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# Professional Perspectives on Supporting Those with Alcohol-Related Neurocognitive Disorders: Challenges & Effective Treatment

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## ABSTRACT

We interviewed health and social care professionals ( $n = 17$ ) supporting those with Alcohol-Related Neurocognitive Disorders (ARNDs) to better understand the challenges they face and garner recommendations for effective treatment. Thematic qualitative content analysis was used to systematically analyze interview transcripts. Key challenges associated with treating ARNDs included the challenging behaviors of those with the disorders, their significant physical and mental health needs, stigmatization from others, and a general lack of understanding and awareness of ARNDs. Multiple recommendations for effective treatment were proposed, including first ensuring a comprehensive assessment and diagnostic process is undertaken that informs treatment, multidisciplinary input, and person-specific interventions.

**ABBREVIATIONS:** ARBD: Alcohol-related brain damage; ARND: Alcohol-related neurocognitive disorder; ARD: Alcohol-related dementia; AUD: Alcohol use disorder; DSM: diagnostic & statistical manual of mental disorders; KS: Korsakoff’s syndrome; NICE: National Institute for Health and Clinical Excellence; WE: Wernicke’s Encephalopathy; WKS: Wernicke’s Korsakoff syndrome

## KEYWORDS

Alcohol-related neurocognitive disorders; Korsakoff’s syndrome; alcohol-related dementia; alcohol-related brain damage; qualitative content analysis

## Introduction

Alcohol-related neurocognitive disorders (ARNDs) result from excessive and chronic alcohol consumption combined with dietary deficiencies and/or liver dysfunction (Fama et al., 2017; Ritz et al., 2016). Seven ARND syndromes<sup>1</sup> are recognized (Zahr & Pfefferbaum, 2017), including Wernicke-Korsakoff’s syndrome (WKS) and Hepatic Encephalopathy (see Table 1). Although, it is important to note that the Alcohol-Related Dementia (ARD) diagnosis remains contentious (see Heirene, John, & Roderique-Davies, 2018). Moreover, in addition to the seven syndromes, the Diagnostic Statistical Manual (DSM-5; American Psychiatric Association, 2013) refers to “Alcohol-related neurocognitive disorders”, including mild and major forms, the latter of which is further divided into amnesic-confabulatory (i.e., WKS) and non-amnesic forms (potentially reflecting ARD). The umbrella term “Alcohol-Related Brain Damage” (ARBD) has also been used to encompass the spectrum

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**Table 1.** Alcohol-related neurocognitive disorders (ARNDs).

Syndrome	Hypothesized aetiology	Characteristic clinical symptoms
Wernicke Korsakoff's Syndrome	Thiamine deficiency (TD)	Wernicke's Encephalopathy (WE): dietary deficiencies, oculomotor abnormalities (e.g., nystagmus, ophthalmoplegia), cerebellar dysfunction, altered mental state or mild memory impairment, & coma <sup>a</sup> . Korsakoff's Syndrome (KS): anterograde & retrograde amnesia <sup>b</sup>
Hepatic encephalopathy	Liver dysfunction	Personality changes (apathy, irritability, disinhibition), asterixis, disorientation, somnolence, stupor, & coma <sup>c</sup>
Alcohol-related dementia	Alcohol neurotoxicity and/or TD	An insidious decline in global cognitive function (excl. language) <sup>d</sup>
Alcohol related cerebellar degeneration	Alcohol neurotoxicity and/or TD	Decreased voluntary control of muscles (i.e., ataxia), including oculomotor abnormalities, dysarthria (i.e., disorder of speech), & difficulties with walking & balancing <sup>e</sup>
Marchiafava-Bignami disorder	B vitamin deficiency	Altered mental state, ataxia, loss of consciousness, dysarthria, seizures, impaired memory, & oculomotor abnormalities <sup>f</sup>
Central pontine myelinolysis	Rapid correction of hyponatremia	Dysphagia (i.e., difficulty swallowing), dysarthria, ophthalmoplegia, diplegia (i.e., paralysis affecting symmetrical parts of the body), an altered mental state, & coma <sup>g</sup>
Pellagra	Niacin deficiency	The 3 D's: diarrhea, dermatitis, & dementia/delirium <sup>h</sup>

Only the characteristic symptoms are presented for each disorder (others are commonly associated with each syndrome).

<sup>a</sup>Caine, Halliday, Kril, and Harper (1997).

<sup>b</sup>Arts et al. (2017).

<sup>c</sup>Ferenci (2017).

<sup>d</sup>Ridley et al. (2013).

<sup>e</sup>Fitzpatrick, Jackson, and Crowe (2012).

<sup>f</sup>Olivares et al. (2013).

<sup>g</sup>Hillbom et al. (2014).

<sup>h</sup>Zuccoli et al. (2010).

of brain damage and functional consequences occurring in those with Alcohol Use Disorders (AUDs), subsuming WKS, ARD, and others under one diagnostic rubric (Heirene et al., 2018).

Characteristic symptoms of ARNDs include cognitive dysfunction, affective changes, and motor and coordination difficulties (Arts, Walvoort, & Kessels, 2017; Sachdeva, Chandra, Choudhary, Dayal, & Anand, 2016); although heterogeneity in the degree and specific symptom types is common. Clinicians in Heirene et al.'s (Heirene, Roderique-Davies, Angelakis, & John, 2020) study of ARND prevalence reported a diverse range of symptoms among their patients, including impaired cognition (with particular deficits in memory and executive function), peripheral neuropathy, ataxia, and neuroimaging evidence of atrophy of the cerebrum and cerebellar. Comorbidities were also commonly reported, including head injuries, psychiatric conditions such as depression, cerebrovascular disorders, and liver disease (Heirene et al.). Further complicating treatment, case studies suggest that individuals with ARNDs can be non-compliant with interventions and frequently relapse, although varying levels of recovery have been documented (Carota & Schnider, 2005; Cochrane et al., 2005).

The most commonly advocated treatment for alcohol-related neurocognitive impairment is prompt thiamine administration,<sup>2</sup> given the central role of thiamine deficiency in the etiopathogenesis of WKS (Arts et al., 2017; Thomson, Marshall, & Bell, 2012a) and milder forms of ARND (Pitel et al., 2011). However, recommendations for thiamine supplementation appear to be mostly based on clinical experience as robust trials are lacking at present (Day, Bentham, Callaghan, Kuruvilla, & George, 2013). Multiple case

studies describe individuals admitted to hospital with WKS whose symptoms resolve following thiamine administration (e.g., Basoglu et al., 2014; Bilici et al., 2014; Nishimoto, Usery, Winton, & Twilla, 2017), although it is difficult to conclude thiamine was the principal factor in their recovery. Moreover, thiamine administration has not been shown to reduce every patient's symptoms (Nishimoto et al., 2017) and no associations between dose and outcome have been observed (Alim et al., 2017).

