

Assessing outcomes of alcohol-related brain damage (ARBD): What should we be measuring?

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Abstract

The recent move towards outcomes-focused assessment in health and social care has made it important to identify which outcomes are relevant to alcohol-related brain damage (ARBD). Clinical outcomes guidance for ARBD is currently absent from policy documentation. Thus, the aim of this review is to evaluate the current evidence base to determine recommendations for the measurement of ARBD outcomes. A total of 71 separate references were identified through a systematic online database and hand search. The screening and exclusion strategy left 7 articles to be included in this review. The findings indicate that research into ARBD has focussed on a number of outcome domains, including type of accommodation and provision of support; drinking status; employment status; number of deaths; mental health and psychiatric symptoms; activities of daily living; social functioning; and cognitive functioning. The identified outcomes suggest that practitioners should focus on a comprehensive range of clinical outcomes for ARBD service users. Nevertheless, the paucity of the existing evidence base makes it difficult to make clinical recommendations for the measurement of ARBD outcomes. Further research is necessary to shed light on long term outcomes for people with ARBD and to increase the strength of the evidence in this area.

Introduction

The term Alcohol-Related Brain Damage (ARBD) refers to a range of neuropsychiatric conditions, which are associated with neurocognitive impairments such as severe anterograde amnesia and executive dysfunction, as well as adverse psychosocial consequences such as reduced quality of life, anxiety and depression (MacRae & Cox, 2003; Thomson et al, 2012). Despite the severity of the impairments associated with ARBD, it has been estimated that approximately 25% of individuals diagnosed with ARBD will make a full recovery, whilst a further 50% will recover to some degree and the remaining 25% will show no improvement over time (Smith & Hillman, 1999). The majority of people diagnosed with ARBD therefore have the potential for rehabilitation, providing that rehabilitation programmes are abstinence based and personalised to meet their specific needs (Kopelman et al, 2009, Thomson et al, 2012).

One of the overarching aims of all health and social care interventions is to improve outcomes for service users (Department of Health, DoH 2013a; DoH, 2013b). Interventions for ARBD primarily aim to improve the cognitive, psychiatric, social and functional status of individuals diagnosed with the condition (Thomson et al, 2012; Svanberg & Evans, 2013). A recent systematic literature review by Horton et al (2014) revealed that a variety of standardised neuropsychological and psychosocial instruments have been used in the assessment of ARBD. With the recent move toward outcomes-focused assessment in health and social care (Miller, 2010) there is the potential for such neuropsychological and psychosocial assessment tools to be used to measure clinical outcomes in ARBD.

Current clinical guidance for the assessment and management of alcohol-use disorders focusses primarily on alcohol misuse and dependence and fails to make any recommendations for the management of ARBD (National Institute for Health and Clinical Excellence [NICE], 2011). There is also a lack of specific information about outcome domains in the current NICE guidance. Nevertheless, the NICE

guideline for alcohol-use disorders highlights the importance of measuring outcomes and states that “the outcomes chosen should reflect both observer and service user-rated assessments of improvement and the acceptability of the treatment” (p.37, NICE, 2011). In the broader health and social care context, quality of life is included as a key outcome domain, both for NHS patients with long term conditions and for social care service users with care and support needs (DoH, 2013a; DoH, 2013b).

The emphasis on outcomes within current policy initiatives is consistent with a growing focus on outcomes within research (Miller, 2010). In particular, Williamson and Clarke (2012) highlighted a need for standardised sets of outcome measures for healthcare research, known as ‘core outcome sets.’ The COMET (Core Outcome Measures in Effectiveness Trials) Initiative has been set up to establish a database of relevant outcomes research, and to develop core outcome sets for a variety of health conditions (COMET Initiative, 2014). There is currently no ‘core outcome set’ for ARBD. However, a number of outcome domains and measures have been identified in the wider context of traumatic brain injury (TBI) and dementia care. Wilde et al (2010) identified a range of recommended outcome domains for traumatic brain injury, including global outcome; neuropsychological impairment; psychological status; cognitive, physical and behavioural functioning; social role participation; perceived health-related quality of life and health economic measures. Furthermore, Moniz-Cook et al (2008) identified a range of patient and caregiver outcome measures for European psychosocial intervention research in dementia care. The identified patient outcomes for dementia covered the domains of mood; quality of life; activities of daily living; behaviour and global functioning. Despite the current lack of recommended outcomes for ARBD, the above outcomes for TBI and dementia are clearly of relevance to ARBD, as these conditions are also characterised by cognitive impairment and have an impact on quality of life, psychosocial functioning and an enduring impact on functional capacity.

The aim of this review is to examine the evidence for outcome measurement within the context of ARBD service provision. The review will identify which outcome

measures have been used within ARBD research to date, whilst allowing recommendations for future research to be made. The findings from the review will also help to ascertain whether the existing research in this area is sufficiently robust to allow guidance to be provided for practitioners concerning the measurement of outcomes within ARBD services.

Method

A literature search, guided by Moher et al's (2010) PRISMA statement, was conducted on June 27, 2014 to identify relevant journal articles examining outcomes measurement in ARBD (Figure 1., PRISMA flow diagram). The following online databases were searched using EBSCOHOST: CINAHL Plus with Full Text; Health Source: Nursing/Academic Edition; MEDLINE; Psychology and Behavioural Sciences Collection: PsycINFO. Combinations of the following key words were entered to identify appropriate articles for inclusion in the review: alcohol-related brain damage/Korsakoff's Syndrome/Wernicke-Korsakoff Syndrome AND outcome*/follow up. The database search revealed a total of 86 references. Seventeen of these references were duplicates, leaving a total of 71 articles.

