

Alcohol related brain damage:  
knowledge and attitudes of frontline  
care staff

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February 2005

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## **Introduction**

Concern about ARBD in Scotland led to the commissioning of an expert group on needs of people with ARBD by the Scottish Executive in 2003. The report from this group (Cox et al 2004) and the literature review complementing it (MacRae and Cox 2003) highlighted issues for further research. The Expert group found that there was little awareness of the condition among non-specialist service providers and, therefore, the needs of people with ARBD were not being met. This project aimed to look in more detail at the knowledge and attitudes of staff currently working with people with ARBD with two aims. First, to explore the knowledge and attitudes of staff working with people with ARBD exploring how their knowledge had developed. Second, to draw on their knowledge and experience to learn about caring for people with ARBD in care homes. The project also investigates the management of alcohol within care homes. The management of alcohol is influenced both by formal policy and by the knowledge and attitudes of care staff. This project explores these two aspects influencing alcohol management in care services, with the aim of providing useful information for care staff, their managers, the families and carers of people with ARBD.

The first part of this report reviews current literature on ARBD exploring both the medical and social aspects of the condition. The report goes on to describe the methods used within the research. The findings from the project are discussed in detail in the light of current research literature. In conclusion, recommendations for further research are outlined.

## **Background**

### **Introduction**

Alcohol related brain damage (ARBD) is an increasing challenge for service providers working with older people and adults. ARBD has a complex aetiology and medical treatment of the condition is important. ARBD does not show a progressive course in the same way as most other causes of dementia. There are also important social issues around the use of alcohol and society's attitude towards alcohol consumption.

Many people with ARBD are placed within services, which may or may not provide specialist care for them. The staff in these services often play an important part in the continued patterns of drinking of these individuals. Care staff may not have access to accurate information about ARBD and may not fully understand the implications of continued drinking for people with ARBD. It is still the case that many people with ARBD are not diagnosed as such and, therefore, are not recognised as having issues concerning alcohol. There is a good possibility of recovery from cognitive damage for people with ARBD but they may be denied this opportunity if the people caring for them do not understand their condition or have not been given the correct information concerning it. Alongside the possibility of incorrect or incomplete information the staff will also have their own ideas and attitudes around alcohol use and misuse. These attitudes may affect how they 'manage' alcohol within services. Alcohol Concern (2002: v) identifies frontline workers as a key network through which care can be enhanced through training and education. Recognition and understanding of ARBD by frontline care staff is important in providing good care and increasing the health and quality of life for individuals.

### *Alcohol in Scotland*

In the past thirty years there have been marked increases in problems related to alcohol reported within Scotland (Public Health Institute of Scotland 2002). The UK is within the top ten countries in the world in terms of alcohol consumption (World Drink Trends 2004) and within the UK people in Scotland and the north of England show the highest consumption (National Statistics 2002). One in four adults in the UK are drinking hazardously (Scottish Executive 2002a) with people aged between 16 and 24 in Scotland the most likely to exceed recommended limits (NHS Scotland 1998). Increasing numbers of women are drinking above recommended limits and women are more susceptible to alcohol-related health problems (Scottish Executive 2002b). This suggests that women and younger people will now be more likely to develop conditions such as ARBD. Traditionally and currently such conditions have the highest prevalence among men between 50 and 60 years (McRae and Cox 2003). ARBD is associated with deprivation and men within the most deprived areas in Scotland are seven times more likely to be admitted to hospital with an alcohol-related condition than those in least deprived areas (Public Health Institute of Scotland 2002).

## *Alcohol and older people*

People commonly recognised as having ARBD are typically men aged between 50 and 60 years old (Elleswei 2000; Price et al 1988; Chiang 2002). However, alcohol problems in older people are increasingly common (O'Connell et al. 2003; Simpson et al. 1994; Alcohol Concern 2002). This is due to a number of reasons including under-diagnosis of alcohol problems and ARBD in older people (Alcohol Concern 2002). Alcohol use by older people is often found to be associated with cognitive impairment caused by ARBD (Thomas and Rockwood 2001). Alcohol problems may not be identified by GPs or other primary care and frontline staff and older people rarely access specialist alcohol services (Thomas and Rockwood 2001; Simpson et al. 1994; O'Connell et al. 2003).

It has been found that significant numbers of people over 65 exceed recommended drinking limits (Wattis and Seymour 2000). These limits are usually set for the population in general and so may already represent excessive amounts for older people. Alcohol abuse is relatively common among older people, particularly men and those around 65 years of age (O'Connell et al 2003). Alcohol abuse in older people is often associated with cognitive impairment (Thomas and Rockwood 2001).

Traditionally alcohol services have not been available for older people and there has been a lack of appreciation of the problems associated with alcohol for older people (O'Connell et al 2003). Studies in the USA found that up to 15% of older people had problems associated with alcohol (Simpson et al. 1994). Studies in the UK find between 3-9% of older people drink to excess (Thomas and Rockwood 2001; Oslin et al. 1998). Generally, however, the amount individuals' drink decreases with age. People who have drunk to excess during their lives seldom live into later life. There is some indication that drinking among older people in the UK is increasing (Simpson et al. 1994). As there is an ageing population the number of older people with alcohol related problems is likely to increase (O'Connell et al. 2003).

Traditionally the social work approach to alcohol problems has been passive. There is an acceptance that people drink and that older people are too old for it to really matter (Simpson et al. 1994). This is often underpinned by the understandable, even laudable, aspiration to ensure protection of an individual's right to choice. However, coupled with this is a cultural acceptance of drinking which may cause people to overlook alcohol problems and a lack of training among social workers on the effects of alcohol and the potentially serious consequences of drinking for older people (O'Connell et al 2003). Early intervention is often successful in reversing or reducing alcohol problems and so this is a useful area for training among professionals. As discussed below an awareness of the effects of alcohol can be crucial in stopping and even reversing the effects of ARBD. It seems likely that alcohol abuse among older people is under attributed (Simpson et al. 1994; O'Connell et al 2003). This discussion indicates a lack of knowledge of alcohol problems among staff working with older people. It seems possible, that because of this, older people with ARBD are not diagnosed as such. In

addition, although many people diagnosed with ARBD are not over 65 many are cared for within services for older people, as is discussed further below.

## **Alcohol related brain damage**

### *What is ARBD?*

The term ARBD is used to refer to the range of conditions caused by excessive alcohol misuse which result in damage to the brain, leading to cognitive impairment. There are more specific terms such as Wernicke's encephalopathy and Korsakoff's syndrome which are encompassed by the term ARBD.

Alcohol causes damage to the brain in a number of ways:

- It has a toxic effect on the central nervous system
- It results in changes to metabolism, heart functioning and blood supply
- It interferes with the absorption of thiamine (Vitamin B1, an important brain nutrient)
- It is commonly associated with poor nutrition
- It can cause dehydration which may lead to wastage of brain cells
- It can lead to falls and accidents that injure the brain

(ARBIAS 2003)

There is an ongoing debate with regards to the nature of alcohol-related neurological conditions (Lishman 1990; Smith and Atkinson 1995; Oslin et al. 1998). Alcohol causes damage in two main ways and these are discussed below. There is debate as to whether these conditions both come under the single title of ARBD or should be seen as two distinct conditions. Within this report the two types of damage are treated as types of ARBD. In contrast Gow and Gilhooly (2003:68) state the different underlying causes result in two separate conditions.