Various other interventions have also been investigated for ARND treatment. For example, a recent review of interventions for WKS concluded that two medications commonly used to alleviate symptoms in AD, memantine and donepezil, may have some value in improving cognitive symptoms, although the existing evidence for these and other medications is limited (Johnson & Fox, 2018). The neuropsychological intervention *Errorless Learning* (EL) has also been studied. Using EL, individuals are given explicit instructions and demonstrations for a task (e.g., making a cup of tea) in order to reduce the possibility of making errors in recall that could be subsequently retrieved in place of the correct response. Research with KS patients suggests EL is associated with less discomfort during the learning process (Kessels, Van Loon, & Wester, 2007), improvements in quality-of-life ratings (Rensen, Egger, Westhoff, Walvoort, & Kessels, 2017a), and an increased ability to undertake activities of daily living (e.g., cleaning) independently (Rensen, Egger, Westhoff, Walvoort, & Kessels, 2017b). Lastly, Irvine and Mawhinney (2008) investigated the effectiveness of a supported housing project in Northern Ireland for four persons with ARNDs, finding variable levels of improvement in mental and physical health and engagement with family.

The evidence discussed above highlights the variety of promising interventions that can be used as a part of ARND treatment, some of which can militate against onset of ARNDs (i.e., thiamine administration) and others that can improve the lives of those with the condition (e.g., EL). Despite this, the existing evidence base surrounding each intervention – and the treatment of ARNDs in general – is scant (Johnson & Fox, 2018; Svanberg & Evans, 2013). Moreover, as concluded by a recent systematic review of the ARND treatment literature (Horton, Duffy, & Martin, 2014), existing studies have focused almost exclusively on isolated pharmacological or neuropsychological interventions, with little research exploring how these interventions and those focused on psychosocial health can be best integrated to provide a multifaceted rehabilitation program. Finally, it has been argued that there is a lack of strategy and clinical guidance relating to ARNDs (Royal College of Psychiatrists, 2018). Accordingly, the focus of the present study was on improving the understanding of ARND care and treatment, with a focus on developing knowledge that could be used to inform more holistic interventions and clinical guidance.

Horton et al. (2014) have specifically recommended that qualitative research could bridge the gap between theory and practice and attempt to gain a rich understanding of the value of specific interventions currently used with this group. At present, however, there is a dearth of qualitative research in this field. One non-peer-reviewed paper by McCabe (2006) details reports from 12 interviews with staff from older-adult and ARND-specific care homes in Scotland. McCabe found the staff had a poor understanding of the condition and had received no formal training on ARNDs. Notwithstanding, the interviewees provided rich accounts of the challenges they faced when working with this group, including managing volatile behavior, repetitive speech, and multiple health problems. While McCabe's (2006) findings provide some insight into the treatment and management of ARNDs, multiple health and social care professionals are involved the treatment of the condition (e.g.,

psychiatrists, social workers; henceforth termed “professionals”) and thus the development of rehabilitation models and clinical guidance is likely to require a comparable level of simultaneous input. Accordingly, the present study used qualitative interviews to explore current perspectives on the care and treatment of individuals with ARNDs by a variety of professionals. Based on McCabe’s finding that there are several difficulties associated with treating ARNDs (e.g., aggressive behavior), interviews also focused on the challenges involved in supporting this group. To date, no research has directly explored and categorized these challenges, limiting the ability to put in place measures to address them.

## Methods

### Participants

Seventeen participants were recruited for interviews using purposive sampling. All were required to have worked with those with ARNDs for a minimum of one year.<sup>3</sup> Participants included Specialist Nurses (Substance misuse [ $n = 1$ ], Homelessness [ $n = 1$ ], & Alcohol-liaison [ $n = 2$ ]), Consultant Addiction Psychiatrists ( $n = 3$ ), Substance Misuse Social Workers ( $n = 3$ ), ARBD residential home managers ( $n = 2$ ), Hostel Support Workers ( $n = 2$ ), early-onset dementia Nursing Home Staff (Manager [ $n = 1$ ] & Mental Health Nurse [ $n = 1$ ]), and an Older-Adult Psychiatrist ( $n = 1$ ).<sup>4</sup> The number of participants selected within each of these professions was weighted against their relative involvement and expertise in this field. Recruitment ceased when a diverse sample of professional perspectives was achieved. Interviewees worked across four National Health Service (NHS) University Health Boards (UHBs) in Wales, UK.

### Materials

A semi-structured interview guide was developed by the research team. Interview questions were developed with the aim of eliciting information relating to: [1] the barriers and challenges currently precluding participants’ ability to effectively support or treat this population (e.g., What difficulties have you faced in supporting this group?) and [2] strategies for their effective treatment (e.g., What are the components of an ideal service for those with ARNDs?).

### Procedures

A semi-structured approach to interviews was used, providing the flexibility needed to pose a selection of core questions to all participants whilst also allowing for interviews to be guided by the specific expertise and experience of each participant. Interviews were conducted in participants’ workplaces and lasted between 36 and 113 minutes (*mean* = 55.6; *standard deviation* = 19). Interviewees were provided with a study information sheet and all provided consent to participate. Analysis of interview transcripts did not occur until all data were collected. Study approval was obtained from four local UHBs in Wales, UK, and full ethical approval was obtained from the University of South Wales’ Ethics Committee.

## Data analysis

Qualitative content analysis was used to analyze interview transcripts. This method was selected as it involves a set of clearly demarcated, ordered, and standardized steps that can be followed, thereby increasing the transparency of the process and its replicability (Bengtsson, 2016; Schreier, 2014). We followed the 8-step process for content analysis outlined by Schreier (2014).

**Step 1 – Deciding on a research question:** Two research questions were addressed: (i) What are the challenges faced by professionals caring for and treating those with ARNDs? And (ii) Based on their experience and expertise, what are their recommendations for effective ARND treatment?

**Step 2 – Selecting material:** Material from transcripts deemed patently irrelevant to the research (e.g., discussions of local weather) was omitted from analysis. All other material from transcripts was included for analysis. All excluded material was decided by RH and reviewed by a second researcher (MO) who confirmed its irrelevance.

**Step 3 – Building a coding frame:** To develop a content analysis coding frame, we initially developed two overarching categories in a concept-driven way to match the aims of the study and labeled these “Challenges associated with ARND treatment” and “Strategies for effective treatment”. A brief description was developed for each overarching category to inform the type of main categories relevant to each. Next, three interview transcripts representative of the entire dataset were selected and used to identify concepts of interest to form detailed subcategories. All subcategories were assigned a definition, indicators (i.e., key words relating to the concept), and two example quotations. As the analysis progressed and common themes or patterns emerged, subcategories were grouped to form main categories representing more abstract concepts or themes. Where two or more similar subcategories were subsumed under the same main category, these were either combined when appropriate or “decision rules” were developed to guide coding decisions (see Table 2 for example subcategories from the coding frame). The entire process of main/sub-category development and refinement was then repeated for the remaining interview transcripts.

[4] **Segmentation:** Following the initial development of the coding frame, all material within transcripts was divided into discrete units or segments. A thematic approach to segmentation was used, wherein a segment was defined as a quotation of any length that focused on one concept or theme and was demarcated by the beginning and end of the focus on this.

**Step 5 – Trial coding:** Next, the coding frame was piloted by RH and MOH using three transcripts, after which the coders met to discuss any coding inconsistencies and agreed upon any required changes to the frame to reduce future disagreements.