FIGURE 1. ABOUT HERE

The titles and abstracts for each of the 71 articles were screened to ascertain whether they were suitable for inclusion in the review. The following inclusion and exclusion criteria were applied:

Inclusion criteria

1. Human study population
2. Repeated measures/longitudinal design or follow-up study

3. English language
4. Participants described as having ARBD or meet DSM or ICD diagnostic criteria for alcohol-induced amnesic syndrome
5. Focus is on outcomes

Exclusion criteria

1. Papers published in languages other than English
2. Participants do not meet diagnostic criteria for alcohol-related brain damage
3. Focus is on diagnosis, treatments or interventions, rather than outcome

Of the 71 screened references, 67 were excluded on the basis that they did not meet the inclusion criteria for the review: 41 papers were excluded because they did not focus on ARBD; 4 were excluded because they concerned pharmacological treatments for ARBD; 2 were excluded because they were not in English; 13 were excluded because they focussed on diagnosis and assessment; and 7 were excluded because they focussed on prevention and interventions rather than clinical outcomes. The exclusion process left a total of 4 articles to be included in the review (Lenanne, 1986; Noel et al, 2001; Fujiwara et al, 2008; Wilson et al, 2012). A hand search revealed an additional 4 relevant articles which were suitable (Price et al, 1988; Blansjaar et al, 1992; Ganzevles et al, 1994; Irvine & Mawhinney, 2008). One of the papers identified during the hand search was published in German (Ganzevles et al, 1994) and was therefore excluded. This left a total of 7 papers to be included in the review.

Results

A total of 7 articles were included in this review (Lenanne, 1986; Price et al, 1988; Blansjaar et al, 1992; Noel et al, 2001; Fujiwara et al, 2008; Irvine & Mawhinney, 2008; Wilson et al, 2012). Table 1. outlines the key outcome domains and methods of outcomes measurement identified within each of the 7 papers. A range of outcome domains were identified, including type of accommodation and provision of

support; drinking status; employment status; number of deaths; mental health and psychiatric symptoms; activities of daily living; social functioning; and cognitive functioning. Each of these outcome domains are presented below.

TABLE 1. ABOUT HERE

Type of accommodation and provision of support

Three of the studies included type of accommodation and provision of support as outcome domains (Lenanne, 1986; Price et al, 1988; Wilson et al, 2012). In Lenanne's (1986) study, a group of 104 Australian patients with moderate to severe ARBD were followed up an average of 16.4 months (range = 8-24 months) after admission to a structured inpatient rehabilitation programme. At follow-up, Lenanne (1986) reported that 51% (n = 53) of the 104 patients previously admitted to hospital were successfully placed in the community. Thirty-nine of the 'successfully placed' individuals were residing in boarding houses with meal provision and self-care and medication supervision; 5 were living with relatives; 6 were living in nursing homes and 2 were living independently. Of the remaining 49% who were not successfully placed, Lenanne reported that 10.6% (n = 11) were in hospital; 4.8% (n = 5) were known to be dead; 9.6% (n = 10) were not contacted; and 24% (n = 25) were lost to the study.

Price et al (1988) followed-up 37 patients with ARBD for at least 12 months following discharge from hospital to the community. The patients included in this study received no ARBD-specific rehabilitation following discharge from hospital. Price et al (1988) reported that only 27% (n=10) of the patients were 'successfully placed' at 12-month follow up, whilst 54% (n = 20) were described as "dysfunctional," and 19% (n = 7) were deceased. Price et al also reported that patients previously admitted to general hospital facilities (n = 18) were receiving more support from relatives, friends and statutory or voluntary services at follow-up than those admitted to psychiatric

facilities and rehabilitation units (n = 19). Moreover, patients who were previously admitted to hospital due to acute problems were found to be receiving more support at follow up than those with chronic problems. Nevertheless, the number of patients who were admitted due to acute problems was not made explicit.

In Wilson et al's (2012) UK study, a series of 41 patients, who were referred successively to a recently commissioned community-based tertiary service for individuals with severe ARBD were followed up after an average of 25 months. Three types of accommodation were identified including institutional care, nursing home care and supported living at home. Each patient progressed through an abstinence-based rehabilitation programme involving 5 therapeutic phases of varying durations, and referrals to the service were made on a rolling basis. The patients were therefore at different therapeutic phases when they were reviewed. At follow-up, 39% of patients (n =16) were in the 'psychosocial assessment' phase of the programme, 19.5% (n = 8) were undergoing therapeutic rehabilitation and 41.5% (n = 17) were in the 'adaptive rehabilitation', 'social integration' and 'relapse prevention' phases. Approximately 39% (n = 16) of the individuals were living in institutional care at follow-up, whilst less than 1% (n = 3) were in nursing homes and 41% (n = 17) were receiving support at home.