The term Wernicke-Korsakoff syndrome refers to excessive alcohol consumption which results in thiamine deficiency in the brain damaging brain tissue. This deficiency first becomes apparent during Wernicke's encephalopathy. Wernicke's encephalopathy describes acute episodes of confusion, impairment of consciousness and problems with mobility. These acute episodes lead to the chronic condition of Korsakoff's psychosis which is characterised by persistent memory deficits (Smith and Atkinson 1998; Jacques and Stevenson 2000). These two conditions are seen as part of the same condition called Wernicke-Korsakoff syndrome. There is often oversimplification and over stress on Wernicke-Korsakoff syndrome and cases of alcohol related dementia may be misdiagnosed as Wernicke-Korsakoff syndrome (Lishman 1990).

Other terms such as alcohol related dementia, alcoholic brain damage, alcoholic dementia and so on refer to excessive alcohol consumption which affects the brain in a more diffuse manner causing more general cognitive

impairment. Alcohol is a neurotoxin and may result in shrinking of the brain. It is also probable that alcohol affects how blood perfuses the brain and it may also interfere with neurotransmitter systems (Crowe 1999; Lishman 1990).

This condition is more difficult to diagnose and its existence is a matter of debate (Oslin et al. 1998; Cutting 1978; Lishman 1990). Some people suggest that it is merely part of Wernicke-Korsakoff syndrome (Crowe 1990) while others state Wernicke-Korsakoff syndrome is a part of alcohol related dementia (Lishman 1990). Some argue that this condition is more common than Wernicke-Korsakoff syndrome (Oslin et al. 1998). More research needs to be done in this area. The differences between these two types of alcohol related brain damage are, however, important as they have different implications for treatment and the progression of the conditions.

Due to a lack of clear neuropathy and therefore clear definitions and diagnosis many professionals reject the concept of alcohol related dementia or do not make such a diagnosis (Oslin et al. 1998). Ascertaining alcohol histories is problematic and there is evidence that older people tend to under-report their alcohol consumption (Oslin et al. 1998). It also seems probable that alcohol is a contributing factor in other types of dementia. Studies in North America suggest that 21-24% of people with dementia have alcohol as a contributing factor of their condition but classifications are difficult (Smith and Atkinson 1995).

Within this discussion the term alcohol related brain damage (ARBD) is used to include all of these terms and conditions described above. There are a number of characteristics commonly associated with ARBD:

Cognitive and memory problems such as:

- Confusion about time and place
- Impaired attention and concentration
- Difficulty in processing new information
- Inability to screen out irrelevant information
- Confabulation
- Inaccurate accounts of recent events
- Apathy
- Depression and irritability

Physical problems such as:

- Ataxia - a gait disorder
- Damaged liver, stomach and pancreas
- Possibility of traumatic brain injury reducing cognition further
- Peripheral neuropathy – numbness, pins and needles, burning sensations or pain in hands, feet and legs

(MacRae and Cox 2003: 5)

Vulnerability to the effect of alcohol on the brain is highly variable. Differences in the patterns and types of drink may affect susceptibility, including the beverage chosen, thiamine content of beverage, patterns of drinking and patterns of dietary neglect (Lishman 1990; Cutting 1978). It is also probable that there are individual differences in susceptibility perhaps related to genetics (Goodwin 1999). There are two main types of damage as described above so there may be individuals who are naturally resistant to one or both kinds of damage or conversely susceptible to one or both kinds of damage although dual susceptibility seems rare.

### *Progression and treatment of ARBD*

ARBD has a better prognosis than other types of dementia (Smith and Atkinson 1995). In general one quarter of people with ARBD experience a full recovery, one quarter experience significant recovery, one quarter experience slight recovery and one quarter no recovery (Smith and Hillman 1999). The degree of cognitive recovery varies between individuals and depends on various factors relating to the extent of brain damage. Recovery also depends on the cause of brain damage. This fact emphasises the need for knowledge and awareness of the effects of alcohol misuse.

Abstinence from alcohol halts the progression of the condition and recovery may be seen. Acute episodes of Wernicke's encephalopathy can be treated with high doses of thiamine (vitamin B12) and the persistent effects of Korsakoff's syndrome can be prevented or reduced with abstinence and continued vitamin supplements and recovery can continue for up to two years (Elleswei 2000; Lishman 1990). Other types of ARBD respond to abstinence from alcohol (Elleswei 2000; Lishman 1990; Oslin et al. 1998).

For all types of ARBD it is shown that continued abstinence is crucial. Abstinence allows the brain to recover to different degrees. There is also evidence that people with ARBD remain particularly susceptible to the effects of alcohol. Following detoxification and treatment even small amounts of alcohol may adversely affect the individual (Cox et al 2004). This means that continued abstinence is an important part of support for people with ARBD. There is debate, however, among drug and alcohol professionals as to the effectiveness of promoting complete abstinence, often a policy of harm reduction is followed. Complete abstinence may be very difficult for many people with alcohol problems (Smith and Hillman 1999).

### *Other conditions associated with alcohol misuse*

Alcohol consumption is damaging to a number of physiological and neurological systems within the body. Excessive consumption of alcohol is implicated within many medical conditions including gastro-intestinal problems, seizures, head injury, cerebrovascular and cardiovascular disease and cancer (Cox et al 2004: 63). Alcohol has acute effects as in intoxication, semi-permanent effects and chronic, permanent effects. As discussed above,



alcohol causes vitamin deficiencies and can affect neurotransmitter systems (Crowe 1999).

Alcohol is often a contributory factor in depression (McIntosh and Ritson 2001). People with dementia often have a diagnosis of depression in addition to dementia and the link with alcohol is important to note. Alcohol may also disrupt sleep and has complicated interactions with prescription drugs (Wattis and Seymour 2001). Many residents of care homes take prescriptions drugs so this interaction is also important to consider.

As people age the safe level of alcohol consumption decreases. Alcohol has a stronger effect on the older body. This is due to different factors including increasing inefficiency of liver enzymes, reduced renal clearance and interaction of alcohol with medications (Cox et al 2004). Symptoms of alcohol problems may manifest at lower levels of alcohol consumption in older people. Alcohol consumption also increases the risk of falls and accidents.

### *Prevalence of ARBD*

The exact prevalence of ARBD is difficult to ascertain as it often remains undiagnosed. Awareness of ARBD is low among frontline workers in health and social care and therefore it is probably significantly under-diagnosed (MacRae and Cox 2003; Cox et al. 2004). It is also probable that people with ARBD and their families may conceal the condition. The general consensus is that the prevalence of ARBD is increasing in Scotland particularly in areas characterised by multiple deprivation. At present most people with ARBD are male although there are increasing numbers of women and the age of onset is decreasing (Smith and Hillman 1999; Elleswei 2000).

ARBD is a condition associated with socio-economic deprivation. There are population pockets where ARBD has a high prevalence related to socio-economic conditions (MacRae and Cox 2003). Individuals within deprived areas have higher prevalence rates of alcohol problems and poorer nutrition than those within areas with higher socio-economic status thus making them more susceptible to ARBD. These patterns are seen in the few epidemiological studies which have been undertaken on ARBD (MacRae and Cox 2003).