**Step 6 – Evaluating and modifying the coding frame:** Piloting the coding frame allowed for its subsequent evaluation in relation to both reliability and validity. The reliability of the coding frame is central to content analysis (Lombard, Snyder-Duch, & Bracken, 2002) and reflects the extent to which the analysis results from a clear and reproducible interpretation of the data (Hayes & Krippendorff, 2007), as opposed to the individual opinions or idiosyncrasies of the analyst. Krippendorff’s Alpha ( $\alpha$ ) was used to quantify inter-observer consistency (Hayes & Krippendorff, 2007; Krippendorff, 2004). Achieving a minimum of  $\alpha \geq .700$  ( $\alpha_{\min}$ ) has been advocated, although  $\alpha \geq .800$  is preferable (Krippendorff, 2004; Lombard et al., 2002). An SPSS macro for  $\alpha$  provided by Hayes and

Table 2. Example subcategories from coding frame.

Main category	Subcategory	No.	Definition	Indicators	Coding instructions & decision rules	Example units
Clinical challenges	Difficulties achieving diagnosis	22	Several participants reported that obtaining an official diagnosis for anyone with the condition was difficult for several reasons, including a lack of clinical history, the prolonged assessment period required, & difficulties in determining the cause of somebody's symptoms. Illustrating this latter point, one participant reported that it was often difficult in hospital settings to know whether somebody's confused state was the result of psychosis or some organic disorder such as WKS. The absence of an officially recorded diagnosis was viewed as a barrier to accessing adequate care & support.	Prolonged, diagnosis, confusion	Units coded here should focus on difficulties associated with determining diagnoses for this group. They should not focus on the failure to assess or poorly conducted assessments (see subcategory no. 25)	"Then the other cohort which we often see is from, again they are all widespread and, patchiness, sometimes in the acute medical units on long stay wards, sometimes even in the mental health units, where there is confusion about why this person is confused and is it caused by a psychotic illness or affective illness or is it something organic going on?" "I: And what was the diagnosis . . . ? P: It was, well, it was Korsakoffs, alcohol dementia-Korsakoffs, at the time. But that took a long, long, long, time – we're talking years and years – back and forward Mental Health, Sections"
Comprehensive treatment components	Support Independence	127	Participants recommended independence should be promoted & encouraged. One participant recalled an instance where her service had supported an individual with ARBD to travel independently in the community, gradually reducing the amount of support received with public transport over a period of time. This participant also stated that when individuals reside in residential units, they should be supported to be independent within that environment, developing their own rules & routines. It was suggested that (re-)teaching basic life skills such as cooking, budgeting, & cleaning represents an important component of rehabilitation by several participants. It was also stated that learning skills such as budgeting & cooking represent an important component of rehabilitation & promoted independence.	Independent, independence, autonomy, pride	Strategies for promoting independence are relevant to be coded here, as well as stories that illustrate this. Although a routine was said to promote independence, units only relating to routines without central reference to the promotion of independence should be coded under subcategory no. 131.	"I think, if we have to make them more socially productive individuals, then there might be a road for some vocational/employment, you know, help as well, because if you've managed to bring them to a level where they are functioning reasonably well, then every individual needs a purpose in life to do something . . . OK, the social welfare system is there to give them the benefits, but if we can, why not try and make them do some activity and take them down the work route?" "Because we joined the Headways group . . . we thought well, just try it – you don't have to go if you don't want to go, no-one's forcing you, and he's still going . . . it all helps, as I said, to promote that independence."

Krippendorff (2007) was used which produces the observed  $\alpha$  level, 95% Confidence Intervals (CIs), and probabilities values that different  $\alpha_{\min}$  levels (e.g., .700) would not be achieved if the analysis were applied to the entire dataset of units (i.e., segments coded).<sup>5</sup> Our observed  $\alpha$  for the pilot coding process (178 pairs of coded segments) was .840 [95% CIs: .788, .891] and the probability of not achieving  $\alpha_{\min}$  levels of 700, .800, .900 was 0%, 9.5%, and 99%, respectively. The validity of the coding frame in content analysis is determined by the degree to which it describes all material relevant to the research questions (Schreier, 2014). Thus, an indication of the validity of the coding frame is the number of residual categories created during the pilot phase. In the present study, only two units could not be coded under any existing subcategory, although both researchers agreed that the units contained material that was irrelevant to the research aims and therefore omitted them from further analysis.

**Step 7 – Main analysis:** In the main analysis, all transcripts were coded in full using the finalized coding frame. A further four interviews were coded by a second observer so that 50% of interview transcripts were double coded in total. A second  $\alpha$  analysis was conducted based on the outcomes from the pilot coding and main coding process combined, which showed improved interobserver consistency. Our observed  $\alpha$  (466 pairs of coded segments) was .865 [8.32, .895] and the probability of not achieving  $\alpha_{\min}$  levels of 700, .800, .900 was 0%, 0%, and 99%, respectively.

**Step 8 – Presenting and interpreting the findings:** Findings are combined with a discussion of the wider literature to best contextualize them within the current understanding of ARND treatment. Frequency counts are presented for the number of segments coded under each subcategory and for the number of individuals that referred to the concepts covered by a subcategory. Quantitative analysis of frequency differences (e.g., Chi-square) between the different professions was deemed inappropriate due to the small and unequal number of participants in these groups. A reflexive account of the data analysis process was undertaken and is reported in a Supplemental Document.

## Results & discussion

The final coding frame contained six main categories under the overarching category *Challenges associated with ARND treatment* and seven main categories under *Strategies for effective treatment*.

### *Challenges associated with ARND treatment*

Six main categories were developed to describe the key challenges associated with ARND care and treatment reported by participants. Within these, 25 subcategories were created to closely reflect and elucidate the specific challenges faced. Each subcategory, along with its respective main category, are reported in [Table 3](#) and discussed below.

#### *Person-specific challenges*

Several challenges reported were specific to individuals with the condition. For example, persons with ARNDs were said to present with significant physical and mental health needs which complicates their treatment and requires substantial medical attention.



**Table 3.** Main and sub-categories: challenges associated with ARND treatment.

Main category	Subcategory	No. of units coded	No. of participants*
Person-specific challenges	Significant physical & mental health needs	42	11
	Challenging behaviors	40	10
	Poor engagement with services	19	8
	Continued alcohol use	10	6
	Lack of insight into the condition	9	6
	Concealing or “masking” symptoms	8	5
Resource-related challenges	Current welfare system	4	3
	Lack of funding, time & resources	52	14
	Lack of appropriate treatment services	53	13
	Poor access to clinical & social care services	31	8
	Difficult to access housing	6	4
	Lack of community support services	4	3
Stigma & poor understanding	Lack of understanding & awareness	35	10
	Stigma	20	7
Clinical challenges	Failure to adequately assess & diagnose	18	8
	Difficulties in achieving diagnosis	15	7
	Poor detoxification practices	8	6
	Failure to intervene early-on	8	5
Poor care coordination	Diagnostic nomenclature	4	1
	“Nobody is taking responsibility for it”	34	11
	Lack of treatment pathway	12	10
	Inappropriate residential placements	17	8
Mental capacity issues	Poor communication between services	11	6
	Ethical considerations in capacity assessment	14	4
	Failure or inadequate assessment of capacity	10	4

\*Total number of participants for which at least one segment from their interview was coded within the subcategory (out of 14, as 3 interviews contained 2 participants whose data were conflated).