Drinking Status

Four of the papers included drinking status as an outcome (Lenanne, 1986; Price et al, 1988; Irvine & Mawhinney, 2008; Wilson et al, 2012). In Lenanne's (1986) study, only 1 of the 53 individuals who were successfully placed had resumed drinking alcohol at follow-up. Lenanne described this outcome as 'impressive.' Nevertheless, as the remaining 49% of patients were either in hospital, not included in the follow-up, or deceased, the success of the inpatient rehabilitation programme in promoting long term abstinence from alcohol can be questioned. Price et al (1988) categorised the 37 participants in their study according to whether they were drinking frequently (n =7), intermittently (n =18) or not at all (n =12) at 12-month follow-up. Moreover,

Irvine and Mawhinney (2008) reported that one of the four individuals living in a supported accommodation facility in Northern Ireland consumed alcohol on one occasion during the 12-month study period, whilst the three other residents had no incidence of relapse. Lastly, Wilson et al (2012) reported that 30 of the patients were abstinent at follow-up, whilst 3 were categorised as being in controlled drinking and 4 relapsed into uncontrolled drinking.

Employment Status

Lenanne (1986) was the only study to include employment status as an outcome domain. Unemployment was high at follow-up, with the majority of patients receiving social security benefits. The 2 individuals who were living independently at follow-up continued to engage in vocational activity at the hospital's industrial therapy workshop. Moreover, only 1 person was in open employment at follow-up, although the type of accommodation this individual was living in was not reported.

Deaths

Four of the studies reported numbers of deaths at follow-up (Lenanne, 1986; Price et al, 1988; Blansjaar et al, 1992; Wilson et al, 2012). Of the original 104 participants in Lenanne's (1986) study, 10 were known to be dead at follow-up (mean age = 53.8 years). Price et al (1988) reported 7 deaths amongst the 37 patients who were followed up (mean age = 55.1 years). Blansjaar et al (1992) followed-up 44 patients with alcohol amnestic disorder over a period of 3 years and reported 4 deaths during the observation period (mean age = 52 years). In Wilson et al's (2012) study, 4 of the original 41 participants were deceased at follow-up (mean age = 54 years).

Mental Health and Psychiatric Symptoms

Three papers reported mental health and psychiatric outcomes (Blansjaar et al, 1992; Irvine & Mawhinney, 2008; Wilson et al, 2012). Blansjaar et al (1992) used the Brief Psychiatric Rating Scale – Expanded (BPRS-E; Overall & Gorham, 1962) to measure psychiatric symptoms. Five of the 44 patients had psychiatric diagnoses upon recruitment to the study. BPRS-E ratings were found to be low with only 8% of all scores within the pathological range (ratings of 4 and above), mainly for anxiety and depression. 47% of the scores for grandiosity and 50% of the scores for disorientation were found to be out with the normal range, and Blansjaar et al (1992) asserted that the relatively high scores for grandiosity reflected patients' lack of insight into their amnesia. Ratings of uncooperativeness were found to be higher in nursing home patients than in patients living in supported accommodation, which the authors reasoned might reflect nursing home residents' discontent with their living situation.

Irvine and Mawhinney (2008) used semi-structured interviews with residents and monthly staff reports, as well as the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) to measure mental health over the 12 month study period. Three of the residents scored within the severe depression range on the CES-D, whilst the fourth resident reported no depression. Depression scores on the CES-D fell for all 4 participants over the 12-month study period, although the 3 residents scoring high remained within the severe depression range. Staff reported fluctuating mood and mental health for 2 of the participants with high depression scores over the 12-month period. No information was provided about mental health status on the basis of the semi-structured interviews with residents.

Wilson et al (2012) used the Health of the Nation Outcome Scale - Acquired Brain Damage (Honos-ABI; Fleminger & Powell, 1999) to measure participants' mental health and psychiatric symptoms. On referral, 17 of the 41 participants had comorbid depression, whilst 8 had comorbid aggression, 1 had bipolar affective disorder and 1

had post-traumatic stress disorder. The Honos-ABI was repeated with 17 of the participants who were in the final therapeutic phases of the rehabilitation program. Only 5 of these individuals were found to have on-going depression or other mental health problems, although group severity ratings of depression and other mental health conditions increased rather than decreased.

Activities of Daily Living (ADL)

Two of the papers included ADL as outcome measures (Irvine & Mawhinney, 2008; Wilson et al, 2012). Irvine and Mawhinney (2008) used the Self-Care subscale of the Life Skills Profile (LSP; Parker et al, 1991) to measure residents' personal care ability. At baseline, all 4 participants had above mid-range self-care ratings, although self-care ratings declined for 2 of the residents between baseline and 6 months. The authors suggested that the observed decline in self-care ability during the first 6 months might reflect a number of issues, including anxiety, challenging behaviour and reduced mobility. Wilson et al (2012) used the Honos-ABI to measure 17 participants' ability to perform basic self-care and more complex everyday activities safely. In terms of functional ability, ADL problems ranged from considerable, requiring supervision and constant prompting (n = 3); through to moderate problems with more complex tasks (n = 8); minimal problems but still able to function effectively (n = 4); and effective ADL functioning with no problems (n = 2).

Social Functioning

Three papers reported outcomes related to social functioning (Blansjaar et al, 1992; Irvine & Mawhinney, 2008; Wilson et al, 2012). Blansjaar et al (1992) used the Groningen Social Disabilities Scale (GSDS; Wiersma et al, 1988) to measure social role behaviour. Social functioning was found to be compromised in 90% of all assessments, with complex roles such as occupational functioning being most significantly impaired. Social functioning was found to improve within the sheltered accommodation, whilst it deteriorated in nursing home settings. Irvine and

Mawhinney (2008) measured social functioning using the Social Contact subscale of the LSP (Rosen et al, 2006). Two of the residents scored low on the Social Contact subscale over the 12-month study period. The other 2 residents scored high at baseline, whilst they scored substantially lower at 6-months and subsequently scored relatively higher at 12-months. The authors noted that several factors influenced scores on the Social Contact subscale, including poor mental health, aggression and inappropriate behaviour, which hindered social interaction and restricted participation in meaningful social activities. Wilson et al (2012) use the Honos-ABI to measure social functioning, focussing specifically on 'active disturbance of social behaviour' and 'problems with relationships.' The authors reported that the average group scores for social functioning improved at follow-up, although they did not state whether this improvement was statistically significant.

