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# **Rapid Evidence Review**

## **Dual diagnosis, double stigma: a rapid review of experiences of living with alcohol-related brain damage (ARBD)**

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## Foreword

In developing its future programme of grant-funded research, Alcohol Change UK wished to explore what is known, and what is yet to be understood, in a series of key areas, as follows:

- Topic one      The role of alcohol in intimate partner relationships
- Topic two      The impact of alcohol on the human brain
- Topic three     Alcohol interventions and the criminal justice system
- Topic four     The relationship between alcohol and mental health problems
- Topic five      Drinking problems and interventions in black and minority ethnic communities
- Topic six      Digital interventions to reduce alcohol related harm

These areas were selected through stakeholder engagement and consultation, as well as 'horizon-scanning' the research, policy and practice environment to identify where particular gaps appeared.

Rapid evidence reviews were commissioned on the six topics and their findings will allow Alcohol Change UK to synthesise knowledge on this particular range of subjects. This will help inform its own work, as well as leading to outward-facing publications that will allow the public, practitioners and policy-makers to better understand the research in these key areas.

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## Institutional details

The University of Edinburgh is a global university, rooted in Scotland. It is globally recognised for research, development and innovation and has provided world-class teaching to students for more than 425 years. The University of Edinburgh is the largest university in Scotland with over 39,000 students and over 9,700 full-time equivalent staff. The University of Edinburgh is a founding member of the UK's Russell Group of leading research universities and a member of the League of European Research Universities.

Nursing Studies at the University of Edinburgh, established in 1956, was the first academic department of Nursing in Europe. The department is part of the School of Health in Social Science within the College of Arts, Humanities and Social Science (CAHSS). Nursing Studies at the University of Edinburgh engages in innovative social science research which aims to improve patient and family experiences, develop practice and enhance nurse education through both empirical and conceptual research. Drawing on a diverse range of methodologies and theoretical approaches, the interdisciplinary research impacts on policy, health and social care delivery and interventions. The purpose is to optimise the health potential of individuals and populations in local and global contexts and make a difference in people's lives.

## Acknowledgements

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This report was funded by **Alcohol Change UK**. Alcohol Change UK works to significantly reduce serious alcohol harm in the UK. We create evidence-driven change by working towards five key changes: improved knowledge, better policies and regulation, shifted cultural norms, improved drinking behaviours, and more and better support and treatment.

Find out more at [alcoholchange.org.uk](https://alcoholchange.org.uk).

Opinions and recommendations expressed in this report are those of the authors.

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## Executive summary

Chronic alcohol use can cause temporary or permanent damage to the brain, captured under the umbrella term alcohol-related brain damage (ARBD) or alcohol-related brain injury (ARBI) (Royal College of Psychiatrists, 2014). ARBD is thought to be under-diagnosed and can go unrecognised by health professionals as those living with the chronic effects of alcohol on the brain do not fit within many existing care services (Brighton et al., 2012). From a health economics perspective, lack of specialised services may increase the burden on the health system, as patients are frequently presenting in A&E, primary care and mental health services. Service provision is variable across the country but services for those with cognitive impairment under the age of 65 years often excludes those whose impairment is related to alcohol and ARBD input is often offered in an 'ad hoc' fashion at the time of crisis (Place 2014). The experience of living with ARBD and engaging with ARBD services is poorly understood, contributing to a 'dual stigma' of both alcohol problem and cognitive impairment.

### Objective

This rapid review aimed to explore the experience of living with ARBD and the associated treatment or support offered. The literature was reviewed to find what models of care exist and what professionals and/or patients with ARBD consider best practice.

### Method

The literature search strategy was developed with input from an Academic Support Librarian. Database searches were conducted in five bibliographical databases and results were screened by two researchers. Of 864 identified records, 39 were selected for full-text screening. Hand and Google Scholar searches added a further seven papers to the screening. Following full-text review, nine papers were included in the review.

### Findings

Nine papers were included the review demonstrating the dearth of literature about the experience of living with ARBD and experience of service provision for the ongoing cognitive effects of alcohol-related harm. Studies focused on specific service developments and redesign (Dawber 2010; Irvine & Mawhinney 2008; Rota-Bartelink & Lipmann 2007 & 2010; Wilson et al., 2012) as well as more specific aspects of the ARBD experience such as memory, personal narratives, loneliness and knowledge (El Haj & Nandrino, 2017; Keady et al., 2009; Oudman et al., 2018; Van den Hooff & Goossensen, 2015). Findings are presented around three key themes:

- Specific service requirements
- Ongoing insight about experience
- Staff education and training

## **Specific service requirements**

Studies report the experience of those living with ARBD and their support in a range of innovative services. The complexity of the client group was reported consistently across studies from a range of settings (Dawber, 2010; Irvine & Mawhinney 2008; Rota-Bartelink & Lipmann, 2007; Rota-Bartelink & Lipmann, 2010; Wilson et al., 2012). The importance of staff building relationships with service users in order to provide meaningful support and activity was important (Irvine & Mawhinney, 2008). Relationships between service providers and professionals involved in care were also considered important in shaping both individually tailored services and service organisation (Dawber, 2010; Wilson et al., 2012). The importance of appreciating different stakeholder views, for example in relation to perceptions of risk, is central to the development of both meaningful relationships and ultimately successful services (Keady et al., 2009) and shaped the development of innovative inpatient services (Rota-Bartelink & Lipmann, 2007; *ibid.*, 2010) and community rehabilitation initiatives (Wilson et al., 2012).

