Alcohol-Related Neurocognitive Disorders: A Naturalistic Study of Nosology and Estimation of Prevalence in South Wales, United Kingdom

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ABSTRACT. Objective: Existing studies relating to the prevalence of alcohol-related neurocognitive disorders (ARNDs; e.g., Korsakoff's Syndrome, alcohol-related dementia) are now outdated and few have been undertaken in the United Kingdom. The aim of this study was to estimate the prevalence of ARNDs in South Wales, U.K., and determine the specific diagnostic terms and criteria used in clinical practice. **Method:** A naturalistic, survey-based prevalence study was undertaken wherein data were collected retrospectively for all individuals with ARNDs attending services during all of 2015 and 2016. A diverse sample of health and social care services ($N = 60$) in South Wales took part in the study. **Results:** A total of 490 individuals with ARNDs were identified by participating services, equating to an age-specific rate of 34 individuals per 100,000 inhabitants. Variability was observed across age ranges and genders, with most identified in the 45–64 year age range and a male:female ratio of 2.6:1. Twenty-three individuals younger than age 35 were identified, demonstrating an increase in younger cases compared with previous studies. Various diagnostic terms were used, with "alcohol-related brain damage" being most common. Only 6.3% of cases were diagnosed according to specific criteria and 44.3% were reported as having a "probable" ARND, meaning no official diagnosis had been designated but initial assessments indicated that they likely had an ARND. **Conclusions:** Findings provide a novel understanding of ARND prevalence in a previously understudied area, although the prevalence estimate is conservative and should be interpreted cautiously for reasons discussed. Findings also highlight an inconsistency between diagnoses presented in nosological systems (e.g., International Classification of Diseases–10th Revision) and those used in practice and therefore a need to evaluate novel diagnostic conceptualizations of alcohol-related neurocognitive impairment. (*J. Stud. Alcohol Drugs, 81,* 584–594, 2020)

FEW STUDIES HAVE INVESTIGATED the prevalence of alcohol-related neurocognitive disorders (ARNDs) such as Wernicke–Korsakoff Syndrome (WKS) and alcohol-related dementia (ARD) in recent years (see Table 1 for an overview of ARND diagnoses and nomenclature). Postmortem investigations have been commonly used to estimate WKS prevalence (Cook et al., 1998) and have identified WKS-like brain lesions in around 1.5% of the population worldwide, with substantial variation between regions (0.4%–2.8%; Harper et al., 1986, 1995); however, few such investigations appear to have been conducted since the 1990s. A small number of survey-based studies have also been used to study WKS prevalence. In a survey of healthcare workers within The Hague, the Netherlands, Blansjaar et al. (1987) attempted to collect clinical data for all individuals with WKS in the region and thereby determine the prevalence of the condition. They found a total of 215 cases, amounting to a prevalence of 4.8 per 10,000 inhabitants. However, the study is limited by the lack of information regarding the number and type of services that participated and details of services that did not respond. In the United Kingdom, a survey-based study by Smith and Flanigan (2000) reported a Scottish prevalence of 3.5 WKS cases (including non–alcohol-related forms) per 100,000 residents, although this figure was based on surveys of psychiatric units.

Studies relating to the prevalence of ARD have typically investigated this as the proportion of dementias attributable to the condition. Carlen et al. (1994) studied the distribution of dementias within an elderly sample in institutionalized care in Canada, finding that ARD was responsible for 24% of dementias. A review of seven epidemiological studies found that between 1% and 14% of early-onset dementias could be attributed to ARD (Vieira et al., 2013). However, as with WKS, most studies of ARD prevalence were conducted 10–25 years ago and are therefore outdated. Additionally, it is unclear whether the ARD diagnosis is used in modern clinical practice, given the dearth of direct studies on the disorder in the last 10 years. Diagnostic criteria for ARD have been proposed that define it as a more global decline in cognition compared with WKS (Oslin et al., 1998), which is characterized primarily by severe deficits in episodic memory (Fama et al., 2012). The condition is

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TABLE 1. Alcohol-related neurocognitive disorders: Diagnostic terms used in practice and in nosological systems

General diagnostic terms	Closest ICD-10/11[a] terms (diagnostic code)	Closest DSM-5 terms
Wernicke's encephalopathy; Wernicke–Korsakoff syndrome	Wernicke's encephalopathy (E51.2/5B5A.10)	Alcohol-induced major neurocognitive disorder (amnestic-confabulatory type)
Korsakoff's syndrome; Korsakoff's dementia; Korsakoff's psychosis; Wernicke–Korsakoff syndrome;	Amnesic syndrome (alcohol-related; F10.6)/Wernicke–Korsakoff Syndrome (5B5A.1); Korsakoff Syndrome (5B5A.11); Amnestic disorder due to use of alcohol (6D72.10)[b]	Alcohol-induced major neurocognitive disorder (amnestic-confabulatory type)
Hepatic encephalopathy (alcohol-related)	Alcoholic hepatic failure (K70.4); Alcoholic cirrhosis of liver (K70.3)/Alcoholic liver disease (DB94); Hepatic encephalopathy (DB99.5)	*No related diagnosis*
Alcohol-related dementia; alcohol-induced dementia; primary alcoholic dementia	Residual and late-onset psychotic disorders (alcohol-related; dementia specified; F10.7)/Dementia due to use of alcohol (6D84.0)	Alcohol-induced mild/major neurocognitive disorder (non-amnestic-confabulatory type)
Alcohol-related cerebellar degeneration; cerebellar atrophy (alcohol-related)	Degeneration of nervous system due to alcohol (G31.2)/Ataxia due to alcoholic cerebellar degeneration (8A03.30)	*No related diagnosis*
Marchiafava-Bignami disease (alcohol-related)	Central demyelination of corpus callosum (G37.1/8A46)	*No related diagnosis*
Central pontine myelinolysis; osmotic myelinolysis[c]	Central pontine myelinolysis (G37.2/ 8A45.31)	*No related diagnosis*
Pellagra (alcohol-related)	Niacin deficiency (Pellagra; E52); Dementia in other specified diseases classified elsewhere (F02.8, E52)/Dementia due to pellagra (6D85.8)	*No related diagnosis*
Alcohol-related brain damage; alcohol-related brain-injury; alcohol-related brain impairment	*No related diagnosis*	Alcohol-induced mild/major neurocognitive disorder (non-amnestic-confabulatory type) [?]
Other:	ICD-10: Alcohol-related psychotic disorder (F10.5) ICD-11: Alcohol-induced psychotic disorder (6C40.6); Alcohol-related myopathy (8D44.1); Alcohol-Related neurological disorders, unspecified (8D44.Z)	*No related diagnosis*