Cognitive Functioning

Four papers reported outcomes relating to cognitive functioning (Blansjaar et al, 1992; Noel et al, 2001; Fujiwara et al, 2008; Wilson et al, 2012). Blansjaar et al (1992) used the Mini-Mental State Examination (MMSE; (Folstein et al, 1975), Wechsler Memory Scale (WMS; Wechsler, 1945) and Raven's standard Progressive Matrices (Raven et al, 1984) to measure cognitive functioning at 3 years follow-up. **Scores on all three instruments were indicative of impairment and** remained stable over the 3 years. Noel et al (2001) presented the neuropsychological profile of a single individual (54 year old male) at 60 days, 180 days and 270 days after admission to a psychiatric hospital ward. A range of neurocognitive assessments were used to examine episodic memory, working memory and executive functioning. The findings from this study revealed episodic memory deficits, coupled with impairments in executive functions such as inhibition, rule detection and flexibility 60 days after admission to hospital. At 9-month follow-up, the participant's performance reached the normal range on almost all tests, apart from those measuring episodic memory (California Verbal Learning Test, Delis et al, 1987; Verbal Selective Reminding Task, Buschke, 1973; 3 minute delayed recall of Rey Complex figure, (Rey, 1970); AB-AC Task, (Wickens, 1970), and inhibition (Hayling Test, Burgess &

Shallice, 273). Nevertheless, as no parallel forms of the tests used by Noel et al (2001) were available, the authors noted that practice effects could not be ruled out.

Fujiwara et al (2008) used a range of neuropsychological instruments to assess cognitive functioning in 20 detoxified alcoholic Korsakoff syndrome patients, in comparison to a control group of 20 healthy individuals. The Korsakoff patients scored within the normal range for estimated premorbid intelligence quotient, as measured by the German version of the National Adult Reading Test (NART; Nelson, 1982). However, their performance was significantly worse than the comparison group on most of the tests, and they were out with the normative range on all tests apart from the Mini Mental State Examination (MMSE). Performance on the majority of the tests remained stable at the 2 year follow-up. However, improvements were found on the Information subtest of the Wechsler Adult Intelligence Scale-Revised (WAIS-R; Tewes, 1991), as well as on delayed recall of the Rey-Osterrieth Complex Figure (Osterrieth, 1944) and verbal fluency in the FAS Test (Spreen & Strauss, 1998). Wilson et al (2012) used the Honos-ABI to measure 'cognitive problems' at follow-up and found that group average scores decreased, indicating improvements in cognitive functioning. Wilson et al (2012) also used Addenbrooke's Cognitive Examination (ACE-R; Mioshi et al, 2006) to measure cognitive functioning, although this instrument was only administered following referral to the service and not at follow-up. The neurocognitive outcome measures used in these 4 studies provide evidence for preserved general intellectual functioning, coupled with enduring deficits in the domains of memory and executive functions such as inhibition. These outcome measures are appropriate because they tap into the underlying neuropathology associated with ARBD, such as damage to diencephalic brain regions such as the mammillary bodies, anterior thalamus, mammillothalamic tract and hippocampus (Kril & Harper, 2012; Zahr et al, 2011), as well as damage to the prefrontal circuitry involved in higher order executive functions such as behavioural inhibition (Oscar-Berman, 2012).

Discussion

The seven studies included in this review indicate that a range of domains have been used in investigating ARBD outcomes, including accommodation type and provision of support; drinking status; employment status; number of deaths; mental health and psychiatric symptoms; activities of daily living; and social and cognitive functioning. Nevertheless, the scarcity of existing ARBD outcomes studies demonstrates a lack of longitudinal ARBD evidence and indicates that this area of investigation is currently under-researched. Within the reviewed papers, there was a lack of consistency in terms of the outcome measures used. Furthermore, discrepancies were noted in the time frames used, with patients being followed up over periods ranging from eight months (Lenanne, 1986) to three years (Blansjaar et al, 1992). As only three of the identified studies were conducted within the last decade (Fujiwara et al, 2008; Irvine and Mawhinney, 2008; Wilson et al, 2012), this review also revealed that there is a paucity of up-to-date research evidence concerning ARBD outcomes.

The most frequently reported outcomes were drinking status, cognitive functioning and number of deaths, all of which were measured in four of the reviewed studies. At follow-up, approximately half of the 104 individuals in Lenanne's (1986) study were abstinent from alcohol, whilst around a third of the 37 participants in Price et al's (1988) study were abstinent. All four participants in Irvine and Mawhinney's (2008) study were abstinent at follow-up, with one of them having had a single incidence of relapse. Approximately three quarters of the 41 participants in Wilson et al's (2012) study were abstinent at follow-up. Taken together, these findings reveal that around one third to three quarters of individuals with ARBD were abstinent from alcohol at follow-up periods of approximately one to two years. Although these findings are based on a small number of disparate studies, they suggest that a significant proportion of individuals with ARBD may return to controlled or uncontrolled drinking following detoxification. Thomson et al (2012) noted that abstinence from alcohol is crucial in aiding recovery from ARBD. It is therefore crucial that ARBD services employ relapse prevention strategies (Hendershot et al, 2011), as well as pharmacological treatments such as disulfiram (Kalra et al, 2014), acamprosate and

naltrexone (Maisel et al, 2013), to facilitate recovery from ARBD and to prevent unnecessary hospital readmissions due to continued alcohol misuse.