### **Social aspects of ARBD**

Problematic alcohol use through a lifetime affects many aspects of an individual's life. People with ARBD may have lost touch with family members or their relationships with them may be problematic or inconsistent (MacRae and Cox 2003; Cox et al 2004). It is possible that the individual's partner also has alcohol problems and there may be some co-dependence. This would make abstinence particularly difficult. Social networks are often formed around alcohol also making abstinence problematic. These factors mean that people with ARBD may have little social and family support. They face increasing social isolation as the symptoms of ARBD may make these fragile relationships even more difficult to sustain (Jacques 2000; Elleswei 2000).

People with ARBD may have had periods of unemployment due to their alcohol use and this will have led to periods of financial instability. This may affect their housing and make it difficult for them to secure a tenancy. Coupled with little family or social support this leads to many people with ARBD becoming homeless or having temporary and insecure housing (Cox et al 2004).

Currently there are many more men with ARBD than women but this is changing in relation to changing patterns of drinking over the past fifty years as discussed above. There are expected to be many more women with ARBD in the near future. This makes the social support for people with ARBD different. Men may be more likely to leave their family through problematic alcohol use and therefore end up with little social support whereas the situation for a woman with children may be different. These differences have important implications for services and how they should develop (MacRae and Cox 2003; Cox et al. 2004).

Another important aspect for all people with different forms of cognitive impairment or dementia including those with ARBD is the stigma associated with the condition. Younger people with dementia may particularly feel this as it is not generally understood that younger people get dementia. Younger people with dementia may also reject or deny that they have dementia as they see it as a condition of the 'old' (Keady and Nolan 1994). For people with ARBD the situation is more complex and may be more stigmatising. They may face stigmatisation on three levels: associated with alcohol, mental health problems and dementia (Cox et al 2004: 19). ARBD may be seen by many as a self-inflicted condition. As a society we accept that people drink but when they do this to excess our attitudes change and people are seen as having little control and being to blame for their problems relating to alcohol whether it be alcohol misuse or ARBD. Stigma is displayed by individuals but more importantly within institutions which may provide care and services for people with alcohol problems. There is further evidence that people with ARBD face stigma through the manner in which they are 'bounced' between services (Cox et al 2004) and this is discussed further below.

### *Carers of people with ARBD*

As discussed above people with ARBD may have limited social networks and contact with family members. However, for those people with ARBD who maintain social and family ties these individuals may fulfil the role of informal carer for the person with ARBD (Consultation Involvement Trust Scotland 2003). There are issues around caring for a younger person with a form of dementia such as ARBD. In one study 'carer burden' was found to be higher for carers of younger people with dementia regardless of the severity of dementia or the level of behavioural disturbance (Freyne et al. 1999). This difference is attributed to social factors relating to younger people with dementia. The lack of support and information available to carers of younger people with dementia means they often feel isolated and this increases the

challenge of caring (Parahoo et al. 2002). Family members and social contacts of people with ARBD may also have alcohol problems. Co-dependency may make it very difficult for a person with ARBD to maintain abstinence. In addition, family members may face stigma or they may hold prejudices of their own which make it difficult for them to care for people with ARBD. However, family networks are crucial in process of rehabilitation for people with ARBD (Jacques and Anderson 2002). Carers can support detoxification and ongoing abstinence. It may be the case that abstinence helps to repair relationships. The role of carers and services and support for them are, therefore, crucial when caring for people with ARBD. One study found that there is almost no support available to informal carers of people with ARBD despite their crucial role (Consultation Involvement Trust Scotland 2004).

### *Issues for service providers*

Identification of ARBD is often difficult and it is predicted that the incidence and prevalence of ARBD is under estimated (Cox et al 2004). Alcohol is often overlooked as a risk factor for dementia and as discussed above older people may hide the true extent of their alcohol intake (Oslin et al 1998). There is also little awareness of ARBD among service providers although this is changing. Improvement with abstinence may be one way of identifying ARBD. Woodburn and Johnstone (1999) find that improvement in cognitive ability following abstinence characterises the group of people with ARBD in their study.

When ARBD is identified it is crucial that medical support and treatment are provided as highlighted above. For individuals experiencing an acute episode of Wernicke's syndrome it is vital that intravenous thiamine is administered quickly (Elleswei 2000; Lishman 1990). Once ARBD has been identified there follows a lengthy period of recovery. People with ARBD may show improvement in their cognitive abilities for up to two years following detoxification with continued abstinence (Cox et al 2004; MacRae and Cox 2003). This means that the rehabilitation period for people with ARBD is lengthy and it may not be possible to predict an individual's future needs until two years following detoxification. This emphasises the need for good rehabilitation and assessment services for people with ARBD. An individual's needs may change considerably over this two year period.

Due to the differences in degree of recovery (Smith and Hillman 1999) people with ARBD may be left with a range of cognitive difficulties. People with ARBD who show almost full recovery may still need ongoing support to maintain their abstinence and initial support with financial needs and perhaps to gain a tenancy. Others may retain significant cognitive impairment and need ongoing support with daily living as well as support to remain abstinent.

This suggests that people with ARBD need support from alcohol specialists to help with detoxification and initial treatment and then follow up support perhaps in the form of counselling to maintain their abstinence and deal with

the background to their alcohol problems. Alcohol services are not, however, designed to support people with cognitive impairment and, therefore, people with ARBD may find that these services are not appropriate for them (Cox et al 2004).

People with ARBD do not clearly fit into one group of services making service provision problematic. Service providers and professionals may regard ARBD as 'not their problem' due to the complexity of the condition (Bouhey 2003). Alcohol services may meet some of their needs but may not be appropriate for people with cognitive impairment. Generic services for older people could provide long term care for people with ARBD and permanent cognitive impairment but many people with ARBD are often younger than 65 and have issues around their alcohol problems which older peoples' services may not be designed to cope with. In the same way specialist services for people with dementia may provide a useful response for people with ARBD but again may not be designed for people under 65 and may not have staff with the appropriate training to cope with alcohol problems.

Overall, there is a lack of services for younger people with dementia such as people with ARBD. Many younger people with dementia including people with ARBD are inappropriately placed within services for older people (Freyne et al. 1999; Cox et al 2004). More younger people with dementia are found to die in residential and nursing homes than ten or twenty years ago suggesting that more younger people with dementia are inappropriately placed within residential and nursing homes for older people (Kay et al. 2000). It seems likely that there are a considerable number of people with ARBD who have been inappropriately placed within residential care. Another effect of this may be that the individual is not given support with abstinence. They may not be correctly diagnosed and so may continue with a corresponding deterioration in their condition.

There are a growing number of specialist residential services for people with ARBD and these are often found to be a useful response. Specialist services provide appropriate rehabilitation and continued assessment and may provide opportunities for people with ARBD to move back to the community depending on their recovery (Cox et al 2004). The services investigated within this project include both specialist and non-specialist residential services.