## **Offering insight about experience**

Person-centred approaches to care prioritise the views of individuals in shaping their own care and have become integral to health care provision worldwide. Van den Hooff and Goossensen (2015) found that those living with ARBD had their own, previously unheard, views of their situation and of their world within the care setting. They could articulate those views, offering insights which have potential to shape staff responses and facilitate responsive care services. The importance of attending to insights from patients and service users was also highlighted in work by Oudman et al. (2018) who explored loneliness in those living with Korsakoff's syndrome. These two studies, both carried out in the Netherlands, highlight the importance of exploring experience in shaping both care practice and also future service development. Personal identity is also central to the way individuals see themselves and their lives. Keady et al. (2009) report a detailed narrative account of the lives of those living with ARBD, highlighting the adjustments to personal identity required by memory deficits and by the fracturing of relationships resulting from alcohol use. Keady et al.'s (2009) study demonstrated the importance of staff responses and understanding of the perspective of the service user in facilitating an effective supportive relationship.

## **Staff education and training**

Interaction with those who have ARBD and the process of gaining insights into their personal experience, memories and perspectives on care raises important issues for staff education and training. Communication skills are central to successful interactions which can be complex in the case of individuals who may confabulate or demonstrate very short periods of lucidity (Keady et al., 2009; Oudman et al., 2018; Van den Hooff & Goossensen, 2015). Wilson et al. (2012) emphasises the need for services to promote rehabilitation with a design which gradually facilitates the independence of the service user while Keady et al. (2009) highlight different constructions of risk between service users and professionals. Both interpersonal and interprofessional communication require specific training and education if their potential to inform service provision is to be realised. Education to increase professional awareness of the potential for recovery in ARBD and to promote meaningful engagement with those living with the condition offer opportunities to address stigma and develop future service provision.



## **Conclusion**

The findings of this review demonstrate a very limited field of literature addressing either experiences of people living with ARBD, or of those providing services and support to that population. This is particularly disappointing in the context of increasing personalisation of healthcare services worldwide. The literature highlights the complexity of the lives of those living with ARBD in terms of both social situation, comorbidities and engagement with services. Understanding these life experiences should be a research priority in order that future service provision, support and interaction can effectively meet the needs of individuals and their families. Staff supporting this population who live with the dual stigma of cognitive impairment and alcohol problem require education and training in order to meet patient/client needs. Much of this education should focus on understanding the experiences and perspectives of those living with ARBD in order to inform approaches to care. Developing innovative ways of engaging with complex health and social care needs, promoting a rehabilitative framework and initiating person-centred approaches to care have the potential to facilitate both recovery and improved quality of life in this vulnerable population.

## Introduction

Alcohol is a leading cause for mortality and morbidity on a global scale; in Europe alcohol causes 10.1% of deaths and is attributable to 10.8% of disability-adjusted life years (DALYs). The leading cause for alcohol-related DALYs globally is unintended injury (30%), whereas 13.9% are due to alcohol use disorders (AUDs) (WHO, 2018). Whilst the physical impact of alcohol on the body, such as increasing the risk of cardiovascular disease or cancer, is acknowledged in UK policy documents (HM Government, 2012; Scottish Government, 2018), there is little recognition of the significant impact chronic alcohol use has on memory and cognition. Whilst the 2018 Alcohol Framework, published by the Scottish Government, acknowledges “damage to the brain and nervous system” (p.112) and the impact on brain development in young people (Scottish Government, 2018), the UK Alcohol Strategy does not mention the word “brain” once (HM Government, 2012). The Northern Irish *New Strategic Direction on Alcohol and Drugs* does not make specific references to impact on the brain or risk of cognitive impairment risks (DHSSPS, 2006) although the Royal College of Psychiatrists (2018) document available ARBD support services in their review of treatment. The Welsh substance misuse strategy makes general reference to the increased risk of acquired brain injury and increased risk of dementia (Welsh Assembly Government, 2008) but more recently, Public Health Wales (2015) have gone on to produce a document scoping the scale of ARBD and associated services in Wales. This profile, produced in partnership with the Welsh Assembly Government, provides some recommendations for future research and service development and goes further than other areas of the UK in profiling the extent of ARBD and the support needs of those living with it in Wales.

Chronic alcohol use can cause temporary or permanent damage to the brain, captured under the umbrella term alcohol-related brain damage (ARBD) or alcohol-related brain injury (ARBI) (Royal College of Psychiatrists, 2014). For consistency, this report will use the term ARBD. The term includes Wernicke’s Encephalopathy, Korsakoff’s Syndrome, alcohol-related dementia, and alcohol amnesic syndrome (McRae & Cox, 2003). Wernicke’s Encephalopathy is an acute condition, caused by thiamine (vitamin B1) deficiency in the brain. Patients experiencing Wernicke’s Encephalopathy display confusion, ataxia (impairment of balance, coordination and speech), nystagmus (involuntary eye movements), and ophthalmoplegia (paralysis of eye muscles) (Sechi & Serra, 2007). There are several conditions which can lead to Wernicke’s, such as anorexia nervosa or gastric carcinoma, as the condition is caused by thiamine deficiency, through poor intake or absorption (Royal College of Psychiatrists, 2014). In alcohol-related Wernicke’s, liver damage reduces vitamin storage and has an impact on absorption of thiamine, often impacted further by malnutrition (Thomson et al., 2012).