Notes: ICD-11 terms are not presented if they are the same as used in ICD-10. The ICD terms presented are those used in the United Kingdom, which differ from those used in the United States. [a]Based on ICD-11 Version 04/2019: https://icd.who.int/browse11/l-m/en; [b]it is important to note that although this diagnosis is included alongside Korsakoff Syndrome (i.e., the most comparable general diagnostic term), according to ICD-11 an exclusionary criterion for giving this diagnosis is a diagnosis of Korsakoff Syndrome or Wernicke–Korsakoff syndrome; [c]see Zhar & Pfefferbaum (2017).

also said to improve with abstinence, again unlike WKS, in which memory deficits persist long after abstinence (Oslin et al., 1998). However, the ARD diagnosis is contentious, as evidence suggests it may be caused by the same underlying pathology as WKS (i.e., thiamine deficiency), and thus those given this diagnosis may have asymptomatic WKS (Hayes et al., 2016).

One approach that has attempted to resolve some of the controversy surrounding the distinctions, or lack thereof, between ARD and WKS is the use of the term *alcohol-related brain damage* (ARBD), subsuming these conditions under one label (Heirene et al., 2018). Although some view ARBD as a conceptual category as opposed to specific diagnosis (Svanberg & Evans, 2013), diagnostic criteria for probable ARBD have been proposed that require only a substantial history of alcohol misuse, an attributable cognitive deficit or evidence of confusion, and a history of three or more hospital admissions related to alcohol misuse in the last year (Wilson et al., 2012). The latter use suggests ARBD refers to cases of alcohol-related neurocognitive impairment not meeting criteria for WKS, in a similar way to which the ARD diagnosis is used. Limited evidence indicates that this approach has started to be adopted in U.K. clinical practice (Wilson et al., 2012), although the extent to which it is employed and whether WKS and ARD diagnoses are still used instead of or alongside the ARBD label remains unknown. Gilchrist and Morrison (2005) have conducted the only examination of ARND prevalence using the ARBD label, although they did not define the disorder(s) they were studying clearly or discuss the criteria used to make diagnoses. The authors reported an elevated prevalence of 21% in a sample of hostel dwellers in Glasgow, consistent with the high rates of alcohol misuse found in the homeless population (Fazel et al., 2008).

One further approach to ARND nosology is the alcohol-related neurocognitive disorder diagnoses presented in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; American Psychiatric Association, 2013). This approach has been praised for distinguishing between the type (non-/amnestic-confabulatory) and severity (mild/major) of impairment and for its focus on the role of neuropsychological assessment in diagnosis (Walvoort et al., 2016). However, no studies have explored the prevalence of ARNDs when adopting the DSM-5's conceptualization, and little is known about whether the criteria and diagnostic terms are used in clinical practice.

Overall, the number of epidemiological studies in this field is small. Additionally, almost all studies at the population level have focused on WKS. The Royal College of Psychiatrists (2014) in the United Kingdom has suggested that WKS is a "relatively rare manifestation" and that more comprehensive investigations of prevalence are required because of the more prevalent non-amnestic changes in neurocognition that are associated with alcohol misuse and labeled using terms such as ARD or ARBD. This suggestion, combined with the heterogeneous and overlapping presentations associated with these disorders (see Heirene et al., 2018), highlights the need for a broad and inclusive approach to best understand the prevalence of clinically significant ARNDs as seen in practice. Therefore, the primary aim of the present study was to provide an estimate of ARND prevalence through a comprehensive survey of clinical, social, community, and housing services, using a broad definition that included those with WKS, ARD, and ARBD. A secondary aim was to determine the diagnostic terms and criteria (e.g., DSM-5) currently used in clinical practice.

Method

Study design

A naturalistic, period-prevalence design was used, wherein case data were collected from services retrospectively for a 2-year period (January 1, 2015–December 31, 2016). Retrospective prevalence investigations are recommended when the population prevalence of a disorder is low and there is a prolonged period between the first exposure to a hazard (i.e., alcohol misuse) and the onset of the condition (Coggon et al., 2019). The geographical area investigated included the following National Health Service (NHS) University Health Boards in South Wales: Abertawe Bro Morgannwg, Cardiff and the Vale, Cwm Taff, and Aneurin Bevan. South Wales was selected for study as a representative region that contains a range of urban (including several major cities) and rural areas and has levels of alcohol consumption similar to the wider United Kingdom (Office for National Statistics, 2018).