The reviewed studies also provided evidence to suggest that cognitive deficits remain relatively stable over time in people with ARBD (Blansjaar et al, 1992; Fujiwara et al, 2008). Nevertheless, Fujiwara et al's (2008) participants scored within the normative range on the NART measure of premorbid intelligence as well as on the MMSE. Furthermore, Noel et al's (2001) participant scored within the normal range on measures of selective attention, speed processing and abstract reasoning throughout the duration of the study, and was found to improve on all neurocognitive domains apart from episodic memory and response inhibition. Wilson et al (2008) reported that group ratings on the 'cognitive problems' domain of the Honos-ABI (Fleminger, 1999) were lower upon follow-up, suggesting that cognitive recovery is possible. As a whole, these findings from these four studies are indicative of sustained deficits in memory and executive functioning over time, although they also suggest that people with ARBD may have some capacity for cognitive improvement. Despite the limited nature of this evidence, it is important that ARBD services incorporate cognitive rehabilitation strategies such as errorless learning, visual imagery and semantic processing, as well as compensatory strategies such as memory aids and environmental modifications, to facilitate improvements in service users' cognitive functioning (Horton et al, 2014b).

The four studies reporting number of deaths revealed that the proportion of deaths was between around 10% (Lenanne, 1986; Blansjaar et al, 1992; Wilson et al, 2012) and 19% (Price et al, 1988) at follow up. Participants' ages ranged from early-forties to mid-sixties, with the average age of participants falling at early to mid-fifties in all four studies. The average life expectancy for people living in the countries where these studies took place was 81 to 83 years in 2012 for the United Kingdom, Netherlands and Australia respectively (World Health Organisation, 2014). As participants ages ranged from early forties to mid-sixties, the findings from the reviewed studies suggest that ARBD is associated with reduced life expectancy.

Nevertheless, these four studies also reveal that there is a lack of large scale, up-to-date evidence for ARBD mortality rates. It is therefore difficult to ascertain whether the reported proportion of deaths can be generalised to the wider population of individuals with ARBD. In order to elucidate the relationship between ARBD and premature mortality, there is a clear need for epidemiological research into ARBD mortality rates to be conducted.

Type of accommodation and provision of support, mental health status and social functioning all appeared in a total of three of the reviewed studies, making these outcomes the next most frequently reported. Only around one quarter of the participants in Price et al's (1988) study were successfully placed at follow up, compared to around half of the participants in Lenanne's (1986) study. In Lenanne (1986) and Wilson et al's (2012) studies, approximately 40% of participants were residing in supported accommodation at follow up, whilst a small minority were living in nursing homes. Lenanne (1986) reported that only 2 participants were living independently, whilst 17 individuals in Wilson et al's (2012) study were receiving support in their own homes at follow up. Although these findings are not sufficiently robust to make generalisations with confidence, they do suggest that only a small minority of people with ARBD may return successfully to independent living within one to two years of being hospitalised or attending community rehabilitation services. The findings also suggest that the majority of people with ARBD will continue to require some degree of long-term support, either within supported accommodation or in their own homes.

Mental health and social functioning were measured by Blansjaar (1992), Irvine and Mawhinney (2008) and Wilson et al (2012). Three standardised outcome measures were used to measure psychiatric symptoms (CES-D, Radloff, 1977; BPRS-E, Overall & Gorham, 1992; Honos-ABI, Fleming, 1999). Social functioning was also measured using standardised assessment tools (GSDS, Wiersma et al, 1988; Honos-ABI, Fleming, 1999; LSP, Rosen et al, 2006). Collating the findings from these studies, comorbid depression and anxiety was found in a minority of

participants, whilst pathological levels grandiosity and disorientation were found in approximately half of the participants in Blansjaar's (1992) study. Although grandiosity was rated within the pathological range, Blansjaar et al (1992) noted that this reflected participants' denial, or lack of insight into their amnesia, rather than grandiosity per se. Blansjaar et al's (1992) findings also suggest that ARBD is associated with long-term deficits in social functioning, particularly within nursing homes, although improvements in social functioning over time are possible (Blansjaar et al, 1992; Wilson et al, 1992). It is not possible to generalise these findings due to the relatively small sample sizes, inconsistencies in the way the outcomes were measured and differences in service provision across the studies. Moreover, as the identified mental health and social functioning outcome measures have not specifically been validated with ARBD, further research is required to confirm which instruments are psychometrically sound for use with this client group.

Activities of daily living were measured in two of the studies (Irvine & Mawhinney, 2008; Wilson et al, 2012), whilst employment status was measured in only one study (Lenanne, 1986). These studies revealed long-term problems with performing basic self-care and instrumental daily activities, with only a minority of individuals with ARBD functioning effectively with no need for support. Only a small minority of individuals were engaged in vocational activity at follow-up in Lenanne's (1986) study, suggesting that the majority of people with ARBD do not return to work, whether in a paid or unpaid capacity. These findings raise questions about the long term potential for people with ARBD to return to independent living. Nevertheless the wider applicability of these findings may be limited, especially as Lenanne's study was conducted almost thirty years ago in an Australian context, before the current welfare to work agenda was implemented in the UK (Department for Work and Pensions, 2012).