Korsakoff’s Syndrome is often, but not always, developed as a result of Wernicke’s Encephalopathy; up to 85% of patients who survive Wernicke’s (mortality in around 20% of cases) develop Korsakoff’s Syndrome (Royal College of Psychiatrists, 2014). Korsakoff’s Syndrome is a memory disorder, characterised by severe amnesia though the patient is still able to maintain some degree of function, which make them appear to be capable. The number of withdrawals from alcohol appear to play a part, with more cognitive impairment in those who have been through detoxification more than once (Gupta & Warner, 2008). It is important to note that whilst around 25% of Korsakoff’s patients will need long-term care, the remaining 75% make significant recovery with appropriate treatment and adequate nutrition (Smith & Hillman, 1999). Alongside Wernicke’s and Korsakoff’s Syndrome, there is a recognition of alcohol as a risk factor for dementia. A recent study of hospital admissions in France showed that 38.9% of early-onset dementia cases were alcohol-related. ARBD (Wernicke-Korsakoff) was recorded

for 6.7% of male-dementia cases and 1.2% of female dementia cases (Schwarzinger et al., 2018). With an overall burden from conditions like dementia, due to an ageing population, reducing preventable risk factors such as alcohol is key.

Patients with ARBD tend to present at an age of around 40 to 60 years, with women seemingly more vulnerable to impairment of cognition as they present at a younger age than men, with a shorter period of chronic alcohol misuse (Royal College of Psychiatrists, 2014). Evidence around prevalence of ARBD is lacking, unsurprisingly since it is under-diagnosed. Studies from the Netherlands in the late 1980s and early 1990s reported prevalence of 3.0 and 4.8 per 10,000 population, whereas incidence in Glasgow, UK, was estimated to 0.01–0.65 per 10,000 (Arts et al., 2017). As with prevalence, evidence around mortality is limited. Post-mortem studies provide greater estimates of prevalence; a meta-analysis of autopsy of brains from general populations in American and European studies indicated that 1.5% had Wernicke-Korsakoff lesions (Cook et al., 1998 as cited in Royal College of Psychiatrists, 2014). In populations who are alcohol dependent, however, the prevalence of Wernicke-Korsakoff is estimated to be 35% as evidenced from post-mortem studies (Royal College of Psychiatrists, 2014). One study followed 51 patients with Wernicke-Korsakoff in a tertiary hospital in Spain over a median follow-up time of 5.3 years, showing that survival prognosis was poor. Cumulative mortality was 45% in the sample, corresponding to a mortality rate of 7.4 per 100 person years (95% CI: 4.8–10.9). Patients died at an average age of 65 years, with the main causes being infection (44.5%) and cancer (33.3%) (Sanvisens et al., 2017).

A review of the international literature on ARBD concluded that the condition is under-recognised and lacks adequate treatment and service response. Firstly, the diagnosis is often not made due to lack of awareness among health professionals as well as other symptoms occurring simultaneously, such as delirium, making diagnosis more complicated. This is particularly influenced by the lack of adequate screening instruments (Brighton et al., 2013). A review of the evidence for ARBD screening instruments showed that few studies have assessed the validity and reliability of specific tools, limiting their clinical utility (Horton et al., 2015) and there is no gold standard instrument used specifically in ARBD. Secondly, limited pathways for people with ARBD and lack of specialist services result in patients appearing in multiple services without adequate support. Thirdly, people with ARBD report experiencing double stigma of having an alcohol problem and a memory problem. The literature notes that some health professionals may consider patients with the condition as ‘undeserving’ of services due to their brain damage being self-inflicted, further enhancing stigma. Finally, the literature suggests that lack of interventions and services for people with ARBD contribute to individuals ending up homeless, which may relate to behaviour problems which may make living in the family home or supported accommodation difficult (Brighton et al., 2013).

As ARBD patients do not fit within existing care services, many patients may go undiagnosed (Brighton et al., 2012). The lack of services and under-recognition of the condition is important as patients may present at a number of services; homelessness, A&E, primary care, mental health services. In Scotland, deinstitutionalisation has led to patients with ARBD being moved from psychiatric care into residential or nursing care facilities (Smith, 2012). However, a key issue is that individuals under the age of 65 with memory problems are excluded from memory services, whilst services for younger individuals with dementia excludes those whose impairment is related to alcohol (Place, 2014). Across the UK, service provision is patchy with some areas where there are good practices but many areas where specialised ARBD services are not the norm (Thomson et al., 2012). Services that are put in place for identified individuals are described as ‘ad hoc’ and only becoming available when crisis point is reached. From a health economics

perspective, lack of specialised services may increase the burden on the health system, as patients are presenting in A&E, primary care and mental health services. This scattered presentation contributes to under-recognition of ARBD as a dual diagnosis of cognitive impairment and alcohol dependence (Place, 2014).