I think one of the things that we overlooked or we didn’t expect, in terms of barriers to treatment is, is things like, people’s health, physical health, very time consuming to sort those things out with them, the impact of that, not only the impulsivity, the mental health thing but, the lack of people’s ability to concentrate on things, which can, you know, within several cases, was due to pain that they were in, but until you could address that pain, it might only be possible to work with people for fifteen minutes, or so you know.<sup>6</sup>

Various challenging behaviors or characteristics were also reported, including physical violence, impulsivity, being quick to anger, unpredictability, and verbal aggression. These were reported as challenging as they hindered attempts to socially integrate individuals, prevented interventions being properly delivered, and were a risk to other patients in general hospital wards.

It’s behaviours, you see, that can be quite challenging, and sometimes because they’re random and sometimes there’s no warning with them, it can make you feel a bit (pause) stunned, if you know what I mean? And you just think “oh, where did that come from”?

Participants also suggested that individuals with ARNDs do not engage well with services in several ways: [1] they isolate themselves and do not enter mainstream substance abuse treatment services, [2] they frequently disengage by self-discharging or not attending appointments, and [3] they often refuse offerings of support or make it difficult for services to support them. Some participants attributed the failure to attend appointments to cognitive impairments, particularly memory deficits and executive dysfunction:

And if you send them an appointment, they aren't going to turn up . . . They're not going to turn up because they can't remember the appointment . . . You then look on their bloody hospital record and you've got: "Epilepsy Clinic, didn't turn up, we've discharged him"; "Gastro Clinic, didn't turn up, we've discharged him"—for God's sake! . . . they don't turn up for their appointments because they can't remember they've got them.

The continued consumption of alcohol was also viewed as challenging as this acted as a barrier to accessing appropriate housing and made accurate assessment difficult.

I think trying to get a diagnosis for anyone in the community when they're still drinking is just like a no, no, really – that's very challenging for anybody, you know? Because they're still drinking, we don't really know how much damage is really being caused. We don't know how severe the ARBD is, you know?

Moreover, some individuals with the condition, according to participants, attempt to conceal their symptoms from professionals in order to be perceived as functioning as normal. Conversely, the poor insight some individuals display into their level of impairment or the role alcohol has played in causing their symptoms was also viewed as a challenge. This, in turn, was said to be associated with poorer treatment outcomes, including relapse, as it was thought that individuals did not realize that they were using alcohol at a harmful level.

Many of the person-specific challenges identified here are consistent with reports from previous studies, including challenging behaviors (Gerridzen & Goossensen, 2014), a lack of insight (Walvoort, Van Der Heijden, Wester, Kessels, & Egger, 2016), and suggestions that this population do not engage well with services (Bell & Craig, 2013). Unique to this study, three participants indicated that the current Personal Independence Payment welfare scheme in the UK was not appropriate for those with AUDs as they receive large sums of money in a single instance (as opposed to having this money divided over several payments), allowing them to spend this quickly on large amounts of alcohol.

### ***Resource-related challenges***

Resource-related challenges were commonly reported by participants; although these were highly context specific and are therefore not discussed at length here.

. . . the number one thing is resources, and I don't think there is any dedicated resource given to the drug and alcohol services, or for that matter, to any services to cater to the needs of this population.

The lack of resources and specialized services for ARNDs reported by participants here is consonant with a history of general suggestions that UK service provision for the condition is poor (e.g., Cox, Anderson, & McCabe, 2004; Emmerson & Smith, 2015; Wilson, 2011). Specific concerns were reported regarding the clarity and applicability of NICE<sup>7</sup> guidelines, suggesting there is a need to improve clinical guidance regarding ARNDs and the prescription and administration of thiamine, in particular.

## **Stigma & poor understanding**

It was commonly suggested that the general public and professionals involved in the care and support of this group may not be aware of ARNDs or possess sufficient understanding of the condition. This, in turn, was associated with a number of the other challenges reported here, such as the failure to adequately assess and diagnose those with the condition and inappropriate residential placements. These concerns accord with the lack of understanding reported within care staff by McCabe (2006) and other reports suggesting there is a general lack of knowledge surrounding the condition (Cox et al., 2004; Mental Welfare Commission for Scotland, 2010).

If you say to members of the public “What part of the body does alcohol damage?” they’ll go “Liver”, and that’s probably as much as they’ll understand. If you say actually, it’s much more likely to affect the brain, and they don’t know that, and they ought to know that . . . I do some work with two different residential rehabs, and the one is just a sort of general one and you hear them talking about how people have behaved in group work, and their classic phrase is: “he doesn’t seem to scan properly when he’s in group” and you go: “well, maybe do you think he’s cognitively impaired then and that’s why he can’t hold on?” “He keeps saying the same thing all the time”. “Well do you want me to do an Addenbrooke’s on him, shall we do this?”

Seven participants stated that individuals with AUDs face stigma from health professionals. In the context of ARNDs, participants intimated that the consequences of this may include overlooking a person’s symptoms or only giving a cursory examination when in hospital. The negative perceptions of those with ARNDs may be even greater than for individuals with AUDs and no associated cognitive impairments. Indeed, in addition to beliefs that people “*brought the problem on themselves*” and that they do not “*deserve*” treatment (Svanberg, Morrison, & Cullen, 2015), those with ARND are likely to be perceived as “*unmotivated*” or “*unwilling*” to engage with services due to executive dysfunction and related symptoms (e.g., apathy; Beaunieux, Eustache, & Pitel, 2015).

## **Clinical challenges**

Participants reported that clinicians frequently failed to adequately assess the neurocognitive health of those with AUDs, often attributing symptoms to intoxication and not considering the possibility of more permanent impairment. The failure to assess appropriately and to reach diagnoses when appropriate may be due to lack of understanding and stigma:

. . . and very often they get pushed under the carpet, don’t they? Nobody really . . . everything’s down to drink . . . everything gets put down to drink.

You’re talking about the highest risk patient group in greater numbers, with the highest risk pattern of detox, and the highest risk taking in terms of their, their cognitive function. If you look at the discharge reasons, disengagement reasons that the services of all sectors give as being the most prevalent, it’s usually disengagement, lack of motivation, various descriptors all around the same thing, all of which when you look dysexecutive syndrome, may be explained by symptoms that reflect ARBD all and yet those patients are still not diagnosed and still not included in any sort of feedback figures.

A failure to adequately assess has been previously reported as an issue within the UK by Wilson (2013), and it has been commonly suggested that the conditions are underdiagnosed (Canaris & Jurd, 1991; Isenberg-Grzeda, Kutner, & Nicolson, 2012; Wilson, 2015). Closely

related, it was stated that obtaining an official diagnosis for anyone with a suspected ARND was difficult (see [Table 2](#)).

Some participants stated that individuals with AUDs were being detoxified without any follow-up plan in place and/or they were not receiving adequate medical support to withdraw from alcohol, including thiamine supplementation. Relatedly, failing to recognize and/or intervene early-on in the condition was said to present a significant barrier to subsequent treatment. For example, many individuals were said to be identified early in the course of their condition, but due to a lack of appropriate services, treatment pathways, and funding they do not receive prompt intervention, resulting in a progression to WE and then KS. The need to intervene early-on in the course of the disorder, particularly with thiamine administration, has been emphasized as an essential step in improving prognosis (Thomson, Cook, Touquet, & Henry, 2002; Thomson, Guerrini, & Marshall, 2012b). Combined, the concerns raised by participants highlight the need to increase the understanding and awareness of ARNDs and improve screening measures in order to enhance early identification.

