

Executive summary

Rapid Evidence Review

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

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Key findings

- Understanding about the personal experience of living with alcohol related brain damage (ARBD) is poorly understood in the academic literature which can lead to a dual stigma of both alcohol and memory problems.
- Those living with ARBD can offer insights into their own experiences and service needs offering potential to develop more person-centred services and enhance care quality.
- Many people living with ARBD have complex social and family circumstances and benefit from the development of supportive relationships with key staff in order to thrive.
- ARBD requires a specific service response which includes a range of professionals and agencies providing coordinated support, tailored to individual needs.
- Staff need specific education and training in order to effectively support those who live with ARBD through effective communication, the development of supportive relationships and the provision of personalised care.
- Staff education offers an opportunity to highlight the potential for recovery in ARBD and ensure that health and social care professionals instigate effective support when individuals present to care services.
- Policy should take account of the experiences of those living with the effects of alcohol on the brain, ensuring that their voices are heard in the development of policy.
- Further research is required to explore the experience of living with ARBD and to guide development of effective, person-centred service responses.

Research team

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Background

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.

Aims

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.

Methods

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.

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