This review revealed that there is a clear lack of research into ARBD outcomes and a scarcity of randomised-control trials measuring the clinical effectiveness of ARBD interventions. It is therefore difficult to make any conclusions about the outcomes

arising from specific health and social care interventions for ARBD. Changes in policy, practice and service provision over time also make it difficult to ascertain which factors lead to the reported outcomes. As the reviewed studies were conducted at different time periods in a range of geographical contexts including the UK, Australia, Germany, Ireland, Belgium and the Netherlands, their findings may be of limited applicability within the current UK context.

In accordance with current UK policy (NICE, 2011; DoH, 2013a; DoH, 2013b), there is a clear need for further research into clinically relevant ARBD outcomes. In particular, the development of a 'core outcome set' is warranted to provide evidence-based recommendations for which outcome measures should be used by ARBD researchers and practitioners (COMET Initiative, 2014). The existing recommendations for dementia and traumatic brain injury outcome measures include perceived health-related quality of life and health economic measures (Moniz-Cook et al, 2008; Wilde et al, 2012). Both of these outcome domains were absent from the reviewed studies. Future ARBD outcomes research should therefore incorporate these measures, especially as quality of life is one of the key outcome domains in the current NHS and social care outcomes frameworks (DoH, 2013a; DoH, 2013b). As one of the central aims of current ARBD services is to promote functional recovery and independence (Thomson et al, 2012; Wilson et al, 2012), research focussing on functional outcomes is also an important area of future enquiry.

Conclusion

This review demonstrates that a number of ARBD outcome domains have been studied in the last thirty years, although the sparsity of the existing evidence base indicates that ARBD outcomes research is in its infancy. It is difficult to extrapolate the findings from this review beyond the identified studies due to their relatively small sample sizes, as well as the paucity of up-to-date studies reflecting current policy and ARBD service provision. Despite these limitations, this review suggests that several outcome domains should be taken into account within ARBD services. The

identified outcomes reflect the complex and heterogeneous nature of this population and indicate that health and social care interventions for ARBD should be individualised to meet the unique needs of service users, whilst targeting all relevant outcome domains. It is anticipated that future research in this area will shed further light on the long-term outcomes for people with ARBD, particularly in the domains of health-related quality of life and functional recovery. Future outcomes research will also have wider implications for future ARBD service provision, as it may help to ascertain which specific intervention strategies have greatest clinical effectiveness.

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Declaration of interest

The authors report no conflicts of interest.

References

Bardenhagen, F.J., Oscar-Berman, M. & Bowden, S.C. (2007). Rule knowledge aids performance on spatial and object alternation tasks by alcoholic patients with and without Korsakoff's amnesia. *Neuropsychiatric Disease and Treatment*, 3, 6, 907-918.

Blansjaar, B.A., Takens, H. & Zwinderman, A.H. (1992). The course of alcohol amnesic disorder: a three-year follow-up study of clinical signs and social disabilities. *Acta Psychiatr Scand*, 86, 240-246.

Burgess, P.W. & Shallice, T. (1996). Response suppression, initiation and strategy use following frontal lobe lesions. *Neuropsychologia*, 34, pp.263-273.

Buschke, H. (1973). Selective reminding for analysis of memory and learning. *Journal of Verbal Learning and Verbal Behaviour*, 12, pp. 543-550.

Cermak, L.S. (1975). Imagery as an aid to retrieval for Korsakoff patients. *Cortex*, 11, 163-169.

Cermak, L.S. (1980). Improving Retention in Alcoholic Korsakoff Patients. *Journal of Studies on Alcohol*, 41, 1, 159-169.

COMET Initiative. (2014). Available at: <http://www.comet-initiative.org/> [Accessed 27 June 2014].

Delis, D.C., Kramer, J.G., Kaplan, E. & Ober, B.A. (1987). *The California Verbal Learning Test*. New York, Psychological Corporation.

Department for Work and Pensions (2012). The Work Programme. Department for Work and Pensions. Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/49884/the-work-programme.pdf [Accessed 27 June 2014].

Department of Health. (2013a). The NHS Outcomes Framework 2014/15, Department of Health. Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256456/NHS_outcomes.pdf [Accessed 27 June 2014].

Department of Health. (2013b) The Adult Social Care Outcomes Framework 2014/15. Department of Health. Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256456/NHS_outcomes.pdf [Accessed 27 June 2014].

Fleminger, S. & Powell, J. (1999) Evaluation of outcomes in brain injury rehabilitation. *Neuropsychological Rehabilitation* 9, 225 -230.

Folstein M., Folstein S.E. & McHugh P.R. (1975) 'Mini-Mental State' a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 12, 189–198.

Fujiwara E., Brand M., Borsutzky S., et al. (2008) Cognitive performance of detoxified alcoholic

Korsakoff syndrome patients remains stable over two years. *Journal of Clinical and Experimental Neuropsychology* 30, 576–587.

Ganzelvels, P.G.J., Geus, B.W.J. & Wester, A.J. (1994) Cognitive and behavioural aspects of Korsakoff's syndrome: the effect of special Korsakoff wards in a general hospital. *Tijdschrift voor Alcohol Drugs en Andere Psychotrope Stoffen*, 20, 20–31.

Horton, L., Duffy, T. & Martin, C.R. (2014a). Comprehensive assessment of alcohol-related brain damage (ARBD): Gap or chasm in the evidence? *Journal of Psychiatric and Mental Health Nursing*, Published online 21 May 2014.