One participant highlighted the inconsistencies in the way which diagnostic terms are used in relation to ARNDs and suggested that the term “alcohol-related brain damage” may be off-putting for individuals as they may view the term as suggestive of severe and irreversible damage, regardless of the true extent of the person’s neurocognitive impairment. It was suggested that the DSM-5’s alcohol-related neurocognitive disorder may be an appropriate alternative as the term appears medical, formal, and less colloquial.

I think the other problem with alcohol related problems is the terminology itself is very confusing because people talk about Wernicke’s Encephalopathy and alcoholic dementia and alcohol related brain damage and each term has a different meaning to whoever is using them . . . even the so-called official definitions of each condition sort of tend to overlap a lot, so I think the terminology is a big problem. What we actually do is we tend to talk about memory problems or cognitive problems, that are due to alcohol or that are strongly influenced by alcohol and avoid the, try to avoid the dementia word because it’s, usually it’s unhelpful, definitely avoid the brain damage word, avoid the Wernicke’s Korsakoff’s stuff because that again sort of tends to put people in a particular pigeon hole, whereas cognitive problems, memory problems related to alcohol doesn’t pigeon hole people and so it gives them lots of different access to services.

Concerns regarding confusion around diagnostic definitions have been reported elsewhere (e.g., MacRae & Cox, 2003) and the ARBD diagnostic conceptualization has attempted to alleviate some of the confusion and inconsistent use surrounding ARND diagnoses (see Heirene et al., 2018). However, if as one participant suggested, the term “brain damage” is not clinically helpful, the DSM-5’s nosological approach may provide an analogous alternative.

### **Poor care coordination**

Many participants stated that there is a lack of clarity as to who should take responsibility for this group and, as a result, many services do not want to support them as they feel it is not within their purview. Participants reported that as ARNDs incorporate symptoms relating to mental health, substance use, and physical health, it leaves services in each of these domains unsure as to which should assume responsibility for this group.

Overall, there was a sense that individuals with ARNDs “do not fit” within existing services.

I think while it's so siloed, everything's got its own silo- there's a camp over here on the one had for substance misuse, there's a camp over here for social care, there's a camp over here for healthcare, while they're all sort of ring-fenced and tribal about what their responsibilities are, the fact is that, in most cases of ARBD the patient kind of overlap, they're a new silo, a silo that kind of overlap the other 3 circles, it's the centre of a Venn-diagram really is the patient group. But because it's not exclusive within one group, they're all going: “It's him it's him, it's A”. B are saying it's A and C; A are saying it's B and C, and nobody is taking responsibility for it.

The view that ARNDs do not neatly fit within any existing healthcare specialty or service domain is a common theme in the literature (Boughy, 2007; McCabe, 2006).

Ten participants highlighted the absence of a treatment and referral pathway for people with the condition as a challenge to providing care for everyone with the condition. It was thought that people may get “lost in the system” as clinicians are unsure as to where to refer individuals with the condition. It was reported that individuals with ARNDs are often placed in older-adult psychiatry wards which were unsuitable for younger adults with the condition. Similarly, many were reported to be accommodated in residential settings that were unable to meet their particular care needs (e.g., older-adult care homes). Placing individuals in such settings was said to worsen prognosis and preclude potential cognitive remediation and is consistent with Cox and colleagues' (2004) concerns regarding the frequent need to accommodate people outside of their local UHB due to the dearth of appropriate services.

There is a need [for ARND-specific services], I mean, the unfortunate thing is, I suppose, about providing care for these clients, is they do not fit in and they do end up, in my eyes, being misplaced.

A smaller number of participants stated that poor communication between services was a barrier to providing the most effective care and support for this group. One participant stated that important clinical details were often not communicated between services, recalling an instance where she was not informed that her client had been admitted to hospital several times in recent weeks.

### ***Mental capacity issues***

Four participants described issues surrounding the ethical decision-making processes relating to capacity assessments, including the moral dilemmas associated with removing somebody's right to make their own decisions.

P1: Yeah, we are depriving them of their liberty. P2: We are depriving people, we are taking control of their finances and maybe sometimes welfare decisions, you know? That doesn't come across lightly, it doesn't come overnight either, you know . . .

Consistent with these concerns, Van Den Hooff and Buijsen (2014) suggest there is a tension between healthcare professionals' duty to act in the best interest of their patients and the autonomy of patients. Four participants highlighted the more general problems they had experienced surrounding the assessment of capacity, including a failure to assess altogether and inadequate or delayed assessments; this was said to

leave individuals with ARNDs vulnerable to abuse in the absence of adequate safeguards. Van Den Hooff and Buijsen (2014) and Van Den Hooff and Goossensen (2015a) provide guidance on assessing decision-making capacity and dealing with ethical issues that arise that could be useful for healthcare professionals involved in supporting this population.

## Strategies for effective treatment

Seven main categories were developed to reflect central themes within participants' recommendations for the effective care and treatment of ARNDs (Table 4). These main categories and their 32 subcategories are discussed below.

**Table 4.** Main and sub-categories: strategies for effective treatment.

Main category	Subcategory	No. of units coded	No. of participants*
Actively support engagement with services	Assertive outreach	8	4
	Make appointment attendance achievable	2	2
Treatment pathway	Comprehensive diagnostic process required	66	14
	Clearly defined treatment pathway required	28	8
	Early identification & intervention imperative	14	7
	Opportunities for identification	33	6
	Use a presumptive approach to diagnosis	3	2
Improve understanding & awareness	Improved awareness, education, & training required	23	8
	Clear & consistent definition of ARBD needed	2	2
Multiservice approach	Input from multiple services required	41	13
	ARBD-specific services required	22	10
	Supported accommodation	13	7
	Use a harm-reduction approach when necessary	11	6
	Use of wet houses	9	5
	Bottom-up service development may be required	8	3
Comprehensive treatment components	Promote independence	15	9
	Promote abstinence whenever possible	17	7
	Foster relationships with family & friends	16	7
	Treatment should be multifaceted	13	7
	Utilize neuropsychological interventions	15	6
	Improve nutritional status	7	6
	Support engagement in hobbies & leisure	10	5
	Treat with dignity & respect	7	5
	Normalize care environment	13	4
	Implement a daily routine	7	2
	Use appropriate pharmacological interventions	3	2
	Promote physical activity	2	1
Tailored approach	Person-specific care required	24	9
	Tailor communication according to cognitive capacity	14	7
Miscellaneous strategies	Improve Pabrinex provision	10	6
	Changes in alcohol-related policy & perceptions required	9	5
	More research & improved clinical guidance required	3	2

\*Total number of participants for which at least one segment from their interview was coded within the subcategory (out of 14 participants as 3 interviews contained 2 participants whose data were conflated).