The literature around ARBD is limited overall, with gaps in knowledge around prevalence, service provision and mortality. Given the specific needs of this population and the dual stigma patients are likely to experience, the service user voice is important to progress the evidence and to inform services for this population. In the UK, prevalence in the general population is estimated to be 0.5%, but to be around 30% for people with alcohol dependence (Royal College of Psychiatrists, 2014). Understanding the needs of people with ARBD is therefore key, particularly as the condition can be improved with adequate treatment and support, enhancing the quality of life of patients and reducing costs to health services. Understanding the experiences of those living with ARBD is central to shaping effective future provision for this complex client group.

# Methodology

## Aims of the review

This rapid review aimed to explore the experience of living with ARBD and the associated treatment or support offered. A secondary aim was to explore what models of care exist and what professionals and/or patients with ARBD consider best practice. The research question for this review was: how is ARBD and/or support and treatment experienced by those living with the ongoing cognitive effects of alcohol on the brain or those involved in support service provision?

## Search strategy

The search strategy was developed in collaboration with an information specialist librarian. Existing literature were used to support the development of the search strings (Macrae & Cox, 2003). The SPIDER criteria (Cooke et al., 2012) for identifying qualitative, quantitative or mixed methods research (as opposed to PICO which focuses on quantitative studies) was used to define which studies to include in the review. These are outlined in Table 1.

**Table 1. SPIDER criteria for the review**

Criteria	Descriptor
Sample	People living with ARBD (spectrum term, includes alcohol-related brain injury, alcohol-related dementia, Wernicke's encephalopathy, Korsakoff's syndrome) or health care professionals who care for people with ARBD.
Phenomenon of Interest	Research examining how and why certain experiences, behaviours and decisions are occurring (in contrast to effectiveness of an intervention).
Design	Any design.
Evaluation	Experiences of ARBD and/or of care/support.
Research type	Qualitative, quantitative or mixed-methods studies.

## Databases

A literature search was conducted on 16 March 2019 in PubMed, CINAHL, Web of Science, PsycInfo and Embase. Box 1 shows the scope of the review in terms of inclusion and exclusion criteria. No limitation by year or geographical location of studies was imposed as initial literature searches indicated that the pool of literature was very small. All databases were searched using the same key search logic of outcome terms (ARBD), evaluation of the topic (e.g. experiences or perceptions), and alcohol. The specific term 'dementia' was not included as it resulted in a large number of irrelevant records on dementia that were not alcohol-related. The truncated term alcohol\* was used to capture any mention of alcohol, alcoholism, alcoholic etc. in relation to the condition and evaluation. Appendix 1 shows the search terms used for each database. In addition to database searches, searches were conducted in Google Scholar and hand searches of reference lists in identified potential studies for inclusion were also undertaken. Reference lists of grey literature, such as key reports on the topic, were reviewed for potential studies to include.

## Box 1. Inclusion and exclusion criteria

### Inclusion criteria:

- Peer-reviewed journal articles
- English language
- Studies on humans
- Qualitative, quantitative and mixed methods research
- Alcohol-related brain damage/injury caused by toxicity of alcohol (rather than trauma) including Korsakoff's Syndrome, Wernicke's Encephalopathy

### Exclusion criteria:

- Non-peer reviewed literature, theses
- Non-English language
- Reviews
- Animal studies, case studies
- Neurological accounts of brain pathology
- Studies focusing on clinical presentation

## Screening

All identified records in the database search were reviewed by two researchers (SR and LS), who screened titles and abstracts for inclusion. Of the 864 identified records, 39 were selected for full-text screening. In addition to the database search, hand searches of reference lists and a Google Scholar search resulted in an additional seven articles. Following full-text review by SR, nine articles were included in the review.

Source	Total search results	Potentially relevant
Database search	864	39
Reference lists		6
Websites		1
Total		46

## Data synthesis

Nine papers were included the review demonstrating the dearth of literature about the experience of living with ARBD and experience of service provision for the ongoing cognitive effects of alcohol-related harm. Full texts of the papers were read by SR. The nine studies represented reports of specific service developments and redesign (Dawber 2010; Irvine & Mawhinney, 2008; Rota-Bartelink & Lipmann, 2007 & 2010; Wilson et al., 2012) as well as four more detailed studies of specific aspects of the ARBD experience such as memory, personal narratives, loneliness and knowledge (El Haj & Nandrino,

2017; Keady et al., 2009; Oudman et al., 2018; Van den Hooff & Goossensen, 2015). No studies were excluded on the basis of quality as within the small field of literature, each of the nine studies contributed to understanding. Many of the service design studies were, by their nature, limited in scope and used case study approaches to demonstrate the value of the services to individuals. Wilson et al. (2012) urges caution in the generalisability of findings from their study but their research uses a range of measures to assess psycho-social rehabilitation, relapse prevention and unplanned hospital admission producing a comprehensive account of the staged rehabilitation intervention and suggesting demonstrable benefit. The quality of the four studies exploring specific aspects of the experience of ARBD was high with specific validated measures being employed in three studies (El Haj & Nandrino, 2017; Oudman et al., 2018; Van den Hooff & Goossensen, 2015) and a detailed narrative analysis being used by Keady et al. (2009).