Initial meetings with professionals from local health and social care services were used to identify relevant services for participation and informed the study's design. For example, clinicians reported regularly supporting individuals who were suspected of having an ARND based on preliminary assessments but were yet to receive an "official" diagnosis, warranting an option for distinguishing such "probable" cases within the survey. Participants were instructed to only report probable cases where sufficient evidence existed to support this view and were required to provide supporting information for such cases (e.g., alcohol use history, areas of neurological/cognitive impairment).

Participating services

An extensive process of identifying and recruiting relevant services for inclusion in the study was undertaken (Figure 1). Based on suggestions that many individuals with ARNDs will not have presented at medical services or addiction treatment centers, or will disengage from these services (Thomson et al., 2012), a wide range of potentially relevant services were identified for participation. In total, there was a response rate

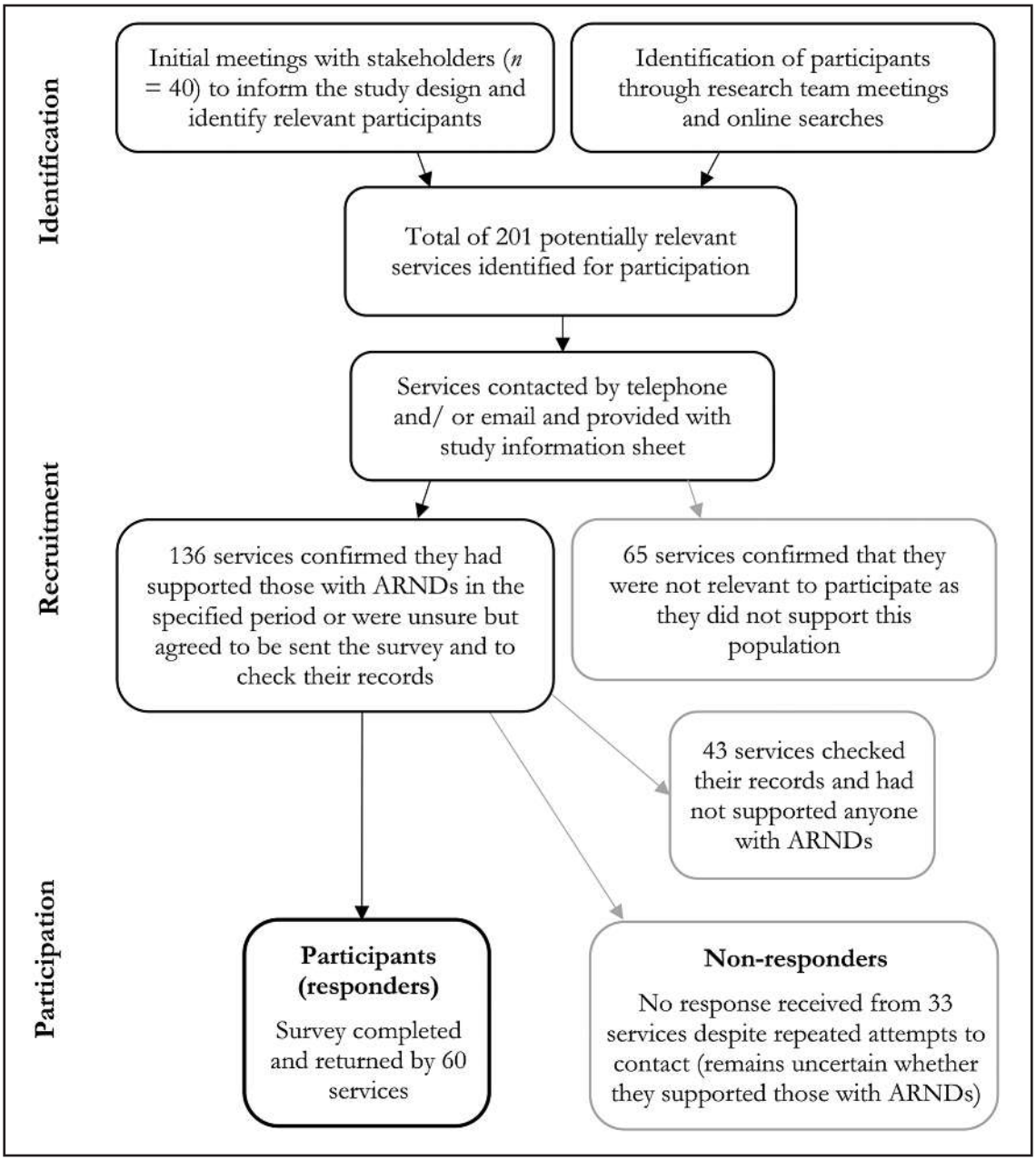

FIGURE 1. Identification and recruitment of participating services. ARNDs = alcohol-related neurocognitive disorders.

of 65% to the survey (not including all those who responded to state that they did not support anyone with ARNDs).

Table 2 displays an anonymized summary of the final 60 participating services' characteristics, along with the basic details of non-responders to allow comparisons between the two[1] (Munn et al., 2014). Most non-responding services were located in Abertawe Bro Morgannwg (there appeared to be less direct recognition of ARNDs in this region and fewer clinicians with an interest in these disorders) and were commonly care homes. Care homes that participated in the study reported an average of 3.1 cases (all services: $M = 9.1$, $SD = 11.1$). There was considerable inconsistency in the services found to support those with ARNDs across regions (Table 2).