### **Actively support engagement with services**

One suggestion to overcome the poor engagement with services seen in this group was to use an assertive outreach approach. This included making home visits (rather than making individual attend services), assisting individuals to attend appointments by arranging travel for them or sending reminders, or taking them to pick up prescriptions. Corroborating these suggestions, research supports the use of text message reminders for increasing attendance at addiction services (Gullo, Irvine, Feeney, & Connor, 2018; Milward, Lynskey, & Strang, 2014), though no research has focused on ARND patients specifically. There is a need for more direct research exploring strategies that could increase engagement in treatment, including those recommended here.

... she didn't want to engage with us, so we kept going back, kept going back ... so I think we are perhaps more persistent because we can get out there. A home visit, I think, gives us the opportunity to do that ... so that's what we will do, that probably isn't in the job description: we will go and get someone to that appointment and support them there, because we want to move this on otherwise things don't get move on.

A second method suggested by participants was to make appointments as easy as possible for individuals to attend given their particular circumstances. For example, if having regular appointments, setting appointment times on the same day and time consistently was said to improve the prospective memory for attendance. Similarly, asking individuals to attend appointments far away from their home without travel assistance was seen as likely to result in nonattendance.

### **Comprehensive treatment pathway**

Eight participants gave suggestions as to the types of care and support individuals with ARNDs should receive at different points in their recovery. Considering all of the suggestions together, the standard treatment pathway recommended by participants included: a preplanned, medically assisted detoxification, a period of assessment whilst being physically and mentally stabilized in a supported residential environment, continued support within this environment until reaching a level of independence at which the person may be able to support themselves more independently, and return home with or without domestic care support or decreased support in a “*step-down*” facility.<sup>8</sup>

You've got to have the whole bang shoot, you've got to have your primary prevention, your secondary prevention, your treatment and your aftercare, and it's got to be, you know, a nice seamless little pathway if you could. The importance of not pitching people into alcohol withdrawal when they don't need to because, you know, the damage it does to the brain ...

While the focus of interviews was on care and treatment, almost all participants referred to the assessment and diagnosis of ARNDs. It was suggested that a comprehensive assessment process is required for accurate diagnosis and to inform treatment options. Combining the recommendations, the components of a comprehensive diagnostic process should include assessment of decision-making capacity, repeated neuropsychological testing, nutritional assessments, neuroimaging (with a preference for MRI over CT scans due to their greater sensitivity to alcohol-related lesions), and functional assessments that can inform the understanding of a person's ability to live independently.

Multiple participants highlighted the importance of identifying ARNDs early in their course to prevent further deterioration and using prophylactic thiamine supplementation. The use of thiamine as a preventative measure for ARNDs has been recommended by Kopelman, Thomson, Guerrini, and Marshall (2009) but has been poorly studied to date (*cf.* Erhabor, Keaney, Gossop, Guerrini, & Morinan, 2011). Potentially facilitating early identification, two participants recommended the use of presumptive or provisional diagnoses, which is illustrated by the below quotation:

I think rather than it being an exclusive process of excluding everything else before the diagnosis is made, I think there is a place for provisional diagnosis, a likely diagnosis, and then step down if that is excluded. Once you've excluded the more acute, obvious infection, you know, high urea . . . you can then, with the history combined and the behavioural pattern known, you can then reasonably assume that it's a likely ARBD and apply the Mental Capacity Act . . . and start treatment. If at some point later on in the assessment process it becomes apparent that it is something else, that there is another dementia etcetera . . . that diagnosis can change . . .

Six participants directly referred to opportunities for identifying those with ARNDs, including during hospital admissions, in General Practitioner (GP) surgeries, or via police referrals. For example, multiple Police Protection Notices for one individual<sup>9</sup> was said to be characteristic of someone with an ARND. Despite being an ideal opportunity for screening, current rates of identification during GP appointments and hospital admissions were thought to be low due to the lack of awareness of the conditions.

### ***Improve understanding & awareness***

Eight participants recommended knowledge of the condition should be improved through better education and access to training.

You may have to intervene first—training, education, right across the whole NHS workforce and the allied non-NHS workforces to make them aware of ARBD . . . there's a lot of homework to be done.

Thomson et al. (2012b) have suggested the NICE (National Institute for Health and Clinical Excellence, 2010a, 2010b, 2011) guidance on alcohol-use disorders can be used to structure training and increase the identification of alcohol-related harms; although these guidelines were criticized by participants here for a lack of specification regarding thiamine administration and dosing.

Two participants suggested that there appears to be some confusion and inconsistency amongst health and social care professionals regarding the definition of ARBD,<sup>10</sup> consistent with Heirene and colleagues' (2020) finding that UK clinicians appear to apply the term in different ways. It was recommended that a clearer definition and/or classification system for the condition is required in order to ensure clear communication between services, including an acknowledgment that it can be heterogeneous in presentation.

I think there's a little bit of, I think if we just had accepted, more widely publicised accepted criteria, I don't know, maybe not criteria, like accepted diagnostic tool or, I don't know, but the thing is in medical circles there's some confusion around that. I also think that practically, on a service level, there's a lot of confusion about the kind of people I think we're all talking about, slightly different groups of people.



### **Multiservice approach required**

According to thirteen participants, the adequate care in support of this group requires the coordinated input of multiple services. It was recommended that a multidisciplinary team should be developed to support this group and guide their care from identification in hospital onwards, and a mixture of clinical and community services should be involved. The value of social services was highlighted due to their role as care coordinators and their ability to refer individuals to relevant services and support them to engage with healthcare services. The use of domestic care services was also frequently promoted to support individuals within their own home.

It's obviously going to be a mixture of community and in-patient sort of scenario, but then all of that would be important to bring in multiple disciplines; it's not just one person's baby, it has to everyone's responsibility, really

The development of specialized ARND services was viewed as necessary in order to adequately support this group. The features of a specialized residential service, according to participants, should include well-trained staff and an appropriately designed environment for people with cognitive impairment. In the literature, several researchers have argued that standardized care homes and dementia services are not able to adequately meet the needs of younger adults with ARNDs (e.g., Cox et al., 2004; Kopelman et al., 2009). Although, it is also important to note that two participants here deliberated over whether it is necessary to have specific services for this group and suggested that well-trained extant services (e.g., care homes, older adult psychiatry) may be sufficient.

So, I would argue that the nature of complexity is the measure of damage. The nature of assessment and their needs that need to be managed—there needs to be dedicated services for this group of people.

Seven participants specifically recommended that supported-living facilities were a key component of the treatment pathway for individuals with the condition following more intensive rehabilitation. Irvine and Mawhinney (2008) found improvements in the general health of four individuals with KS in a supported group living arrangement. However, there is a need for further research to determine the value of supported accommodation for ARND treatment relative to other options, such as assisted living in the community.

but it's when they come out is the problem. Because where do they come out to? What we really, really, really need is supported accommodation for people where the support workers understand ARBD and know what to do with it, because OK, some of them can go home, they've got support from family, others might need full blown care home or whatever, but there's the ones in between that can still be a bit independent but they need a bit more support, they need somebody checking on them, somebody checking that they're taking their medication, that kind of thing. That's what we haven't got – these supported accommodation things – so that's a big gap that we've got, and you can keep people relatively independent for a few more years, well, for ever, but otherwise they go home, they get worse, we detox them again and then they go in a care home. So, it's . . . A waste of time and a waste of money.