## **Discussion**

The range of issues discussed above emphasises the importance that care staff have knowledge and understanding of the issues around alcohol and ARBD. The attitudes and knowledge of staff around alcohol issues affect how they relate to individuals with alcohol problems and also how alcohol is managed within care homes. This in turn affects whether alcohol problems are correctly identified and how they are managed. A member of staff who has experienced an alcoholic and perhaps abusive partner will have very different views and knowledge of alcohol problems than an individual without these experiences. Alcohol is a widely accepted part of society in Scotland

and attitudes towards it are complex and sometimes contradictory. Social drinking is accepted but when an individual crosses a given line they are often viewed with derision and distaste and may be stigmatised (Cox et al. 2004). An exploration of these attitudes will help in the design of educational packages on alcohol problems and ARBD for care staff as well as community groups.

Alcohol Concern (2002: v) identifies frontline workers as a key network through which care can be enhanced through training and education. Recognition and understanding of ARBD by frontline care staff is important in providing good care and increasing the health and quality of life for individuals. However, alcohol is a contentious issue and the management of alcohol for individuals in care homes and community settings is affected by the attitudes and knowledge of staff and managers. It is important to understand these as studies have found that many older people who abuse alcohol rely on other people for their supply of their alcohol (Wattis and Seymour 2001). The focus of this project is the west of Scotland where ARBD is an issue of concern. However, it is important to highlight that ARBD is also of concern in many other parts of the UK and Europe.

## Methodology

### Research methods

The principal aim of this proposal was to explore the understanding of ARBD among frontline care staff working in the community, specifically in care homes. This study further aimed to explore both knowledge about the effects of alcohol for people within care homes and the management of alcohol by frontline care staff.

Due to the small scope of this project the decision was taken to focus on care staff in care homes as a representative group of frontline care workers. It has been found that institutions such as care homes have a higher proportion of people with alcohol problems than community services (Alcohol Concern 2002). These care staff will be drawn from care homes for older people and specialist care homes for people with ARBD as these are the most likely places for people with ARBD to be placed. Although many people with ARBD are under 65 years of age they may be placed in older peoples' services when there are no other suitable services available.

The project involved a qualitative study based on twelve in-depth interviews with frontline care staff in care homes. Before the fieldwork, relevant literature was reviewed as discussed above. This review included academic research as well as reports and grey literature.

The fieldwork involved twelve interviews conducted by the researcher within four care homes in urban and rural areas in the west of Scotland. Within this report the care homes are referred to as Home A, B, C and D. Detail of the four homes and the sampling process are given below. The interviews were semi-structured and qualitative in nature allowing staff space to discuss questions at length but with enough structure to allow comparison between homes. The interviews explored the following themes:

Staff knowledge of:

- Perceived reasons for drinking alcohol
- Attitudes around alcohol
- Older people and drinking
- Use of alcohol within the home (alcohol policies, abstinence, harm reduction, control/choice of alcohol)
- Alcohol in the care home (ethics of control/choice)
- Effects of alcohol on cognition
- ARBD (prevalence, causes, treatment, management, terminology, experience of)
- Alcohol problems and older people (sleep, depression, interaction with prescription drugs)

The data from these interviews was tape-recorded and fully transcribed. These data were then analysed thematically drawing out more information on the key themes discussed above. In addition to this the data from different

homes was analysed comparatively. Due to the small scale and exploratory nature of this project it was not possible to reach saturation of the data during analysis. There was, however, enough consensus within the data to support the discussion within this report. In the analysis data about care staff knowledge is linked with data regarding their attitudes to alcohol in order to understand the processes by which alcohol is managed by care staff. The aim of this analysis is to tease out the key issues around managing alcohol and around recognition of and care for people with ARBD.

### **Ethical considerations**

The British Sociological Association code of research ethics (BSA 2002) was followed by the researcher. The project received an ethical review by an experienced researcher from the Department of Applied Social Science, University of Stirling prior to the project starting. Access to each home was negotiated directly by the researcher through a gatekeeper at each home. For Homes A, C and D the gate keeper was the manager of the home while in Home B it was the manager of the specialist unit for people with ARBD. None of the homes required a formal ethical review process. Issues of informed consent were given careful consideration. The research explored individual knowledge and attitudes and it was therefore important to stress anonymity and confidentiality for the participants. Each research participant was given specific information about the interviews and asked to sign a consent form before taking part in the research.

### **The fieldsites and interviewees**

Interviews took place in two nursing homes for older people (Homes C and D) and in two that offer specialist care for people with ARBD (Homes A and B) in the West of Scotland. All four homes had staff with some degree of knowledge about ARBD. Two homes were registered to work with people with ARBD, one worked exclusively with people with ARBD (Home B) while the second (Home A) worked with all adults with alcohol and drug misuse problems. The other two homes (Homes C and D) were nursing homes registered for 'elderly mentally infirm.' One of these had gained a reputation for looking after people with ARBD whilst the other had a high number of male residents some of which were diagnosed with ARBD and others who probably had the condition but with no formal diagnosis. ARBD is currently more common among men. This sampling of homes was undertaken to reduce the variables between homes and to focus on staff with some experience of working with people with ARBD. It was felt that these staff would offer more insight into caring for people with ARBD and the issues around managing alcohol in care homes. Three of the homes (Homes B, C and D) were in urban areas and the fourth (Home A) in a small village. Appendix A provides details of the numbers of residents with ARBD, registration of the home and other factors relating to each home.

Three members of staff were interviewed in each home and the manager in each completed a short questionnaire. A cross-section of staff was requested in each home and this meant that a range of staff with different backgrounds

and levels of experience were interviewed. Appendix B contains details of the twelve individuals who were interviewed. In the discussion that follows interview quotes are identified by the number given to each interviewee in Appendix B.



## Findings

### How is ARBD understood?

#### *Definition and medical and aspects of the condition*

With regard to terminology it was found that all of the staff used the term 'Korsakoff's' to describe ARBD. Some of the staff particularly those with nursing backgrounds recognised other terms such as alcoholic dementia and Wernicke's encephalopathy but did not use these terms frequently. The staff did not give clear definitions for Korsakoff's and few of them were clear about the effects of alcohol on the brain although all understood that alcohol could be damaging to the brain. Some talked of alcohol destroying brain cells but others did not know anything about this. Most understood some sort of link between poor nutrition and ARBD particularly concerning vitamin B. Staff with nursing backgrounds had more medical knowledge than the staff from care homes A and B although overall medical knowledge of the condition was limited.

*I would say it (Korsakoff's) is a type of brain damage caused by the alcohol because of the particular effect on the vitamin B. And the effect that, it is kind of more likely to have a very permanent (6)*

*Korsakoff's is a form of dementia more or less caused by alcohol abuse. (5)*

*I would say that Korsakoff's is caused by alcohol abuse, years of drinking alcohol and not eating. And it causes short-term memory, which is alcohol-related dementia. It is like a form of dementia that, you can remember years back but not two minutes ago. And it is caused by binge drinking of alcohol and not eating. (2)*

The staff were aware of a range of symptoms associated with ARBD. Most of the staff were clear that short-term memory loss was a key feature of ARBD; they also emphasised repetition as a characteristic of the way people with ARBD speak. Staff emphasised the complexity of ARBD and associated conditions and this is discussed further below. The main symptoms that staff described are short-term memory loss, repetition in speech, poor circulation leading to peripheral neuropathy and problems with mobility. People with ARBD who continue to drink are described as lacking in personal care and often neglect their personal hygiene and general self-care. The staff also described behavioural symptoms common to people with ARBD. One of these is volatility of mood. Some staff described people with ARBD as being like 'Jekyll and Hyde' especially if they had some alcohol. Their moods can change very suddenly and they may become aggressive. Several staff noted that people with ARBD react more strongly to alcohol, becoming more noticeably drunk and having worse hangovers that would be expected.

