient's decision making competence in day-to-day care of patients suffering from Korsakoff's syndrome. *Med Health Care Philos.* 2014;17(4):633-640.
12. Gerridzen IJ, Goossensen MA. Patients with Korsakoff syndrome in nursing homes: characteristics, comorbidity, and use of psychotropic drugs. *Int Psychogeriatr.* 2014;26(1):115-121.
13. Prigatano GP. Anosognosia and patterns of impaired self-awareness observed in clinical practice. *Cortex.* 2014;61:81-92.
14. Aalten P, van Valen E, Clare L, Kenny G, Verhey F. Awareness in dementia: a review of clinical correlates. *Aging Ment Health.* 2005;9(5):414-422.
15. Marková IS, Clare L, Whitaker CJ, et al. Phenomena of awareness in dementia: heterogeneity and its implications. *Conscious Cogn.* 2014;25:17-26.
16. Prigatano GP, Altman IM. Impaired awareness of behavioral limitations after traumatic brain injury. *Arch Phys Med Rehabil.* 1990;71:1058-1064.
17. Clare L, Marková IS, Roth I, Morris RG. Awareness in Alzheimer's disease and associated dementias: theoretical framework and clinical implications. *Aging Ment Health.* 2011;5:936-944.
18. Vasterling JJ, Seltzer B, Foss MW, Vanderbrook V. Unawareness of deficit in Alzheimer's disease: Domain-specific differences and disease correlates. *Neuropsychiatry Neuropsychol Behav Neurol.* 2010;8:26-32.
19. Walvoort SJ, van der Heijden PT, Wester AJ, Kessels RPC, Egger JIM. Self-awareness of cognitive dysfunction: self-reported complaints and cognitive performance in patients with alcohol-induced mild or major neurocognitive disorder. *Psychiatry Res.* 2016a;245:291-296.
20. Walvoort SJ, van der Heijden PT, Kessels RP, Egger JI. Measuring illness insight in patients with alcohol-related cognitive dysfunction using the Q8 questionnaire: a validation study. *Neuropsychiatr Dis Treat.* 2016b;12:1609-1615.
21. Prigatano GP. *Neuropsychological Rehabilitation after Brain Injury.* Baltimore: The Johns Hopkins University Press; 1986.
22. Barskova T, Wilz G. Psychosocial functioning after stroke: psychometric properties of the patient competency rating scale. *Brain Inj.* 2006;20(13-14):1431-1437.
23. Shany-Ur T, Lin N, Rosen HJ, Sollberger M, Miller BL, Rankin KP. Self-awareness in neurodegenerative disease relies on neural structures mediating reward-driven attention. *Brain.* 2014;137(8):2368-2381.
24. Smeets SM, Ponds RW, Wolters Gregório G, et al. Impaired awareness of deficits in individuals with neuropsychiatric symptoms after acquired brain injury: associations with treatment motivation and depressive symptoms. *Neuropsychology.* 2014;28(5):717-725.
25. Jacus JP. Awareness, apathy, and depression in Alzheimer's disease and mild cognitive impairment. *Brain Behav.* 2017;7(4):e00661.
26. Heilbronner RL, Millsaps CL, Azrin RL, Mittenberg W. Psychometric properties of the patient competency rating scale. (*Abstract*) *J Clin Exp Neuropsychol.* 1993;15:67-68.
27. Smeets SM, Ponds RW, Verhey FR, van Heugten CM. Psychometric properties and feasibility of instruments used to assess awareness of deficits after acquired brain injury: a systematic review. *J Head Trauma Rehabil.* 2012;27(6):433-442.
28. Sherer M, Hart T, Nick TG. Measurement of impaired self-awareness after traumatic brain injury: a comparison of the patient competency rating scale and the awareness questionnaire. *Brain Inj.* 2003;17(1):25-37.
29. Winter L, Moriarty H, Robinson KM, Newhart B. Rating competency in everyday activities in patients with TBI: clinical insights from a close look at patient-family differences. *Disabil Rehabil.* 2016;38(13):1280-1290.
30. Kaufer DI, Cummings JL, Ketchel P, et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *J Neuropsychiatry Clin Neurosci.* 2000;12(2):233-239.
31. Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurol.* 1994;44(12):2308-2314.
32. De Jonghe JF, Kat MG, Kalisvaart CJ, Boelaarts L. Neuropsychiatric inventory questionnaire (NPI-Q): a validity study of the Dutch form. *Tijdschr Gerontol Geriatr.* 2003;34(2):74-77.
33. Van der Linde RM, Denning T, Matthews FE, Brayne C. Grouping of behavioural and psychological symptoms of dementia. *Int J Geriatr Psychiatry.* 2014;29(6):562-568.
34. Morris JN, Fries BE, Mehr DR, et al. MDS cognitive performance scale. *J Gerontol.* 1994;49(4):M174-M182.
35. Wester AJ, Bruijnen C, Kessels RP. Effectiveness of treatment in patients with Korsakoff's syndrome and alcohol-related cognitive disorders. http://www.vvgi.nl/include/files//Client%20en%20Familie//Specialistische_Centra//Documenten//Korsakov/Symposium_diagnostiek_behandeling/poster-Wester.pdf.pdf. Accessed 2009.
36. Starkstein SE. Anosognosia in Alzheimer's disease: diagnosis, frequency, mechanism and clinical correlates. *Cortex.* 2014;61:64-73.
37. Vogel A, Waldorff FB, Waldemar G. Impaired awareness of deficits and neuropsychiatric symptoms in early Alzheimer's disease: the Danish Alzheimer Intervention Study (DAISY). *J Neuropsychiatry Clin Neurosci.* 2010;22(1):93-99.
38. Starkstein SE, Brockman S, Bruce D, Petracca G. Anosognosia is a significant predictor of apathy in Alzheimer's disease. *J Neuropsychiatry Clin Neurosci.* 2010;22(4):378-383.
39. Oscar-Berman M. Function and dysfunction of prefrontal brain circuitry in alcoholic Korsakoff's syndrome. *Neuropsychol Rev.* 2012;22(2):154-169.
40. Arts NJ, Walvoort SJ, Kessels RP. Korsakoff's syndrome: a critical review. *Neuropsychiatr Dis Treat.* 2017;13:2875-2890.
41. Cummings JL. Frontal-subcortical circuits and human behavior. *Arch Neurol.* 1993;50(8):873-880.
42. Horning SM, Melrose R, Sultzer D. Insight in Alzheimer's disease and its relation to psychiatric and behavioral disturbances. *Int J Geriatr Psychiatry.* 2014;29(1):77-84.
43. Starkstein SE, Chemerinski E, Sabe L, et al. Prospective longitudinal study of depression and anosognosia in Alzheimer's disease. *Br J Psychiatry.* 1997;171(01):47-52.
44. Van Noppen M, Nieboer J, Ficken M. *An empathic directive approach: caring for people with Korsakoff syndrome.* The Hague: Stichting Saffier; 2008.

How to cite this article: Gerridzen IJ, Joling KJ, Depla MF, et al. Awareness and its relationships with neuropsychiatric symptoms in people with Korsakoff syndrome or other alcohol-related cognitive disorders living in specialized nursing homes. *Int J Geriatr Psychiatry.* 2019;34:836-845. <https://doi.org/10.1002/gps.5093>