A harm-reduction, as opposed to rehabilitative, approach was recommended by participants in certain circumstances. It was suggested that for those unwilling to engage more comprehensively with services, this approach may prevent further neurocognitive decline and improve the quality and duration of peoples' lives. Relatedly, the value of *wet houses*<sup>11</sup>

in supporting this population was a contentious subject. Some interviewees suggested they may be a valuable harm reduction tool, while others suggested individuals are unlikely to receive adequate support in such services and that they may be vulnerable to abuse there. The limited existing research suggests wet houses lead to decreased levels of consumption and public-service-use costs when compared with waitlist controls (Collins et al., 2012; Larimer et al., 2009). Providing training and education relating to ARNDs to wet-house staff, as recommended here, could increase their value as a harm-reduction tool.

... people go to a wet house because they're not prepared to stop drinking. They develop the consequences of drinking constantly, so they frequently develop alcohol-related brain injuries and then, at that point, we have nowhere for them to go and we find it incredibly difficult to get them care ... if we have wet houses, then we really ought to have the situation where they are wet houses where care can be given, that we don't evict people for developing the symptoms of alcohol-related brain injury, but we simply keep them there, acknowledge that that's what it is, and then be able to have care and support for the person in that environment. Moving them out or evicting them and having them living on the streets is not the answer.

More broadly, three participants suggested that it may be necessary to develop services for this group in a bottom-up manner, by recognizing and filling the need for services for this group. Participants viewed direct government investment as preferable to this approach but suggested this was unlikely.

The money isn't there and no-one's forward thinking enough to say 'well, it is costing it all of this, if we can prevent hospital admissions with these people by creating a safe place, it would save, it would pay for their placement'. But unfortunately, health and local authority aren't as forward thinking as that, so it takes a charity or some organisation to go "oh, let's have the guts and the bravery and the financial backing to think we'll do it", and then there is somewhere for them to go.

### ***Comprehensive treatment components***

And once you have actually diagnosed things, then the management essentially depends on keeping alcohol out of the system, but then the other bits begin; the psycho-social needs, the biological needs, you know, if there's any comorbid problems, anxiety or depression, physical health problems, nutritional aspects.

In addition to recommending a variety of specific interventions, seven participants suggested that the treatment of ARNDs needs to be multifaceted to meet the requirements of this group. Specific treatment components recommended included the promotion of independence (see [Table 2](#)), abstinence, and the importance of supporting social integration with family and friends. Participants also referred to the difficult situation faced by family members of those with ARNDs and recommended they be educated and supported alongside the individual. Family members were viewed as an essential part of the treatment and recovery of individuals and were able to assist with care.

Sometimes families can be supportive in that way, if they need to go to hospital for something, or perhaps their behaviour is off that day and you are trying to analyse, what is it that is making them feel that way is it, full moon, is it that they are coming up to an anniversary we are unaware of?

The importance of promoting healthy relationships with family members was highlighted by Irvine and Mawhinney (2008) based on their observations of a supported accommodation unit for KS; although, they reported that family contact was sometimes distressing for individuals who found it difficult to accept their living situation. Cox et al. (2004) also promoted the need for social integration in this population as they suggest their cognitive impairment and related characteristics can lead to exclusion from families and social groups.

Neuropsychological interventions were recommended by six participants. A variety of specific strategies were promoted or reported to be in use currently, including EL, “*brain training*”, and memory training exercises. One participant also recommended integrating cognitive rehabilitation exercises into daily activities:

One of our most recent, patients, it was quite clear he absolutely abhorred the context of being in a classroom situation, and anything that smelled of that. So, all those exercises were carried out in the context of daily living, so, for example, if he went out shopping with a support worker, she would be asking him to remember the names of the streets they had just walked down or went to, he would be asked to remember the names of the things on the shopping list, and for him to make the order and, you know, choose the things in the shop from his memory . . .

As discussed earlier, the use of EL in this population has been shown to have value in improving quality-of-life and engagement in activities of daily living (Rensen et al., 2017a, 2017b). However, to date, specific cognitive training exercises have not been studied in the context of ARNDs and have shown limited value in improving treatment outcomes for those with AUDs (Wiers, 2018), suggesting further research is warranted before the inclusion of these programs within ARND rehabilitation.

Participants also recommended that environmental modification or compensatory techniques be used with this group, including the use of whiteboards, calendars, diaries, and reminders on mobile phones – these were said to promote routine and support recall of daily tasks. These methods have shown value in for KS (Lloyd, Oudman, Altgassen, & Postma, 2019; Oudman, Nijboer, Postma, Wijnia, & Van Der Stigchel, 2015) and traumatic brain injury rehabilitation (Barman, Chatterjee, & Bhide, 2016). One particular strategy thought by participants to compensate for the memory deficits of this population was the use of brief prompts and reminders by care staff. In particular, one participant suggested that regular prompts and reminders to undertake activities (e.g., phone family) are required to ensure their completion and that reminders should be close to the time the activity takes place.

Six participants referred to the importance of improving nutritional status in those with ARNDs and AUDs in general; not only in relation to thiamine but also other vitamins and minerals such as magnesium. One participant recommended individuals with ARNDs should be encouraged to engage in physical activity in order to improve their physical and mental health. Relatedly, five participants suggested that it was important to support engagement with leisure activities and hobbies, including sports, social events, and artistic activities. Supporting engagement with these activities was strongly connected with the other subcategories reported here as this was thought to promote social integration, independence, and be related to the development of a “*homely*” care environment.

Four participants recommended that residential settings for those with the condition should be made to feel “*homely*” and “*normal*” for the residents, avoiding an “*institutionalized*” environment. It was believed that individual should be given the same opportunities and quality of life that they would expect if living independently, including engaging in activities they find enjoyable. This finding is consistent with reports from individuals with KS in Van Den Hooff and Goossensen (2015b) who disliked institutionalized environments. Strongly connected with the normalization of residential homes was the recommendation by participants that residential services should have only a small number (3–5) of those with ARNDs living together at any one time, enabling personalized care and minimizing interpersonal conflict. Including a routine within residential settings was also recommended as it was said to promote a “*normal*” environment, teach scheduling, and maintain cleanliness and personal hygiene.

Five participants stated that treating persons with ARNDs with dignity and respect and avoiding stigma is essential. This also included suggestions that it is important to maintain a calm and respectful attitude in the face of challenging behavior whenever possible.

I’m getting philosophical here, a little bit . . . but at the end of the day they are human beings and if the approach can be just like any other human being who has a problem without judging or putting that stereotyping in place, then things could probably be far better than what they are.

Two participants discussed pharmacological interventions that they had found helpful for individuals with AUDs. The gamma-aminobutyric acid (“GABA”; i.e., an inhibitory neurotransmitter) agonist baclofen was recommended by one participant for support during withdrawal, for reducing cravings and anxiety, and improving sleep quality. While clinical experience should be respected, a Cochrane review and meta-analysis concluded that there was insufficient evidence to draw conclusions about the efficacy and safety of baclofen for the management of withdrawal (Liu & Wang, 2017). Additionally, a recent Cochrane review and meta-analysis conducted by Minozzi, Saulle, and Rösner (2018) to explore the efficacy of baclofen for reducing consumption in individuals with AUDs found little difference between baclofen and placebo; although, it was suggested that some randomized control trials have shown promising results. A second participant here highlighted the value of using non-specified *pro re nata* (“PRN”; i.e., as required) medication as a means of calming distressed patients. However, it has been suggested that psychiatric medications may be overused to manage behavior in this group (Gerridzen & Goossensen, 2014). Overall, there is a need for further research regarding the value of pharmacological interventions for the specific treatment of ARNDs.