*I have seen that happen quite a lot. They want to fight ... But as I said you would have thought they had had a bottle and they have only had two drinks. (10)*

Staff seemed to have little idea about treatment for ARBD several were not aware of the types of medication they were administering. Most knew about vitamins although not all knew which particular vitamins the residents were receiving. Also, they were not clear why vitamins were given some thought these were simply to 'build up' the residents to counteract their poor diet. Some talked of other treatments to treat associated conditions such as depression and behavioural problems. The staff were also unclear with regards to the role of abstinence in the treatment of people with ARBD. Many staff felt that the damage had already been done and that continued drinking would not significantly worsen the brain damage the individual had sustained. They were more concerned that if residents continued to drink they would be more difficult to manage due to behavioural problems.

The range and depth of knowledge of the staff is unsurprising taking into account the lack of training available, discussed below, and also the confusion still existing in the research literature around this condition. The term Korsakoff's seems to have been adopted as a general term to describe people with cognitive impairment related to alcohol misuse. This enables the staff to understand the people they work with without needing more information on the specific medical aspects of the condition. The main significant missing piece of knowledge appears to be that around the benefits of abstinence as emphasised in the literature (Cox et al 2004; Smith and Hillman 1999).

Despite a seeming lack of knowledge on the medical and physiological side of the condition the staff did have a lot of knowledge and advice to give about working with people with ARBD. The complexity of the condition means that staff have to provide a wide ranging care package. For example, in home A the staff emphasised the importance of diet for the residents with ARBD, often working with the GP or a dietician and providing dietary supplements.

### *Complexity of the Condition*

In addition to the cognitive problems associated with ARBD all the staff interviewed were aware of associated multiple health problems both physical and mental which people with ARBD are prone to. These conditions relate to the effects of long-term alcohol misuse discussed above (Cox et al 2004). These conditions complicate the process of caring for this group. The main issues seemed to be nutrition, circulation and gait problems, behavioural problems and self-neglect.

*And we really have got to keep an eye on their health, their circulation and their eating, their nutritional habits because if they don't eat, and if they drink and don't eat they will get into all sorts of problems. (3)*

The issue of nutrition differed between the homes. Of all those interviewed the staff from home A put most stress on nutrition and spoke of working with dieticians regularly in order to improve the diet of their residents with ARBD. The staff spoke of an ongoing struggle to encourage these individuals to eat

well. This may relate to the alcohol policy of home, which allows most residents to continue drinking in a controlled manner. In contrast home B had few problems with nutrition once residents were settled in the home. In fact some staff mentioned the residents putting on a lot of weight and really enjoying their food. Staff from homes C and D did not in general mention nutrition specifically as an ongoing problem although one member of staff did mention it. As discussed, all staff were aware of the link between poor nutrition and ARBD and the need to treat people with ARBD with vitamin supplements.

Another side effect from long-term alcohol misuse is poor circulation and peripheral neuropathy. This often leaves people with ARBD with gait problems (MacRae and Cox 2003). Several staff from different homes talked of a 'Korsakoff's gait' a particular style of walking displayed by people with ARBD. Staff also spoke of continuing deterioration in mobility of some residents who eventually end up in a wheelchair or with other mobility aids.

The behavioural problems described by staff members include volatility in mood, aggression and problems relating to self-neglect. People with ARBD can show rapid mood changes and are described by staff as needing more patience and understanding than other residents. People with ARBD may be more likely to show aggression towards staff and other residents but staff explained that this was often linked to other issues and could be overcome. Some residents continue to need encouragement and prompting with personal care tasks following what may have been years of self-neglect.

*He has been a Korsakoff's for years and years and years. And Tom is really difficult to try and get him to.... He is tricky with his personal hygiene, dress appropriately, come up with meals, take an adequate diet. So you would try and address you know different issues. (5)*

Other residents had more complex long-term effects related to their long-term alcohol misuse including epilepsy, diabetes, seizures and skin problems.

*John has got a lot ... his legs are all ulcerated and he has got holes in his legs and under his feet. ... And this is where the drink obviously, you know years and years. He is diabetic you know, he is epileptic, all these things and he gets very, very frustrated. He is about 17 stones he is a big, big lad. And right now he canny walk because he canny put his weight on his feet because of his ulcers. (7)*

The staff discussed differences between people with ARBD and other types of dementia. Nearly all the staff had experience of working with other groups of people with dementia. The repetition noted in the speech of people with ARBD was seen as characteristic of this group and different to other people with dementia. People with ARBD are described as presenting as 'more normal' than other people with dementia, perhaps they are able to hide their condition more easily. The complexity of other physical conditions also sets people with ARBD aside from other people with dementia. Another important factor is age. Most people with ARBD are on average younger than other

people with dementia. The nursing homes in this study, homes C and D, despite being registered for 'elderly mental infirm' would take people with ARBD who were younger than 65. This younger age group often puts people with ARBD closer in age to staff compared with other residents. In the other two homes all the residents with ARBD were younger than 65. Several staff reflected that the age of the individuals with ARBD affects how they interact with them. One staff member felt that she could relate to them more easily as they were closer to her age. People with ARBD were also seen as more physically able and more prone to aggression and mood changes.

*Well the Korsakoff's tend to be I would say are probably more able and a bit on the younger side than some of the other ones as well. And can do a lot of their basic functional things but they can be very repetitive and quite irritable if they don't get their own way. But it is not deliberate. It is just like a short fuse and poor short-term memory. But they are still able to express themselves in some way. Whereas the other ones that we have got, it tends to be more physically poorer, physically more dependent, less aware of their sort of need for toilet. (6)*

This discussion highlights the challenges faced by staff working with people with ARBD. Cognitive and behavioural problems are complicated by physical conditions relating to long-term alcohol misuse. Staff working with this group have rarely been consulted before and this information has important implications for designing training and information for staff and service providers working with this group.

### **Working with people with ARBD**

From the interviews it seems that the two key elements to caring for this group are controlling alcohol intake and the approach taken by staff when working closely with people with ARBD.

With regards to working with people with ARBD, many of the staff stress the need to take a careful, somewhat cautious approach, allowing the residents to make decisions and maintain control over situations. People with ARBD can be volatile and some have particular trigger points, for example, waiting for a cigarette. Staff also stress the need for patience. This is seen as particularly necessary to cope with the repetition in speech that many people with ARBD show. The quote below gives advice on encouraging someone with ARBD to take a bath.