Data collection survey

No standardized tool existed to collect case-related information for persons with ARNDs. Thus, a survey was designed specifically for this study. The preliminary case details requested were date of birth and first initial (forming a unique identifier), gender, and ARND diagnosis. Following

[1]Repeated efforts were made by the research team to engage non-responders without success.

Table 2. Characteristics of participating services

Variable	Participants *n* [location] (%)	Non-responders *n* [location] (%)
Local NHS UHB		
CV	19 (31.7)	5 (15.2)
AB	16 (26.7)	5 (15.2)
AM	15 (25.0)	16 (48.5)
CT	10 (16.7)	7 (21.2)
Service category		
Private	20 (33.3)	–
3rd sector/voluntary	16 (26.7)	–
NHS	15 (25.0)	–
Local authority	9 (15.0)	–
Service type		
Care home	6[AM], 2[AB], 2[CV], 1[CT] (18.3)	9[AM], 6[CT], 4[CV], 2[AB] (63.6)
Social services	3[CV], 2[AB], 2[CT] (11.7)	–
Recovery support	2[CT], 2[AB], 1[AM], 1[CV] (10.0)	–
Community addictions unit	2[CT], 2[CV], 1[AM] (8.33)	1[AM] (3.03)
Community mental health	2[CT], 2[AB] (6.67)	2[AB], 1[a][CV], 1[CT] (12.1)
Hostel	2[AB], 1[AM], 1[CV] (6.67)	–
Psychiatry (older adult)	2[AM], 1[AB], 1[CV] (6.67)	1[CT] (3.03)
Hospital alcohol liaison	1[CV], 1[AM] (3.33)	1[AM] (3.03)
Psychiatric hospital	1[AB], 1[AM] (3.33)	1[AM], 1[AB] (6.06)
Supported housing/wet house	1[AB] (1.6)/ 1[CV] (1.67)	– / 1[a] [AM] (3.03)
Addictions rehabilitation unit	1[CT] (1.67)	–
Adult long-term care	1[CV] (1.67)	–
ARBD care home	1[CV] (1.67)	–
ARBD clinic	1[AB] (1.67)	–
ARBD supported housing	1[CV] (1.67)	–
Domestic care	1[AB] (1.67)	–
Early-onset dementia	1[CV] (1.67)	–
Homeless nursing & GP	1[AM] (1.67)	–
Homeless outreach	1[AB] (1.67)	–
Memory clinic	1[CV] (1.67)	–
Neurology	1[CV] (1.67)	–
Neuropsychology	1[CV] (1.67)	–
Psychiatry (community)	1[AM] (1.67)	–
Gastroenterology department	–	2[AM] (6.06)

Notes: This table presents the number, location, and type of services that participated in the study. The same information is presented for non-responders—that is, services who did not return the completed survey. It is not known whether non-responders actually supported those with ARNDs during the period of interest. NHS = National Health Service; UHB = University Health Board; AM = Abertawe Bro Morgannwg; CV = Cardiff and the Vale; CT = Cwm Taff; AB = Aneurin Bevan; ARND = alcohol-related neurocognitive disorders; ARBD = alcohol-related brain damage; GP = general practitioner. [a]Represents a non-responding service that was reported to be "covered" by one or more of the participating services (determined during stakeholder meetings when identifying relevant services for participation). That is, a participating service was also involved in caring for any individuals with ARNDs that the non-responder was, and therefore their completed prevalence survey would include these cases.

this, participants were asked to provide relevant details of the diagnosis, including diagnostic criteria used (e.g., DSM-5), the procedures used to inform the diagnosis (e.g., neuropsychological assessment), and clinical characteristics related to the diagnosis.[2]

Procedures

The process of service recruitment occurred in mid-2016, and data collection commenced in January 2017, lasting until December 2017 to maximize participation. Surveys were sent via email or post to participants alongside detailed guidance relating to their completion, including DSM-5 and International Classification of Diseases–10th Revision (ICD-10; World Health Organization, 1992) criteria for ARNDs.

Ethics

As all data collected from NHS services were anonymized and there was no direct work with patients, the study was classified by the NHS as service evaluation. Approval was obtained separately from each University Health Board to carry out the study. NHS ethics applications were also reviewed and approved by the Faculty Research Ethics Com-

[2]The survey used can be accessed as supplemental material: Supplemental Document 1.

Table 3. Age and gender-specific alcohol-related neurocognitive disorders (ARND) prevalence rates

	Number of ARND cases (%)			Population of South Wales as of mid-2016[a]			Age-specific prevalence per 100,000 inhabitants		
Age, in years	Female	Male	Total	Female	Male	Total	Female	Male	Total
16–24	1 (0.20)	0 (0.00)	1 (0.20)	113,700	119,736	233,436	0.88	0.00	0.43
25–44	32 (6.53)	56 (11.4)	88 (17.9)	239,937	240,906	480,843	13.3	23.2	18.3
45–64	72 (14.7)	195 (39.8)	267 (54.5)	249,861	239,358	489,119	28.8	81.5	54.6
65–74	27 (5.51)	69 (14.1)	96 (19.6)	101,377	94,002	195,379	26.6	73.4	49.1
75–84	4 (0.82)	29 (5.92)	33 (6.73)	62,625	49,788	112,403	6.39	58.3	29.4
≥85	2 (0.41)	3 (0.61)	5 (1.02)	28,741	15,243	43,984	6.96	19.7	11.4
Total	138 (28.2)	352 (71.8)	490 (100)	965,395	936,936	1,902,331	14.3	37.6	25.8

Notes: Prevalence rates for ARNDs per 100,000 inhabitants in South Wales, including age- and gender-specific rates. Rate per 100,00 inhabitants calculated as: Number of persons with ARNDs within age group ÷ total population for age group × 10^5. [a]Estimated Welsh prevalence figures (for the four regions in South Wales studied) taken from https://statswales.gov.wales.

mittee at the University of South Wales. An application for the same study with non-NHS services received full ethical review and approval from the University of South Wales Ethics Committee.