## Findings

This review has brought together only nine studies which have been synthesized under three key themes:

- Specific Service Requirements
- Offering Insight About Experience
- Staff Education and training

### Included studies

The nine studies included in the review covered aspects of service design for people living with ARBD (Dawber, 2010; Irvine & Mawhinney, 2008; Rota-Bartelink & Lipmann, 2007; 2010), psycho-social outcomes of a rehabilitation service (Wilson et al., 2012), particular aspects of experience, for example loneliness (Oudman et al., 2018), patient knowledge (van den Hoof & Goossensen, 2014) and autobiographical memory (El Haj & Nandrino, 2017). The final paper (Keady et al., 2009) provided the most detailed account of the experience of ARBD, focusing on risk and constructions of personal identity by six individuals living with ARBD. The studies are detailed in the table below.

Author	Year	Sample	Design	Findings
Dawber	2010	1 patient	Case study	People living with ARBD can have complex comorbid and social profiles. Advanced practitioners can coordinate care. Staff education needs highlighted.
El Haj & Nandrino	2017	19 people with KS and 22 in control group, inpatients or day care setting	Neuropsych. assessment, memory testing, MMSE, autobiographical reliving	Poor recall and detail in autobiographical memory. High emotional value attached to memories. People living with KS can have authentic experiences of memory which could be used in their support.
Irvine & Mawhinney	2008	4 people with KS, supported accommodation setting	Case study design, life skills profiling & interviews	Those living with ARBD have complex social and comorbid situations. Intense staff input is required to support people effectively, promote functional ability and prevent apathy. Staff education needs identified.
Keady et al.	2009	6 people with ARBD, Community based	Narrative research	ARBD has a profound effect on lives. Memory effects require significant personal adjustment both practically and in personal identity. Complex social and emotional effects of alcohol impact on relationship and sense of self. Risk narratives are complex in this population. Future recovery offers hope to individuals.
Oudman et al.	2018	63 people with KS & 14 care givers, inpatient setting	Loneliness scale used to compare patient and carer perceptions	Loneliness is very high in this client group. Care staff rate social and emotional loneliness higher than patients themselves. Loneliness is a serious issue requiring attention in care settings due to potential for significant adverse consequences.
Rota-Bartelink & Lipmann	2007	1 residential setting	Test of concept	Complex client group requiring specifically tailored service. Staff require specific psychosocial education. Service must reflect client needs rather than model of supporting older people in long-term residential care.



Rota-Bartelink & Lipmann	2010	14 participants, 1 residential setting	Action research, ongoing evaluation	Staff/resident relationships are central to success. Challenging to find funding for services for those with ARBD who have support needs but do not fall into traditional funding categories. Routine and support with budgeting & risk management are important.
Van den Hooff & Goossensen	2015	6 KS patients, inpatient setting	Qualitative design using in-depth interviews	Patients with KS interpret their situation and develop an understanding of staff, rules and context of care. Staff should appreciate this perspective in shaping care. Policy should appreciate the need for relational care which values the perspective of those living with KS.
Wilson et al.	2012	41 patients, community-based rehab	Evaluation of rehab intervention	Community rehab service can be effective in reducing unplanned hospital stays. Service relies on person-centred approach and tailored provision. Structured approach is useful. Service should be driven by rehabilitation focus, promoting independence.

*KS: Korsakoff's Syndrome*

## **Participants and settings**

The papers brought together research from across Europe (UK, France, The Netherlands) as well as one setting in Australia. Most of the studies involved health professionals (Dawber, 2010; Rota-Bartelink & Lipmann, 2007; Wilson et al., 2012) and reported service design, development and service metrics. Some also gathered qualitative insights from service users, carers and family members in addition to staff data (Irvine & Mawhinney, 2008; Rota-Bartelink & Lipmann, 2010). Oudman et al. (2018) collected comparative data from service users and care staff while El Haj & Nandrino (2017), Keady et al., (2009) and Van den Hooff & Goossensen (2015) all focused on service users. Participants living with ARBD had either specific diagnoses of Korsakoff's or demonstrated similar cognitive impairment as a result of alcohol-related harm. All service users were recruited from ARBD-specific services including residential settings and supported accommodation.

## **Specific service requirements**

Several studies which reported on the experience of those living with ARBD related specifically to the development and evaluation of services. Irvine and Mawhinney (2008) used a case study design to discuss levels of function in a small sample of four residents in a supported accommodation setting. They stressed the importance of staff building relationships with service users and getting individuals involved in activities. Understanding what might be meaningful for an individual service user allowed staff to suggest appropriate activities and engage people positively. The case study approach included interviews with staff and service users as well as life skills profiling. This multifaceted approach identified the apathy that often surrounds individuals with ARBD and produces a barrier to activity which can be overcome by developing trusting relationships with staff.