*For instance say if you went in and you just went over to one of the guys and went like 'Right that is your bath ready you are going for a bath'. And that person is just going to go 'Ahhhhhh. ... Whereas you don't do that, you don't go in and tell them what you are doing. Because some of these guys are a young age group so you don't go in there and tell them what you are doing. You don't even do that with elderly men anyway but. ... But I feel they kind of blow their top a wee bit more if they think they are getting told what to do. So I would say come down to their level and kind of talk them round'. (8)*

Many staff emphasised that people with ARBD are individuals and all react differently to their condition making it difficult to describe one approach to take to working with them. The fact that people with ARBD are younger than many other people with dementia seems to influence the staff's behaviour towards them. In the above quote there is some sense that the staff member thinks differently about the individual because he is younger and has to remind herself that she should behave in the same manner towards an older person. Residents with ARBD may be similar in age to staff members as discussed above and this can be stressful for staff who may relate closely to individuals.

### *Managing alcohol*

Each of the four homes had different policies in regard to alcohol consumption by residents. Home A, the specialist unit for people with drug and alcohol misuse problems had a formal but flexible approach to managing alcohol. Alcohol was available for residents and the home appeared to pursue a policy of harm reduction. All alcohol was kept by the staff and given to the residents as agreed in formal 'alcohol agreements' kept in their care plans. These were drawn up at review meetings and signed by the resident and key worker. These agreements often set out how many drinks an individual could have each day and of what kind. These drinks would then be dispensed by the staff. The agreements were often constrained by the budget available to each resident. Staff would encourage residents to drink different drinks such as those low in alcohol or less harmful to their digestive systems. Drinks such as cheap strong cider would be discouraged as a way of further controlling and limiting alcohol intake. The policy was seen as effective by staff although there were some problems as alcohol was available in shops a short walk from the home and residents would occasionally bring in additional alcohol or go to the local pub. Residents had been known to sell their possessions in return for more alcohol. The fact that the residents were still drinking also appeared to perpetuate other associated problems such as a poor diet. The staff within this home, as with most of the others, appeared to think the policy was necessary to prevent further problems for residents and staff as well as health problems for the residents. All the staff interviewed agreed with the policy and worked within its constraints.

In home B the specialist unit for people with ARBD there is no alcohol available at all. The residents are given non-alcoholic lager at the weekends but otherwise have no access to alcohol. Any alcohol brought into the home would be taken from them. Any residents unable to remain abstinent were usually moved on to other accommodation such as long term hospital care. This policy seems to help the residents in terms of physical health, most are on little medication and all eat well and have put on weight since entering the home. The staff, however, had reservations about the policy feeling that it was too strict. The staff interviewed felt that it would do the residents no harm to have one or two drinks at the weekend. They felt that the residents had gone past the stage of being problem drinkers and would not be harmed by a small amount of alcohol. The policy was a result of their officer in charge attending a training course on ARBD which had advised a policy of total abstinence. The manager of the specialist unit felt this policy was difficult to

adhere to and unfair on the residents as all the places they would go to, to relax involve alcohol. This made it difficult to arrange social outings for the residents. However, the staff stated that it was rare for the residents to actively seek alcohol. One other member of staff also had reservations about the policy, feeling it was too strict. This individual had personal experience of the problems of alcohol misuse but still felt that the residents should receive alcohol. This illustrates the cultural acceptance of alcohol in the West of Scotland. Both homes A and B had formal written alcohol policies for their residents created by their unit managers.

In the two nursing homes C and D there were very similar policies on alcohol. Alcohol was generally discouraged and residents could not keep their own. Alcohol would be provided at weekends and special occasions for those who wanted it. The staff would generally discourage people with ARBD from taking a drink or just give them a very weak drink. As these were nursing homes staff tended to have a more medical stance and were aware of issues such as the interaction of alcohol with various prescription drugs. One member of staff talked specifically of getting approval from a GP before alcohol would be offered to a resident. Another spoke of a total ban on alcohol because of the condition of the residents but this was not repeated by other staff members. Neither of the nursing homes had formal written policies regarding alcohol consumption by the residents and it was left to the unit managers to decide how or if it should be controlled.

It seems all of the homes control alcohol consumption to some extent and policies seem to be dictated by the managers of each home. These policies vary accordingly. The staff in general agreed with the alcohol policies followed.

*Yes I think it (the policy) is a very good.... It is very satisfying when we get a resident in who is rock bottom and seeing them gradually coming back up...They are putting on weight, they are tidy they are least getting cared for. They don't have sores on their body, you know with lying in the gutter. (2)*

*You have to have a control. You have to have some kind of control. It is a must. (2)*

*No everybody here, the residents, relatives and the GPs are quite happy with it. And if anybody wanted it particularly every night as I say we would arrange that if that is what they are having and it is not contraindicated by any thing that they are on.(6)*

Others questioned strict alcohol policies especially those in home B. Several felt that some amount of alcohol would not do the residents more harm. They were of the opinion that the damage had already been done to the brain of people with ARBD and that more alcohol would not increase or exacerbate this damage.

*A wee one occasionally wouldn't do them any more damage I don't think. (4)*

*they absolutely love getting this pint tumbler of non-alcoholic you know. ..And I feel that a wee can of Guinness ... They could enjoy a wee can of Guinness and that would be it. Because I think the guys we have got just now are kind of beyond the stage of wanting alcohol anyway but it would just be something that they enjoy a wee glass of it or something. (8)*

In home B there was the additional dilemma of providing the residents with non-alcoholic lager but effectively pretending it was alcoholic. The staff justified this pretence in two ways. Firstly they stated that all the residents had originally been told that the lager was non-alcoholic and secondly, they felt that the residents really enjoyed the drink and it was the highlight of their week.

*At the weekends and things like that and they are satisfied to them it is alcohol so that keeps them satisfied. I don't know if that is the right thing to do but we do it. And it does keep them happy, they are quite happy to get a wee glass of Kaliber (non-alcoholic lager). (7)*

The staff at all homes had an understanding of the social and physical problems that could arise if alcohol was not controlled by the homes. Many felt that the residents with ARBD would become more volatile or aggressive if they had a drink. Others had concerns about starting a cycle of addiction again. There were also concerns about worsening physical problems such as poor circulation and nutritional deficiencies. Few mentioned that continued drinking would cause further brain damage. Some, as described above, felt that one or two drinks now and again would not do any harm at all. All staff agreed, however, that alcohol had to be controlled in some manner for people with ARBD. No staff members questioned the basic right of institutions to control alcohol consumption.

At all of the homes except for home A, the individuals with ARBD had been through some sort of detoxification process, assisting the subsequent control of alcohol. One resident in home A was not allowed any alcohol and one of the reasons given for this was the fact that he had already completed a detoxification programme before entering the home.

*Because of his physical and mental problems it is difficult for him. He has been in hospital for a while. And well he was off the drink for a while so I mean why come in here and start him drinking again when the hospital had got him stabilised. (4)*

#### *Working with other professionals*

Few of the homes had close contact with other professionals and none with alcohol specialists. GPs, dieticians, psychiatrists and community psychiatric nurses (CPN) were the professionals most commonly involved in the care of the residents with ARBD. Home B had some input from the Richmond Fellowship who provided social activity for the residents. No alcohol specialists were involved in the care of the residents with ARBD. There were also problems with other professionals due to the nature of ARBD. The

condition does not fit easily into any single discipline box as illustrated in the quote below.