Horton, L., Duffy, T. & Martin, C.R. (2014b) Interventions for alcohol-related brain damage (ARBD): Do specific approaches restrict the evolution of comprehensive patient care? *Drugs: Education, Prevention and Policy*, 21(5), 408-419.

Irvine, C. & Mawhinney, S. (2008). Functioning of individuals with Korsakoff's syndrome: a pilot study of supported group living in Northern Ireland. *Mental Health Review Journal*, 13, 16-23.

Kril, J.J. & Harper, C.G. (2012), *Neuroanatomy and Neuropathology associated with Korsakoff's Syndrome*. *Neuropsychological Review*, 22(2), 72-80.

Komatsu, S., Mimura, M., Kato, M., Wakamatsu, N. & Kashima, H. (2000). Errorless and Effortful Processes Involved in the Learning of Face-Name Associations by Patients with Alcoholic Korsakoff's Syndrome. *Neuropsychological Rehabilitation*, 10, 2, 113-132.

Kopelman, M.D., Thomson, A.D., Guerrini, I. & Marshall, E.J. (2009). The Korsakoff Syndrome: Clinical Aspects, psychology and treatment. *Alcohol and Alcoholism*, 44, 148-154.

Lennane, K.J. (1986). Management of moderate to severe alcohol-related brain damage (Korsakoff's syndrome). *The Medical Journal of Australia*, 145, 136-143.

MacRae, S. & Cox, S. (2003). Meeting the needs of people with alcohol-related brain damage: A literature review on the existing and recommended service provision and models of care. University of Stirling.

Miller, E. (2010). Can the shift from needs-led to outcomes-focused assessment in health and social care deliver on policy priorities? *Research, Policy and Planning*, 28, 2, 115-127.

Mimura, M., Komatsu, S., Kato, M., Yoshimasu, H., Wakamatsu, N. & Kashima, H. (1998). Memory for Subject Performed Tasks in Patients with Korsakoff Syndrome. *Cortex*, 34, 297-303.

Mimura, M., Komatsu, S., Kato, M., Yoshimasu, H., Moriyama, Y. & Kashima, H. (2005). Further evidence for a comparable memory advantage of self-performed tasks in Korsakoff's syndrome and nonamnesic control subjects. *Journal of the International Neuropsychological Society*, 11, 545-553.

Mioshi, E., Dawson, K., Mitchell, J., Arnold, R. & Hodges, J.R. (2006). The Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry*, 21, 1078-1095.

Moher D., Liberati A., Tetzlaff J., et al. (2009) Preferred reporting for systematic reviews and meta-analyses: the PRISMA statement. *Journal of Clinical Epidemiology* 62, 1006–1012.

Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., De Vugt, M., et al. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care, *Aging & Mental Health*, 12, 1, 14-29.

Morrison, F. & Pestell, S. (2010). The application of cognitive behaviour therapy to individuals with co-morbid depression and alcohol-related brain damage. *Clinical Psychology Forum*, 206, 13-18.

National Institute for Health and Clinical Excellence. (2011). Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence. Manchester: National Institute for Health and Clinical Excellence.

Nelson H.E. & Willison J.R. (1991) *The Revised National Adult Reading Test-Test Manual*. NFER-Nelson, Windsor, UK.

Noel, X., Schmidt, N., Van der Linden, M., Sferrazza, R., Hanak, C., De Mol., J., Kornreich, C., Pelc, I. & Verbanck, P. (2001). An Atypical Neuropsychological Profile of a Korsakoff Syndrome Patient throughout the Follow-Up, *European Neurology*, 46, pp140-147.

Oscar-Berman, M. (2012). Function and Dysfunction in Prefrontal Brain Circuitry in Alcoholic Korsakoff's Syndrome, *Neuropsychological Review*, 22(2), 154-169.

Osterreith P.A. (1944) Le Test du copie d'une figure complexe/test of copying a complex figure: contribution to the study of perception and memory. *Archives of Psychology* 30, 206–356.

Overall, J.E. & Gorham, D.R. (1962). The Brief Psychiatric Rating Scale. *Psychol Rep*, 10, 799-812.

Peterson, L.R., & Peterson, M.J. (1959). Short-term retention of individual verbal items. *Journal of Experimental Psychology*, 58, pp.193-198.

Price, J., Mitchell, S., Wiltshire, B., Graham, J. & Williams, G. (1988). A Follow-Up Study of Patients with Alcohol-Related Brain Damage in the Community, *Australian Drug and Alcohol Review*, 7, 83-87.

Radloff L.S. (1977) The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement* 1, 385–401.

Raven, J.C., Court, J.H & Raven, J. (1984). *Manual for Raven's Progressive Matrices and Vocabulary Scales*. London: HK Lewis & Co.

Rosen A., Hadzi-Pavlovic D., Parker G., et al. (2006). The Life Skills Profile: Background, Items and Scoring for the LSP-39, LSP-20 and the LSP-16. Available at: <http://blackdoginstitute.org.au/docs/LifeSkillsProfile.pdf> (accessed 27 June 2014).

Smith, I. & Hillman, A. (1999). Management of Alcohol Korsakoff Syndrome. *Advances in*

Psychiatric Treatment, 5, 271-278.

Spreeen, O., & Strauss, E. (1998) A compendium of neuropsychological tests: Administration, norms and commentary. 2nd edition, Oxford University Press, New York.