While the importance of individual relationships was a key finding in Irvine and Mawhinney's (2008) study, the importance of tailoring services to individual needs more generally was a theme in a number of other studies. Wilson et al. (2012) followed 41 patients for an average of 25 months through a phased rehabilitation programme which relied on a person-centred approach to planning and follow up. Wilson's (2012) descriptive study of a newly-commissioned service highlights the potential benefit in terms of bed usage of tailored services, demonstrating an 85% drop in inpatient bed usage per patient, per year. Wilson (2012) stresses the importance of support from a range of professionals within a community team and recommends a named individual is identified to coordinate services for those living with ARBD. The complexity of this client group cannot be underestimated and the presentation of individuals who live with comorbid physical and psycho-social health needs requires detailed, active planning and coordination between a range of services. While this communication between services is crucially important, the interaction with patients is also key as the service helps to facilitate a rehabilitation approach, moving individuals to increasing levels of independence. Dawber (2010) outlines the role of the advanced practitioner in taking a lead in the coordination of care packages, acting as the interface between the broad range of care and support agencies. She also emphasises the importance of staff training in facilitating this kind of role and in highlighting the potential for success in the treatment of those living with ARBD.

Rota-Bartelink and Lipmann (2007; 2010) report on the support of people living with ARBD in a long-term residential care facility in Australia. These two papers describe the Wicking Project which was specifically designed to support older people who had experienced homelessness and live with ARBD. As with Wilson et al. (2012) and Dawber (2010), these studies highlight the complexity of the client group and the need to fully

understand that complexity in order to design and develop an appropriate service. The Wicking project supported people over the age of 50 and reported on the experiences of 14 participants using an action research approach. The importance of routine and consistency were central to the success of the service alongside practical support with alcohol and tobacco management and support with management of personal finances. The importance of appreciating different constructions of risk, also noted by Keady et al. (2009), and of diminished decision-making capacity, shaped the operation of the service. Appreciating the individual life experience of the service users was also crucially important. For example, those who had spent many years being homeless had little regard for recreational activities within the residential setting and found them incomprehensible having had no familiarity with such recreational activities during their previous life experience. The importance of appreciating different stakeholder views is central to the development of both meaningful relationships and, ultimately, successful services.

### **Offering insight about experience**

Person-centred approaches to care focus on individuals' views in shaping their own care and have become integral to health care provision worldwide. Van den Hooff and Goossensen (2015) explored the knowledge of patients living with ARBD in discussion of their care experiences. In a grounded theory-informed study, they asked open-ended questions in order to fully explore the views of individuals resident in an inpatient setting. The study found that those with ARBD had their own views of their situation and of their world within the care setting and could articulate those views when asked. They interpreted the way in which rules were applied and reported feeling criminalized, sometimes ignored by staff and under-valued within the care setting. Making these insights explicit offers the potential to improve the service as staff can appreciate the perspective of the resident and amend care effectively. Van den Hooff's study demonstrates that those living with ARBD can contribute their own understandings to discussions about care, offering insights which may shape staff responses and help services to respond appropriately to the needs of service users. The importance of attending to insights from patients and service users was also highlighted in work by Oudman et al. (2018) who explored loneliness in those living with Korsakoff's Syndrome. Like Van den Hooff and Goossensen (2015), Oudman et al. (2018) demonstrated that those living with the ongoing cognitive effects of alcohol can reflect on their own situation and contribute insights into their lives. Loneliness is recognized to be an increasing problem in modern society and is particularly significant for those with cognitive impairment and in those who confabulate. Loneliness was found to be experienced by a large majority of those living with Korsakoff's Syndrome and was related to poor social support, lack of social integration and visits from significant others. Professional carers in Oudman's work rated loneliness more highly than patients, demonstrating a disconnect between the lived experience of ARBD and the staff perception of that experience. These two studies, both carried out in the Netherlands, highlight the importance of exploring experience in shaping both care practice and also future service development.

Gathering insights from those living with cognitive impairment is not without complexity. It is recognized that those living with ARBD may confabulate or may remember aspects of their life inaccurately. However, Oudman's work suggests that confabulation may increase the likelihood of loneliness in individuals. Both Oudman et al. (2018) and Van den Hooff and Goossensen (2015) show the importance for staff in understanding patient perspectives, allowing the needs of individuals to be met more effectively through a shared understanding of experiences. El Haj and Nandrino (2017) explored autobiographical memory in the same client group, noting that even when specific event memories are compromised by cognitive impairment, the emotional response to the life event remained significant in the individual's recall of the memory. While this study focused on individual

life events and individuals may have chosen to highlight events with significant emotional meaning, the importance of the affective elements of memory in shaping personal identity is clear. This study demonstrates that those living with ARBD can experience memories authentically. El Haj and Nandrino highlight the importance of this finding in offering opportunities to clinicians and carers to use memories and emotional responses to those memories in the support of personal identity and sense of self in those living with ARBD.

Personal identity is central to the way individuals see themselves and their lives. Keady et al. (2009) report the challenge of the '5-minute memory' as part of the personal identity of some individuals living with ARBD. The life adjustments required to live with this memory deficit and the use of prompts were recognized as important elements of the narratives of individuals' lives. In order to respond effectively, staff need to be aware of service users' desire for improvement, to rebuild their lives and regain independence. Staff responses are crucially important and understanding the perspective of the service user is central to facilitating an effective response.