Data analysis

Age-specific rates per 100,000 inhabitants were calculated as previous research has found that ARNDs are most common in individuals ages 55–65 years and rare in those younger than 35 (Blansjaar et al., 1987; Ma & Truswell, 1995). Gender-specific figures were calculated because of the preponderance of male cases identified in previous investigations (Carlen et al., 1994). A small number of exploratory analyses were undertaken to compare subgroups of the population (e.g., males and females), using *t* tests or, in cases where normality had been violated, Mann–Whitney *U* tests for continuous data and chi-square analyses for categorical data.[3]

Results

In total, 62 surveys were received from 60 services (2 departments from 2 services submitted separate surveys). The total number of cases reported was 548, including 40 cases reported by two services and 9 reported by three. After the removal of duplicates, 490 individuals with ARNDs remained. In the period studied, 27 (5.5%) of the 490 individuals died. Nonetheless, it is customary in period-prevalence designs to include these individuals within outcomes relating to prevalence (Coggon et al., 2019).

ARND prevalence

Based on mid-2016 population figures for the area studied (https://statswales.gov.wales), the population of those with ARNDs identified equates to a crude prevalence rate of 0.026% and an age-specific rate of 0.034% of the total population in the area studied.[4] The number of individuals in each University Health Board ranged from 82 to 216 (M = 122.5; SD = 62.7), with 216 identified in Cardiff and the Vale (160 men; 56 women; age-specific prevalence = 0.059% [age range: 20–88; 92-year-old excluded]), 97 in Aneurin Bevan (64 men; 23 women; 0.025% [age range: 27–83]), 95 in Abertawe Bro Morgannwg (71 men; 24 women; 0.040% [age range: 31–88]), and 82 in Cwm Taff (57 men; 25 women; 0.029% [age range: 29–85]).

Age and gender-specific ARND prevalence figures per 100,000 inhabitants are displayed in Table 3. In relation to age, prevalence was highest for the 45–64 age range, followed by the 65–74 range. Only one person with an ARND was identified in any of the ranges below 25. Gender-specific rates suggest that the prevalence of ARNDs was substantially higher for males than females, with an overall discrepancy of 23.3 more males per 100,000 residents and a ratio of 2.6:1.

Demographic and clinical characteristics of cases

Of the 490 individuals with ARNDs, 138 (28.2%) were female and 352 (71.8%) male. The average age was 56.2 years (SD = 12.8; range: 20–92). Females were significantly younger than males (female: M_{age} = 53.9, SE = 1.1; males: M_{age} = 57.1, SE = 0.7), $t(488) = 2.484$, $p = .013$, $d = -0.24$. Although more than half of cases (n = 274, 55.9%) were housed in some form, a substantial proportion were in, or awaiting, placement (n = 2, 0.4%) at care homes (n = 67, 13.7%), nursing homes (n = 7, 1.4%), or supported accommodation (n = 27, 5.5%). In addition, a considerable proportion were homeless (n = 69, 14.1%), residing in hostels, rough sleeping, or "sofa surfing." A small number resided in psychiatric (n = 8, 1.6%) or general (n = 2, 0.4%) hospitals. Only 8 (1.6%) were accommodated in specialized ARND treatment settings.

Some clinical description was provided for 436 (89.0%) cases, although the extent varied (ranging from detailed descriptions of symptomology and histories to short descriptions of cognition: "Other than visuospatial, all other

[3]All data were analyzed using SPSS Version 25.0 or RStudio Version 1.2.1578.

[4]This figure excludes one 92-year-old case, as age-specific population figures are only available up to age 90 in Wales.

TABLE 4. Key clinical symptoms of alcohol-related neurocognitive disorders (ARND) cases as reported by participating services

Comorbidities		Cognitive impairments		Neurological & motor control symptoms		Neuroimaging outcomes	
Condition	*n* (%)	Domain	*n* (%)	Symptom	*n* (%)	Observation	*n* (%)
Head injuries	62 (14.2)	Memory	165 (37.8)	Peripheral neuropathy	32 (7.34)	Cerebral atrophy	28 (6.42)
Psychiatric conditions	60[a] (13.8)	General cognition	75 (17.2)	Ataxia	24 (5.50)	Cerebellar atrophy	20 (4.59)
Cerebrovascular disorders	37[b] (8.49)	Executive function	51 (11.7)	Motor disorder[d]	19 (4.36)	Generalized atrophy	11 (2.52)
Alcohol-related liver disease	35 (8.03)	Fluency	22 (5.05)	Aphasia	9 (2.06)	Hippocampal atrophy	6 (1.38)
Epilepsy/seizures	30 (6.88)	Language	21 (4.82)	Nystagmus	6 (1.38)	Iron deposits (globus pallidus)	2 (0.46)
Polysubstance misuse	19 (4.36)	Attention	20 (4.59)	Perseverative speech	5 (1.5)		
Dementias [probable cases]	18[8][c] (4.13)	Planning	16 (3.67)	Incontinence	4 (0.92)		
Learning disability	7 (1.61)	Visuospatial perception	15 (3.44)	Poverty of speech	4 (0.92)		
Central pontine myelinolysis	2 (0.46)	Comprehension	8 (1.83)	Slurred speech	3 (0.69)		
Dystonia	2 (0.46)			Eyesight degeneration	2 (0.46)		
Hypoxic brain injury	2 (0.46)			Diplopia	2 (0.46)		
Brain tumor	1 (0.23)			Dysphasia	2 (0.46)		
Hydrocephalus	1 (0.23)			Impaired spatial awareness	2 (0.46)		
Fetal alcohol syndrome	1 (0.23)			Apraxia	1 (0.23)		
				Dysdiadokinesis	1 (0.23)		
				Dysarthria	1 (0.23)		
				Impaired psychomotor speed	1 (0.23)		
				Ophthalmoplegia	1 (0.23)		