Svanberg, J. & Evans, J.J. 2013, Neuropsychological Rehabilitation in Alcohol-Related Brain Damage: A Systematic Review, Alcohol and Alcoholism, 1-8.

Tewes, U. (1991). Hamburg-Weschler-Intelligenztest für Erwachsene- Revision (HAWIE-R). Göttingen: Hogrefe.

Thomson, A.D., Guerrini, I. & Marshall, E.J. (2012a). The evolution and treatment of Korsakoff's syndrome: Out of sight, out of mind? Neuropsychology Review, 22, 81-92.

Van Damme, I. & d'Ydewalle, G. (2008). Elaborative processing in the Korsakoff syndrome: Context versus habit. Brain and Cognition, 67, 212-224.

Wechsler, D.A. (1945). A standardised memory scale for clinical use. J Psychol, 19, 87-95.

Wickens, D. (1970). Encoding categories of words: An empirical approach to memory. Psychological Review, 77, pp. 1-15.

Wilde, E.A., Whiteneck, G.G., Bogner, J., Bushnik, T., Cifu, D.X., Dikmen, S., et al. (2010). Recommendations for the use of common outcome measures in traumatic brain injury research. Arch Phys Med Rehabil, 91, 1650-1657.

Williamson, P.R. & Clarke, M. (2012). The COMET (Core Outcome Measures in Effectiveness Trials) Initiative: its role in improving Cochrane Reviews [editorial]. Cochrane Database Syts Rev. Available at: <http://www.thecochranelibrary.com/details/editorial/1797057/The-COMET-Core-Outcome-Measures-in-Effectiveness-Trials-Initiative-its-role-in-i.html> (Accessed 27 June 2014).

Wilson, B.A., Baddeley, A., Evans, J. & Shiel, A. (1994). Errorless learning in the rehabilitation of memory impaired people. *Neuropsychological Rehabilitation: An International Journal*, 4, 3, 307-326.

Wilson, K., Halsey, A., Macpherson, H., Billington, J., Hill, S., Johnson, G., Raju, K. & Abbott, P. (2012). The Psycho-Social Rehabilitation of Patients with Alcohol-Related Brain Damage in the Community, 47, 3, 304-311.

Wiersma, D., de Jong, A & Ormal, J. (1988). The Groningen Social Disabilities Schedule: development, relationship with the ICDH and psychometric properties. *Int J Rehab Res*, 3, 213-224.

Zahr, N.M., Kaufman, K.L. & Harper, C.G. (2011). Clinical and pathological features of alcohol-related brain damage. *Nature Reviews Neurology*, 7, 284-294.

Table 1: Outcomes identified from the reviewed papers

Authors	Sample Size and Diagnosis	Outcome Domains and Methods of Measurement
Lenanne (1986)	n = 104 ARBD	Type of accommodation Drinking status Provision of support Employment status: unemployed, sheltered workshop, paid employment Number of deaths
Price et al (1988)	n = 37 ARBD	Ability to ‘cope’ functionally (based on informants’ judgements) Drinking status Provision of support Number of deaths
Blansjaar et al (1992)	n = 44 Alcohol Amnestic Disorder (DSM-III-R)	Cognitive functioning : Mini Mental State Examination (MMSE); Wechsler Memory Scale (WMS); Raven’s standard Progressive Matrices Mental health and psychiatric symptoms: Brief Psychiatric Rating Scale –Expanded (BPRS-E) Social functioning: Groningen Social Disabilities Schedule (GSDS) Number of deaths
Noel et al (2001)	n = 1 Alcoholic Wernicke-Korsakoff Syndrome	Cognitive functioning: Raven’s Progressive Matrices; Brown-Peterson Task; Alpha Span Test; California Verbal Learning Test; Verbal Selective Reminding Test; Rey Complex Figure; AB-AC Task; Flexibility Test; Verbal Fluency Test; Stroop Test; Trail-Making Test; Hayling Test; Brixton Test; Tower of London
Fujiwara et al (2008)	n = 20 Alcohol-Induced Amnesic Syndrome (ICD-10) or Alcohol-Induced Persisting Amnestic Disorder (DSM-IV)	Cognitive functioning: MMSE; National Adult Reading Test (NART); Information subtest of Wechsler Adult Intelligence Scale – Revised (WAIS-R); Stroop Word Trial/Interference; Rey-Osterrieth figure Copy/Delayed; Digit Span Forward/Reversed; Memo Test Immediate/Delayed; FAS Test

Irvine and Mawhinney (2008)	n = 4 Korsakoff Syndrome	<p>Daily living skills: semi-structured interviews with KS individuals; monthly staff reports; Self-Care subscale of Life Skills Profile (LSP)</p> <p>Meaningful activities: semi-structured interviews with KS individuals; monthly staff reports; Social contact subscale of LSP</p> <p>Physical and mental health: semi-structured interviews with KS individuals; monthly staff reports; Centre for Epidemiological Studies Depression Scale (CES-D)</p> <p>Family involvement: semi-structured interviews with KS individuals; monthly staff reports</p> <p>Drinking status: semi-structured interviews with KS individuals; monthly staff reports</p>
Wilson et al (2012)	N = 41 ARBD	<p>Type of accommodation</p> <p>Drinking status</p> <p>Number of deaths</p> <p>Mental health and psychiatric symptoms, social functioning, activities of daily living and cognitive functioning: Health of the nation outcome scale-acquired brain damage (Honos-ABI)</p>

Figure 1: Flow of information through systematic review