*We have got the CPN group who works with dementia who are saying that this chap has got more than dementia, he has got psychological problems. We have got the other group of CPNs who say 'No we are not working with him he is Korsakoff's and that is dementia'. So nobody will help us with him absolutely nobody. (9)*

The lack of involvement by alcohol specialists was not commented on by any of the staff. They did not seem to feel that this support was necessary for them or the residents with ARBD.

#### *Working with family members*

Staff described differences in family contact and support for individuals with ARBD. Long-term alcohol misuse can often lead to a break down in family ties and many people with ARBD have few family contacts (MacRae and Cox 2003; Cox et al 2004). The following quote illustrates this problem.

*Because it must be quite stressful in a family having somebody who is you know abusive towards alcohol and trying to run a home as well. You know if there are children or it is a big family. Or even a small family. You know that they have to look after daddy because daddy likes to go to the pub, that kind of stuff. (5)*

The residents with the ARBD in the four homes within this study had mixed contact with their families. A significant proportion had good links with family members and this seemed to depend on the individual and their family.

*The same with the ordinary dementia side, some people have got good relatives. Some people have got relatives that don't want to come up and see their relative in that condition. And there are some that have had a fall out over something that has nothing to do with the cause of the illness and they still don't come up and visit. So I don't think it is necessarily with the Korsakoff's, it is like everything else, there is always a reason. They will either come up or they won't. (6)*

In home C there was an example of a man with ARBD re-establishing contact with his son after thirty or so years. It may be possible that this contact will continue due to the father no longer drinking and having some stability in his life. Staff spoke of supportive relationships with family members who maintained contact. Family members would usually support and work within the alcohol policies of each home.

Working with people with ARBD appears to be a challenging task for care workers who develop their own strategies based on their experience. Working with people with ARBD in residential care is very much framed by the alcohol policies pursued by each establishment. Whether the home



advocates complete abstinence like B or a policy more akin to harm reduction, home A, effects the particular issues that staff face.

### **Frontline workers working with people with ARBD**

The frontline workers interviewed in this study are influenced by two main factors when working with people with ARBD. First, their own attitudes towards alcohol and alcohol misuse may influence how they relate to individuals with ARBD. Second, their knowledge and experience of ARBD and of working with this group will influence their behaviour and interactions with people with ARBD.

#### *Attitudes towards alcohol and alcohol misuse*

It was difficult to question the staff directly about their attitudes towards alcohol and alcohol misuse, instead they spoke about the causes of alcohol problems. In general the staff appear to see alcohol problems as stemming from the communities in which people live with social backgrounds influencing individual drinking patterns. Some pointed out that problem drinkers can be found in all parts of society, however, most staff emphasised the influence of social backgrounds characterised by socio-economic deprivation. One or two staff spoke specifically about the area in which the home was situated and the particular problems associated with that area. In general staff agreed that drinking was very much a part of the social culture of the West of Scotland. The staff also discussed what is different about people who become problem drinkers. They attributed this progression to particular traumatic life events such as bereavement and divorce. Others mentioned some innate predisposition or a hereditary component to alcohol problems. They described an insidious and gradual progression from drinking into problem drinking. Unsurprisingly they found it hard to pin down a specific reason for someone developing an alcohol problem.

*I mean personally I like a drink, but I can go months, years. But I have got three brothers who can make up for it you know what I mean? ... there are 14 in my family, know what I mean...It just depends, three of my brothers don't drink at all. I suppose there is no real reason you know. You try to explain it but you can't. (7)*

The staff were on the whole non-judgemental about people who have alcohol problems, several mentioned that it is a disease. Several used the term 'alcoholic' to describe problem drinkers although few gave any detail on what they mean.

*To me it is an illness none the less. I mean there is nobody taking them and pouring the drink down them but it is still, it is an illness they have. It is sad (1)*

*Okay they have brought it on themselves but it is still an illness that you have got to help. (9)*

These quotes, however, also show the staff felt the condition is self-inflicted indicating some element of blame placed on the residents with ARBD. This would suggest that the staff stigmatise the residents with ARBD to some extent. The staff also show compassion for the situations people find themselves in although there is a degree of pity is what they say. Particularly regarding people with ARBD whom the staff described as tragic figures.

*I don't know, I don't know I just feel some of their backgrounds they are so sad eh? (3)*

Staff distinguished between people with alcohol problems and people with ARBD and were clear that something different has happened to them. Many of them related this difference to a poor diet, understanding the link between ARBD and nutritional deficiency. Staff appeared to have more compassion for people with ARBD compared with people with alcohol problems. In some way they seemed to feel that it is unfair that they should end up with ARBD while others who drink heavily do not.

Staff related that there is some stigma or a lack of understanding in local communities regarding ARBD. Several stated this is the same stigma faced by all people with mental health problems. One manager did mention that when staff first started to work with people with ARBD they needed specific support and training to get over their own prejudices. As illustrated above, it may be that some staff still hold prejudices to some extent. Some felt these stigmas are changing and lessening but still described a lack of knowledge among most people with regards to ARBD.

*People that outside that you know and they will say 'Oh they are in with Korsakoff's. Och well it is their own fault they are in there, you know. They shouldn't have drank as much'. (4)*

The overall attitudes of the staff towards alcohol misuse and ARBD were not negative. The staff saw people with alcohol problems to some extent as victims of their circumstances and found it hard to articulate specific reasons for people developing alcohol problems. The staff seemed to show more compassion for people with ARBD who are coping with cognitive problems in addition to the physical problems brought on by alcohol misuse. From the interviews there was some indication that some staff may stigmatise people with ARBD to a small degree feeling that their condition is self-inflicted.

#### *Training, knowledge and experience*

Many of the staff had received no formal or specialist training on ARBD. The staff in home A gathered their knowledge through work experience and from their unit manager who would provide information on ARBD through supervision. One member of staff was unaware of ARBD before coming to work in home A and reflected that she had probably working with people with ARBD previously but had never been aware of it. The staff from homes C and D had received no training on ARBD or related issues. These were nursing homes and some staff remembered training on ARBD from their original

nursing training. The unit manager of home C had provided some additional information and informal training on ARBD. Home B had received one or two training sessions on ARBD from external professionals. They related, however, that their unit manager was always stressing that their experience was the most important thing and they did not really need training. One of these staff members related, however, that she would like more knowledge about the condition to help her understanding of the residents' behaviour.

This lack of formal training explains the staff members' lack of knowledge on the medical aspects of ARBD. They seem to have picked up bits and pieces of information about ARBD from various sources such as other staff members and non-specific training courses but this does not provide them with a coherent picture of the condition. Some of the staff had worked with people with ARBD for a substantial number of years and had developed expertise in working with this group through experience. As mentioned above, the staff in home B were considered by their officer in charge to have knowledge more valuable than that obtained from formal training. The staff in homes C and D were generally unconcerned about their lack of training although some in home C appeared embarrassed by their lack of knowledge. The Staff in home B spoke of the usefulness of the training they had received and were interested in gaining more training. Overall it appears that there is a lack of useful training around ARBD.

## **Discussion**

This project has raised some important issues about the care of people with ARBD in care homes and the experiences of staff working with this group. The project focused on frontline staff working with people with ARBD in order to explore the extent and detail of their knowledge about ARBD and also to examine their attitudes towards alcohol and alcohol problems. There is little available research and other literature on the experiences of frontline staff in general (Innes et al 2005) and less so for staff working with people with ARBD. This project illuminates the challenges faced by this group of staff.