Notes: All comorbidities and symptoms are reported here as they were by participating services. These figures should not be interpreted as the true number of cases with each comorbidity/symptom (actual rates may be much higher), but rather the symptoms recorded in the medical/care notes available to the professionals completing the survey. Percentages were calculated as a total of the 436 cases where some clinical description was provided (89% of total sample). [a]Eleven cases had 2 psychiatric conditions and 10 had 3—thus, a total of 91 separate psychiatric conditions were reported across the 60 cases; [b]two cases had 2 cerebrovascular disorders, meaning a total of 39 separate cerebrovascular disorders were reported across the 37 cases; [c]one case was reported as having vascular dementia and probable frontotemporal dementia, meaning a total of 19 dementia diagnoses were reported across the 18 cases; [d]unspecified motor/coordination disorder (could include ataxia).

working areas of cognition were significantly affected"). The comorbidities, cognitive impairments, neurological symptoms, and neuroimaging outcomes reported in case descriptions are set out in Table 4. It is important to note that these figures should not be interpreted as representing the absolute number of cases who experienced each comorbidity/symptom (the prevalence of each may have been substantially higher than reported in surveys), but rather as the key features as described by the professionals working in the participating services. The duration of alcohol misuse was reported for only 21 cases (4.3%), with a mean of 23 years (range: 5–50).

ARNDs reported

Of the 490 individuals with ARNDs, 256 (52.2%) were reported as "confirmed" and 217 (44.3%) as "probable" cases. The remaining 17 (3.5%) were reported as having both confirmed and probable diagnoses. The mean age for those with probable diagnoses (M_{age} = 55.1, SE = 0.9) was significantly lower than for those with confirmed diagnoses (M_{age} = 57.6, SE = 0.8), $t(471) = 2.107$, $p = .036$, $d = -0.20$. The frequency of probable diagnoses was greater in males than females, although the difference was not statistically significant,[5] $\chi^2(1) = 0.647$, $p = .471$, odds ratio = 1.2.

[5]Cases with combined probable and confirmed diagnoses reported were omitted from the two analyses reported in this paragraph.

Although most cases only had one reported diagnosis (n = 403; 82.2%), 73 had two, 13 had three, and 1 had four diagnoses (frequently, the ARBD diagnosis was given alongside more discrete diagnoses such as hepatic encephalopathy or WKS). A total of 28 different combinations of two or more of the confirmed and/or probable diagnoses were reported by services (Table 5). The most common of all possible diagnoses was probable ARBD in isolation (i.e., without any other reported ARND), followed by confirmed ARBD in isolation. Diagnostic criteria were reported for only 31 cases (6.3%), including 26 individuals with ARBD diagnosed according to Wilson et al.'s (2012) criteria for ARBD, 3 with WKS diagnosed according to the ICD-10's F10.6 code for alcohol amnesiac syndrome, 1 diagnosed with ARBD according to Wilson et al.'s criteria and the ICD's F10.6 code, and 1 diagnosed with ARBD according to Wilson et al.'s criteria and the ICD's F10.5 code for alcohol psychotic disorder.

Diagnostic process

Neuropsychological testing was the most frequently used procedure in the diagnosis of ARNDs (n = 307, 62.7%), followed by general medical assessments (n = 227, 46.3%), neuroimaging (n = 187, 38.2%), neurological cognitive examinations (n = 48, 9.8%), and specific "ARBD" assessments (n = 35, 7.1%; these were said to include a combination of neuropsychological testing, alcohol use

Table 5. Distribution of alcohol-related neurocognitive disorders (ARND) diagnoses

Single diagnoses	*n* (%)	Multiple diagnoses	*n* (%)
Confirmed diagnoses		Confirmed diagnoses	
ARBD	88 (18.0)	ARCA & ARBD	13 (2.65)
KS	57 (11.6)	ARBD & ARD	11 (2.24)
ARD	39 (7.96)	ARBD & KS	8 (1.63)
WE	9 (1.84)	KS & WE	5 (1.02)
ARCA	6 (1.22)	ARCA, ARBD, & KS	3 (0.61)
ARCI	1 (0.20)	ARCA & KS	3 (0.61)
Probable diagnoses		ARBD, ARD, & KS	3 (0.61)
ARBD	157 (32.0)	ARBD, KS, & WE	2 (0.41)
ARD	21 (4.29)	ARCA & ARCD	1 (0.20)
KS	15 (3.06)	ARCA, ARBD, & ARD	1 (0.20)
WE	10 (2.04)	ARCD & ARBD	1 (0.20)
		ARBD & HE	1 (0.20)
		ARBD & WE	1 (0.20)
		ARD & WE	1 (0.20)
		Probable diagnoses	
		ARBD & KS	4 (0.82)
		ARBD & ARD	3 (0.61)
		ARBD & WE	3 (0.61)
		ARCA & ARBD	2 (0.41)
		ARCA, ARBD, & ARD	2 (0.41)
		ARD & KS	2 (0.41)
		Mixed confirmed and probable (P) diagnoses	
		ARCA & (P) ARBD	5 (1.02)
		ARBD & (P) KS	4 (0.82)
		HE & (P) ARBD	2 (0.41)
		KS & (P) ARBD	2 (0.41)
		ARCA, ARBD, ARD, & (P) KS	1 (0.20)
		ARCA, WE, & (P) ARD	1 (0.20)
		ARBD & (P) WE	1 (0.20)
		HE & (P) ARD	1 (0.20)