### **Staff education and training**

Interaction with those who have ARBD and the process of gaining insights into their personal experience, memories and perspectives on care raises important issues for staff education and training. Communication skills are central to successful interactions which can be complex in the case of individuals who may confabulate or demonstrate very short periods of lucidity (Keady et al., 2009; Oudman et al., 2018; Van Den Hooff & Goossensen, 2015). Keady et al. (2009), in their detailed narrative analysis of six individual stories, noted that narrative storylines were not usually chronologically focused, requiring detailed engagement in order to ensure that meaning was clear. Keady et al.'s work also discussed 'fractured lives' which service users often described, raising the sensitivity of conversations and the importance of positive interaction in promoting a rebuilding narrative. This kind of engagement and communication requires specific training and education if its potential is to be realised.

Dawber (2010) also raises the importance of highlighting the likelihood of success to professional colleagues who may lack awareness of the opportunity for improvement in a significant number of those living with ARBD. This lack of awareness may also contribute to under-diagnosis. Rota-Bartelink & Lipmann (2007; 2010) raise the importance of staff education and awareness-raising in terms of the specific needs of those living with ARBD who may have experienced homelessness. The importance of specific staff support to engage with recreational activities and to manage finances and life skills may fall outside of the skillsets of traditional care services and care home provision.

Keady et al. (2009) explored ARBD as part of a larger study about risk construction in those living with dementia. This research on risk highlights an important aspect of the thinking of care staff who seek to minimise risk for those in their care. While this approach fits with the prevailing understanding in care settings generally and care homes in particular, it could be addressed in staff education in order to promote a more rehabilitative approach to the care of those with ARBD. Wilson et al. (2012) emphasise the need for services to promote independence with a design which gradually facilitates the independence of the service user. Keady et al.'s work demonstrates the need for staff to adjust their construction of risk in order to allow this to happen and to promote a recovery narrative which is perhaps less familiar within the care home setting. Staff education and awareness-raising could offer potential for development in these care settings and in future services. This is an area which would benefit from specific research and further exploration.

## Discussion

This rapid review aimed to develop a further understanding of the experiences of living with or caring for people with ARBD, as described in the published literature. It is clear that this is an area that urgently needs more research, as individuals with ARBD appear to be a patient group with specific needs, often undiagnosed, which is lacking specialist service provision and often falling between existing services. Research is required across each of the three themes emerging from this review with significantly greater understanding required around individual experiences of living with ARBD. These understandings of experience can shape appropriate models of service provision and the approaches to communication required to facilitate both meaningful interpersonal interaction and effective service collaboration.

The review focused on peer-reviewed research, in which there were only nine papers that fit our criteria. However, there is some additional evidence in the grey literature. McCabe (2005) explored attitudes and knowledge of ARBD among frontline care staff in care homes in Scotland and found a lack of specific medical knowledge around ARBD which could be explained by an overall limited amount of formal training and education on the topic. Care staff perceived ARBD residents as more challenging, due to greater physically aggressive behaviour, particularly if the patient is still drinking. The care homes, of which two were nursing homes and two were specifically caring for individuals with substance misuse problems, had varying policies around alcohol. Some allowed for alcohol in a regulated manner, whereas others restricted all alcohol use. Some staff felt that strict alcohol policies might not be the right thing to do, as they perceived damage to already have been done and small amounts of alcohol would not cause further harm. There was a lack of linking up with other professionals, particularly alcohol specialists, though liaison with GPs and dietitians were mentioned. In general, staff did not hold negative attitudes towards alcohol misuse and ARBD, but there was some indication of stigma as staff considered the condition to be self-inflicted (McCabe, 2005).

The dearth of literature representing the experience of living with ARBD is particularly disappointing given the significant potential for improvement which exists for individuals who have ARBD (Smith & Hillman, 1999). With as many as 75% of those with ARBD making significant improvement, service provision and appropriately tailored support for individuals is central to their future lives. Detailed insights into the support needs, wishes and experiences of those with lived experience of ARBD should be central to future developments in service provision and research.

A key element of the reviewed studies is the importance of good communication and relationship building. This is true of communication between service users and staff as they strive to understand the different perspectives on care, as well as between staff of different services. Tronto's Ethic of Care (1994) argues that effective healthcare requires staff to be responsive, demonstrate attentiveness and respond to the needs and feelings of patients. Only through empathetic, meaningful, authentic engagement can the insights of those living with ARBD be captured and used to shape a personalized care plan or to enhance the promotion of identity and sense of self. In service provision, newly-developing services all highlight the need for strong collaborative communication in developing and sustaining successful services. Models for these two key elements of communication deserve greater exploration in future research.

## **Strengths and limitations**

This review sought to take as wide an approach as possible to the study of the experience of living with ARBD. The database searches used a range of terms and did not limit year of publication or geographical location of studies in order to ensure as wide a literature base as possible. However, the review only found nine studies which fulfilled the inclusion criteria, demonstrating a dearth of empirical research about this important health concern. Literature such as McCabe (2005) emerged from the grey literature, suggesting that there is some information circulating about the topic but not in the form of peer reviewed research. A number of the studies found were found in hand searches and Google searches, which is similar to Brighton (2013) who also used additional search strategies to augment the findings of bibliographical database searches. This is thought to be because of challenges with the use of terms such as Wernicke's and Korsakoff's Syndrome. The review has captured literature around isolated elements of experience such as loneliness, autobiographical memory and patient knowledge. Together these individual aspects of experience lead to a significant strength of discussion around the need for appreciation of patient and service user perspectives on ARBD and the importance of those perspectives in shaping future service provision. The thematic presentation of findings has allowed future research to be recommended under three key themes.