### **Tailored approach**

There’s going to be commonalities, but there needs to be flexibility because each individual is going to have different needs and different rates of progress or not and it’s those issues particular to them.

It was recommended that the specific intervention selected for each person should depend on their clinical presentation. For example, participants suggested that some individuals are able to live in the community with minimal support, whereas others require long-term institutionalized care due to severe memory dysfunction and/or executive control

difficulties. Additionally, it was suggested that support should be tailored to the person's needs, abilities, desires, and interests, and that it is essential to get to know each individual in order to facilitate this. Similarly, seven participants stated that communication with individuals who have ARND should be appropriately matched to their cognitive ability in several ways. The use of prompting was advocated to promote engagement in daily activities, along with a particular approach to phrasing questions that circumvented any issues with low motivation:

... a lot of our patients have had social care packages, so they have care assistants going into the home ... and they don't know how to respond to somebody with ARBD. So, the classic example we had is a guy living in warden accommodation and he had lovely support workers going in three times a day, but they would say to him "do you want a bath?" And he'd go "no". Now, people with ARBD choose the line of least resistance when you question them. When he then transferred to the nursing home, they would say, "your bath is running, [named removed]" and he'd go "OK then", and he'd go and have a bath, because they understood that that is how you encourage people with ARBD to do things, because if you give them the options they'll choose the easiest option.

Moreover, two persons interviewed from one service stated that it was important for their service to separate individuals with ARNDs from those without during therapy sessions due to the differences in cognitive capacity between them. Another reported strategy was to break down tasks into manageable phases so as not to overload individuals with the condition and, similarly, to not ask that multiple tasks be completed at one time.

### **Miscellaneous strategies**

Improving the provision of Pabrinex<sup>12</sup> in hospital and the community was seen as imperative in order to reduce the onset ARNDs. For example, one participant suggested that those with the condition or thought to be at risk of developing it should be regularly visited in the community and "*topped up on Pabrinex*". Participants also recall instances where administering Pabrinex had improved outcomes for patients:

... so working with A & E, and actually, I was there for two years and, literally, in the first month I saw Wernicke's several times, and in the last six months I didn't see it, because people were having Pabrinex as soon as they came into hospital, so it was preventing the onset of the acute kind of condition.

As discussed, clinical experience and case studies support the use of thiamine as a treatment for WKS, though only when administered parentally (Thomson et al., 2012b). The use of *parenteral* thiamine in Wales (Emmerson & Smith, 2015), England (Day et al., 2010), and other countries (Day et al., 2015) has been found to be poor, indicating a need to promote its use and increase the understanding of why this administration method is required.

Five participants suggested that broad, systemic changes to the way alcohol is sold, perceived, and legislated are required. They advocated minimum unit pricing or general increases in the price of alcohol, banning certain types of alcohol, as well as changes in perceptions regarding the "*normalization*" of alcohol consumption. One participant suggested that there was a need for greater clinical guidance relating to ARND, including improved NICE guidance:

We need NICE guidance which says this is how you deal with alcohol-related brain injury . . . There's nothing . . . That's fairly typical when it comes to dependency issues, that's often a challenge, not one I like.

Another participant suggested that there is a need for greater research on the subject of ARNDs, particularly regarding the efficacy of neuropsychological interventions.

## Study limitations

The present study is limited by the exclusion of professionals from other specialties (e.g., gastroenterology) and from geographic locations outside of the UK, decreasing the transferability findings. Professionals from other specialties and those based in other locations could experience alternative challenges when supporting this group, the latter due to differences in service design or available resources. However, as discussed, many of the challenges reported by participants here were consonant with those reported in the literature, suggesting a degree of similarity between the professionals interviewed here and others working with this population.

It is also important to note that some of the challenges and recommendations reported by participants may not be applicable to all of those with ARNDs, given the considerable degree of diversity within this cluster of conditions. Indeed, more short-term disorders such as alcohol-withdrawal delirium and the acute phase of Wernicke's encephalopathy – which are sometimes classed under the ARND and ARBD umbrellas – are likely to require substantially different management strategies than someone in the chronic phase of KS, which was often the focus of participants' experiences and suggestions for treatment.

## Conclusions

This is the first study to attempt to understand the effective treatment of ARNDs and the challenges associated with trying to achieve this from multiple professional perspectives. The most commonly reported challenges were resource-related obstacles (e.g., lack of funding & appropriate treatment services), the significant physical and mental health needs of individuals with the condition and the challenging behaviors they display, the lack of understanding and awareness of the ARNDs, and the lack of clarity as to which services and specialties are responsible for treating this population. The most frequently reported strategies for effective treatment were the use of a comprehensive assessment process to ensure accurate diagnosis and inform treatment options, the need for coordinated input from multiple services, the development of a clearly defined treatment pathway with designated services at each phase, individualized care and treatment programs, improved education regarding ARNDs, and the development of specialized ARND services.

Our findings provide important insights into the unique challenges faced by professionals working with this population and how they can be overcome, making them of direct value to health and social care workers in this sphere. Further, the detailed accounts presented and discussed here can be used by clinicians and policymakers to inform the development of ARND treatment pathways, comprehensive rehabilitation programs, education and training curricula, clinical guidance, and policy, all of which are lacking at present.

## Notes

1. As comprehensive overview of each of these syndromes is beyond the scope of this article, interested readers are referred to the articles cited in the footnote of Table 1 relating to each syndrome.
2. Preferably parenterally as opposed to orally due to alcohol-induced reductions in absorption.
3. Although only one year of experience was required for participation, all participants had worked with those with ARNDs for a minimum of two years.
4. The demographic details of participants were not directly related to the research aims and therefore we did not record them.
5. Confidence intervals for  $\alpha$  and  $p$  (probability) values calculated from 10,000 bootstrap samples.
6. Quotations are not linked to participants' names or job titles to ensure anonymity.
7. NICE: National Institute for Health and Care Excellence – evidence-based recommendations for health and care in the UK.
8. The treatment pathway was said to be indefinite and the time spent in each phase is likely to vary from person to person.
9. Typically, these PPNs were referred to social workers.
10. ARBD was the term most frequently used in practice and by participants.
11. Supported accommodation wherein alcohol consumption is permitted, and minimizing alcohol-related harms is prioritized above abstinence.
12. A vitamin complex containing thiamine.

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## Disclosure statement

The authors declare no conflicts of interest.

## Data availability

Data from transcripts are not available in full due to anonymity and confidentiality concerns. All interviewees participated under the expectation that their entire interview transcript would not be shared outside of the research team.

## Author contributions

RH, BJ, IA, and GR-D were involved in the conception and design of the study. RH conducted all interviews. RH and MO analysed and interpreted findings. RH drafted the manuscript and all authors were involved in revising it in preparation for publication. All authors have read the final manuscript and agree to be accountable for all aspects of the work.

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