Notes: This table presents the various ARND diagnoses given to the 490 cases reported by participating services. ARCA = alcohol-related cerebral atrophy; ARCD = alcohol-related cerebellar degeneration; ARCI = alcohol-related cognitive impairment; ARBD = alcohol-related brain damage; ARD = alcohol-related dementia; HE = hepatic encephalopathy; KS = Korsakoff's Syndrome; WE = Wernicke's encephalopathy.

assessment [e.g., AUDIT: Alcohol Use Disorders Identification Test], general medical testing, and examination of clinical history). The most commonly used neuropsychological tests were the Addenbrooke's Cognitive Examination (ACE-III; $n = 114$), Test Your Memory test (TYM; $n = 43$), Repeatable Battery for the Assessment of Neuropsychological Status (R-BANS; $n = 37$), Montreal Cognitive Assessment ($n = 35$), and Mini-Mental Status Examination ($n = 10$). The services involved in the diagnosis of cases were multifarious (Table 6).

Discussion

This is the first study to examine the prevalence of ARNDs and explore the various diagnostic terms and criteria used in a representative U.K. sample. A total of 490 individuals with ARNDs were reported by 60 services in South Wales, equating to an age-specific rate of 34 individuals per 100,000 residents. However, considerable variation was found across regions, age groupings, and gender, suggesting a need to consult more specific indices of prevalence. It is important to note that the estimation of prevalence derived here is likely to be an underestimate for the reasons discussed below.

Although it is difficult to make direct comparisons between the prevalence rates found here and those from existing studies, some tentative comparisons can be made. The rates found here are similar to those for WKS prevalence in The Hague observed by Blansjaar et al. (1987), the most methodologically similar study. The overall rate for the entire region investigated here was lower (25.8 per 100,000 residents, or 2.6 per 10,000) than for The Hague (4.8 per 10,000). However, rates for Cardiff/the Vale and The Hague were similar (4.4 and 4.8 per 10,000, respectively), and both locations contain a major city and had similar populations at the time of study (490,059 and 455,000 inhabitants). The greatest number and range of services participated in Cardiff and the Vale, and therefore the estimates of prevalence derived there may be most accurate.

The estimates found in this study are lower than those derived from postmortem investigations of WKS prevalence, both in the United Kingdom (0.5%) and internationally (0.4%–2.8%; Cook et al., 1998). There are several possible reasons for this discrepancy. First, most postmortem inves-

TABLE 6. Services involved in making alcohol-related neurocognitive disorders (ARND) diagnoses

Service type	*n* (%)
Community addiction team[a]	173 (35.3)
Neurology	59 (12.0)
Psychiatry services [general/ older adult]	55 [34/21] (11.2)
Hospital medical staff[b]	54 (11.0)
GP service	52 (10.6)
Memory clinic	43 (8.78)
ARBD clinic	38 (7.78)
Substance misuse social workers	20 (4.08)
Community mental health team	18 (3.67)
Addictions support (3rd sector)	11 (2.24)
Neuropsychiatry	6 (1.22)
Psychology (including neuro & forensic)	5 (1.02)
Alcohol liaison (hospital)	4 (0.82)
Early-onset dementia	3 (0.61)
Interdisciplinary domestic care team[c]	3 (0.61)
Gastroenterology	2 (0.41)
Brain injury unit	2 (0.41)
Care home[c]	1 (0.20)

Notes: This table presents the services reported to be involved in making ARND diagnoses by participating services. GP = general practitioner; ARBD = alcohol-related brain damage. [a]Includes specialist addiction psychologists and psychiatrists who were reported to have made diagnoses as these all worked within community addiction teams; [b]includes diagnoses that were reported to have been made during an admission to hospital; [c]all cases reported by these services had unconfirmed diagnoses but were thought to have an ARND by the nursing staff and/or visiting medical staff.

tigations were conducted at least 25 years ago, and prevalence levels could have decreased since. However, estimates from surveys and hospital admissions data collected during a similar period (e.g., Ramayya & Jauhar, 1997: Scottish prevalence of 0.001% in 1990) were also lower than those based on postmortem data (e.g., Harper et al., 1995: Scottish prevalence of 0.5% in 1989/90). Second, some WKS cases identified postmortem may represent non–alcohol-related forms. Although alcohol misuse may be the most common cause of WKS, the literature is replete with evidence of cases of non-alcoholic etiology (Scalzo et al., 2015), and Galvin et al. (2010) report at least 19 non-alcoholic causes of thiamine deficiency. Another possibility is that many individuals with ARNDs are "hidden" from most services or are misdiagnosed (Thomson et al., 2012), meaning that figures derived from clinical records are likely to be underestimates. Although our approach incorporated a variety of different services to maximize identification rates and we included "probable" cases, hidden cases that were yet to present at services may still have been missed. Overall, the prevalence figures derived here should be seen as conservative estimates.