## Recommendations

This report demonstrates that the literature around experiences of ARBD from people who live with the condition as well as those who provide services is lacking. The limited evidence suggests that among alcohol dependent populations, ARBD is likely to be relatively prevalent but often goes undiagnosed. The experiences of living with ARBD are poorly understood and are largely missing from both current literature and alcohol policy. There may also be an underappreciation of the extent to which those with ARBD may improve or recover over the course of their condition with adequate nutrition and abstinence. Greater understanding of this context may encourage greater service development and engagement with existing services. Further research is urgently needed to explore a range of different aspects of the experience of life with ARBD.

In order to fill the gaps in the evidence and understanding we suggest the following:

### **Specific service requirements**

- Research which profiles the support needs and wishes of individuals living with ARBD and their families, including modes of service delivery, personnel and setting.
- Research which explores the role of key professionals in coordinating services and ensuring services can be effectively tailored to the needs of individuals, or models of care which permit effective collaboration across care interfaces.
- A greater appreciation in alcohol policy of the impact of alcohol on the brain and the ongoing support required to support those living with ARBD and their families.

### **Offering insight about experience**

- Studies which fully explore the perspectives of different stakeholders in ARBD – service users, family members, professionals, lay carers.
- Research which compares optimum models of communication between those with ARBD and their carers.
- Research which explores personal identity in ARBD and develops understanding of ways in which personal identity and sense of self can be promoted effectively.
- Studies which examine the concepts of recovery and rehabilitation as developmental opportunities arising in the care of those living with ARBD.
- Projects which facilitate engagement in policy development by those with lived experience of ARBD and their families, ensuring future policy is informed by service user perspectives.

### **Staff education and training**

- Development of models of staff education which promote good communication with those who live with ARBD.
- Awareness-raising of the potential for dual stigma around ARBD – cognitive impairment and alcohol use.

- Awareness-raising of the potential for improvement with effective support, nutrition and engagement with people living with ARBD and an associated drive to improve diagnostic services.
- A strategic approach to the support and education of staff who work with those with ARBD and their families, providing a framework for future workforce development.

The impact of these three key areas of recommendation should also be fully explored in order to ascertain how service provision, personal experience and staff education relate to personal outcomes, quality of life, economic impacts, health service utilisation and family experiences.



## Conclusion

This review has focused on literature about the experience of living with ARBD and the best practice in service delivery. The findings demonstrate a very limited field of literature addressing lived experience. This is particularly disappointing in the context of increasing personalisation of healthcare services and approaches in order to ensure individual needs are met. The literature highlights the complexity of the lives of those living with ARBD in terms of both social situation, comorbidities and engagement with services. Understanding these life experiences should be a research priority in order that future service provision, support and interaction can effectively meet the needs of individuals and their families. Staff supporting this population who live with the dual stigma of cognitive impairment and alcohol problem also require education and training in order to meet patient/client needs. Much of this education should focus on understanding the experiences and perspectives of those living with ARBD in order to inform approaches to care. Developing innovative ways of engaging with complex health and social care needs, promoting a rehabilitative framework and initiating person-centred approaches to care have the potential to facilitate both recovery and improved quality of life in this vulnerable population.

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## Appendix 1 – Search terms

Database(s): CINAHL Plus			
1	TX korsakoff* or wernicke* or amnes* or "thiamine deficien*"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus
2	TX alcohol*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus
3	TX experience* or perspective* or perception* or perceive* or attitude*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus
4	#3 AND #2 AND #1	Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus

Database(s): PsycINFO 1806 to March Week 2 2019, Embase Classic+Embase 1947 to 2019 March 14, Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily 1946 to March 14, 2019			
1	(korsakoff* or wernicke* or amnes* or "thiamine deficien*").mp. [mp=ti, ab, hw, tc, id, ot, tm, tn, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, an, ui, sy]		
2	alcohol*.mp. [mp=ti, ab, hw, tc, id, ot, tm, tn, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, an, ui, sy]		
3	(experience* or perspective* or perception* or perceive* or attitude*).mp. [mp=ti, ab, hw, tc, id, ot, tm, tn, dm, mf, dv, kw, fx, dq, nm, kf, ox, px, rx, an, ui, sy]		
4	1 and 2 and 3		
5	remove duplicates from 4		

Database: Web of Science Core Collection (1900-2019)			
1	ALL FIELDS: (korsakoff* or wernicke* or amnes* or "thiamine deficien*")		Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC Timespan=All years
2	ALL FIELDS: (alcohol*)		Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC Timespan=All years
3	ALL FIELDS: (experience* or perspective* or perception* or perceive* or attitude*)		Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC Timespan=All years
4	#3 AND #2 AND #1		Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC Timespan=All years