In accord with previous research, a preponderance of male cases was identified (Ramayya & Jauhar, 1997). Female cases were significantly younger than male cases, consistent with Smith and Flanigan's (2000) findings and suggestions that females may be more vulnerable to the onset of ARNDs after a shorter period of alcohol misuse (MacRae & Cox, 2003; Nolen-Hoeksema, 2004). Also consonant with existing research, the average age of cases was 56.2, and most were in the 45–65 age range. However, Blansjaar et al. (1987) found only two individuals with WKS in the 35–39 age range and none younger than 34, whereas in this study 25 and 23 individuals, respectively, were identified in these age groups. The cases younger than age 35 had the highest ratio of probable to confirmed diagnoses (2.1:1) of any age bracket, suggesting that there was less certainty regarding the diagnosis of younger cases. Descriptions of younger cases and comparisons with their older counterparts were not reported here because of the wider focus on ARND prevalence, but we recommend that future research investigate the factors associated with early-onset ARNDs.

A variety of ARND diagnoses were reported by services, including WKS, ARD, and ARBD. From the diagnoses and accompanying description, it appears that the term *ARBD* is used in both the broad umbrella sense (as evidenced by the frequent use of ARBD in combination with WKS or ARD) and as a stand-alone diagnosis similar to ARD. Illustrating the latter use, one neurologist stated in a survey:

"I've labelled one of these [cases] as ARD but it could just as easily have been described as ARBD. The working diagnosis from the first consultation has been used."

Wilson et al.'s (2012) criteria for ARBD were the most commonly reported (n = 28). However, overall, few cases were said to have been diagnosed according to specific criteria (n = 31). Understanding which diagnostic criteria and terms are used in clinical practice has important implications for the direction of future research in this field, which has historically focused on WKS. As reported here, WKS appears to be an uncommon diagnosis (27.6% of all cases) when compared with ARBD (64.9%). Research is required to better delineate and define ARBD and to validate the diagnostic criteria proposed by Wilson et al. (2012) in order to justify their use in clinical practice. These findings also have noteworthy consequences for the future of monitoring the prevalence of ARNDs, as the most commonly used diagnostic approach (i.e., ARBD) reported by clinicians here is not included within the nosological system used to record hospital admissions in the United Kingdom and internationally: the ICD.

One additional finding of importance was that a substantial proportion of cases were classed as having a probable ARND diagnosis. These cases were reported to have phrases such as "probable diagnosis made by physicians following inpatient admission" recorded in their medical notes. This suggests that clinicians faced difficulties in accurately diagnosing ARNDs and is consonant with suggestions that underdiagnosis may be related to the lack of expertise in this area (Royal College of Psychiatrists, 2014). Of note, the three most commonly used screening tests in the diagnosis of ARNDs, the ACE-III, TYM, and R-BANS, have not been extensively validated for this purpose (Heirene et al., 2018), highlighting the need to evaluate their diagnostic properties

to support their continued use. The screening properties of the ACE-III and R-BANS for ARNDs were found to be acceptable in a recent small-scale study (Brown et al., 2019).

Study limitations

Although the methods used here were able to identify a large number of those with ARNDs via multiple service participation, there are several limitations that warrant discussion. First, only individuals with ARNDs known to services were able to be identified using the present methodology. Second, it remains possible that relevant services for participation were not identified. Third, some potentially relevant services identified did not return the survey, increasing the chance that some cases of ARNDs could have been missed. Whereas postmortem examinations are likely the only method that could detect individuals with ARNDs who do not engage with services, the risk of the latter two concerns influencing the present findings is low for several reasons. First, an extensive service identification process was undertaken, including meetings with relevant services and online searches. The comprehensiveness of this was evidenced by the failure to find any additional services of relevance once data collection commenced. Second, most non-responders (63.3%) were small care homes not specializing in alcohol-related support and therefore unlikely to support many individuals with ARNDs. Third, it became increasingly common for cases to be reported by more than one service as data collection progressed, with only one new case (of five) identified in the final survey returned, suggesting that a point of saturation was reached. Fourth, participants were asked to report data retrospectively for the preceding 2 years to identify any cases that disengaged from services.

Another limitation is the reliance on the assessment procedures used in routine practice to determine the validity of diagnoses. We attempted to minimize the risk of false-positive cases being reported by instructing participants to only report cases for which there was sufficient evidence to support the diagnosis, whether probable or confirmed. In addition, participants were instructed to only include cases that met the diagnostic criteria for one or more of the ARNDs presented within the survey.

Conclusions

Despite the limitations, the present findings provide a novel and updated understanding of ARND prevalence in a previously understudied area and have important practical implications. The age- and gender-specific rates reported—which have not been reported elsewhere—provide an increased understanding of populations at greatest risk of developing ARNDs and can therefore be used to prioritize screening efforts. Findings also highlight key changes in the criteria and terms used to diagnose and label ARNDs in clinical practice that appear to have outpaced research in this field. Further research is warranted to evaluate the approaches now used in practice, including the criteria (i.e., Wilson et al., 2012) and tests (e.g., ACE-III) used. Finally, future estimates of ARND prevalence could combine the methodological approach used here with hospital admissions data to provide the most accurate estimation of prevalence. Hospital admissions data may identify additional individuals with ARNDs who have been treated in other clinical settings (e.g., gastroenterology wards) without input from substance use and/or neurology services.

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Conflict-of-Interest Statement

The authors declare no conflicts of interest.

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