Despite evidence in the literature that people with alcohol problems often lose contact with family members (MacRae and Cox 2003; Jacques 2000) the staff here spoke of good ties with many of the families of people with ARBD. Jacques and Anderson (2002) stress the importance of family carers in supporting rehabilitation for people with ARBD and this is reflected in the interviews here as staff report working closely with family members. It seems possible that good care and treatment for people with ARBD could help re-establish contact with family members.

The project found that staff lacked specific knowledge on the medical aspects of ARBD but had good knowledge of caring for this group and a clear understanding of the complexity of the condition. A lack of consensus on what ARBD is and how the different specific conditions relate to each other as found in the literature reviewed above (Lishman 1990; Smith and Atkinson 1995; Oslin et al 1998) suggests it is unsurprising that staff have little clear knowledge about the medical aspects of ARBD. Despite reporting little training specific to the condition the staff had developed an understanding of the complexity of the condition and of associated conditions.

The staff interviewed had a range of experience of working with people with ARBD. This experience seems to be the most important factor contributing to their knowledge of ARBD and working with people from this group. This experiential knowledge has not been tapped and could be drawn on to develop training and information for other groups of staff. The following sections highlight recommended future areas for research and the practical outcomes from this project.

### **Recommendations for future research**

- The staff interviewed in this project have a wealth of experience of working directly with people with ARBD. However, the scope of this study was small. Further research involving staff from a wider range of care homes and other services working with people with ARBD, such as those for homeless people, would provide a clearer picture of both the training and development needs of staff and the situation of many people with ARBD. Current research on this area is scarce as highlighted in the literature review. The knowledge of staff could be further drawn on to develop training packages.

- In this project the staff were interviewed but it was not possible to interview the people with ARBD about their experiences of living in the different care homes or of being cared for by the staff interviewed. The literature reviewed highlights the lack of information about the experiences of people with ARBD and their carers. The work of the Consultation Involvement Trust Scotland (2003) has gone some way to addressing this lack of knowledge but further work with these groups is necessary to fully understand their experiences and needs.
- Another major factor discussed within the project is that of managing alcohol in care homes. This was approached in very different ways by different homes although there was consensus on the fact that alcohol should be controlled within care homes to some degree. The management of alcohol appears to depend on the understanding and opinions of care home managers. As these people have their own attitudes to alcohol and alcohol problems this could be a fairly inconsistent approach. Further research on the management of alcohol in care homes is needed to ensure residents' needs are met and their rights are protected.

### **Project outcomes**

This project highlights the challenges faced by staff working with people with ARBD. Cognitive and behavioural problems are complicated by physical conditions relating to long-term alcohol misuse. Staff working with this group have rarely been consulted before and the information collected in this project has important implications for designing training and information packages for staff and service providers working with this group. The results of this project could be used in the development of a training package for frontline workers and their line managers on managing alcohol and caring for people with ARBD. It is also hoped that shorter written outputs will be disseminated through practice and peer-reviewed journals as well as a short project summary for all research participants and other interested parties.

## References

ARBIAS 2003. *Alcohol Related Brain Injury Looking Forward (Information pack)* Fitzroy, Australia: ARBIAS

Alcohol Concern. 2002. "Alcohol misuse among older people" *Acquire* 34 Autumn: I – viii Available at:  
[http://www.alcoholconcern.org.uk/files/20030801\\_134206\\_Older%20People%20factsheet.pdf](http://www.alcoholconcern.org.uk/files/20030801_134206_Older%20People%20factsheet.pdf)

British Sociological Association. 2002. "Statement of Ethical Practice" [Web Page]. Accessed Feb. 2005. Available at  
[http://www.britisoc.co.uk/new\\_site/user\\_doc/Ethicsguidelines2002.doc](http://www.britisoc.co.uk/new_site/user_doc/Ethicsguidelines2002.doc)

Boughey, L. 2003. "His problem? Her problem? Not OUR problem. Then whose problem?" *Signpost* 8(2):16-18

Chiang, C. C. P. 2002. *Wernicke Korsakoff Syndrome in Argyll and Clyde: A Literature Review, needs assessment and recommendation for the prevention, treatment and provision of Wernicke Korsakoff Syndrome*. Part II submission to the Faculty of Public Health Medicine

Consultation and Involvement Trust Scotland. 2003. *Consultation with people affected by alcohol related brain damage, and with people who care for them*. University of Stirling, Stirling: Dementia Services Development Centre

Cox, S., Anderson I. and McCabe L. 2004. *A Fuller Life: Report of the Expert Group on alcohol related brain damage*. University of Stirling, Stirling: Dementia Services Development Centre. Available at:  
[http://www.alcoholinformation.isdscotland.org/alcohol\\_misuse/files/ARBD\\_afullerlife.pdf](http://www.alcoholinformation.isdscotland.org/alcohol_misuse/files/ARBD_afullerlife.pdf)

Crowe, S. 1999. "Alcohol related brain impairment" in *Younger People with Dementia* S. Cox and J. Keady Editors London: Jessica Kingsley Publishers

Cutting, J. 1978. "The Relationship between Korsakov's Syndrome and 'Alcoholic Dementia'" *British Journal of Psychiatry* 132:240-51

Elleswei, R. 2000. "Caring for people with alcohol related brain injury" *Signpost* April:12-13

Freyne, A., Kidd, N., Coen, R. and Lawlor, B. 1999. "Burden in carers of dementia patients: higher levels in carers of younger sufferers" *International Journal of Geriatric Psychiatry* 14: 784-788

Goodwin, D. 1999. "Evidence for a genetic factor in alcoholism" in *Controversies in the Addiction Field* R. Engs Editor Dubuque: Kendall-Hunt Available at: <http://www.indiana.edu/~engs/cbook/index.html>

- Gow, J. and Gilhooly, M. 2003. *Risk factors for dementia and cognitive decline* Glasgow: NHS Health Scotland
- Innes, A., Macpherson, S. and McCabe, L. 2005. *Promoting person-centred care at the frontline* Report submitted to the Joseph Rowntree Foundation
- Jacques, A. 2000. "Alcohol related brain damage – the concerns of the mental welfare commission" *Alcohol and Alcoholism* 35(1): 11-15
- Jacques, A. and Anderson, K. 2002. *A survey of views in Assessment, Management and Service Provision for people with Korsakoff's syndrome and other chronic Alcohol –Related Brain Damage in Scotland* University of Stirling, Stirling: Dementia Services Development Centre
- Jacques, A. and Stevenson, G. 2000. *Korsakoff's Syndrome and Other Chronic Alcohol Related Brain Damage A Review of the Literature* University of Stirling, Stirling: Dementia Services Development Centre
- Kay, D., Forster, D. and Newens, A. 2000. "Long-term survival, place of death and death certification in clinically diagnosed pre-senile dementia in northern England" *The British Journal of Psychiatry* 177(2): 156-162
- Keady, J. and Nolan, M. 1994. "Younger onset dementia: developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers" *Journal of Advanced Nursing* 19:659-669
- Lishman, W. 1990. "Alcohol and the Brain" *British Journal of Psychiatry* 156:635-644
- MacRae, R. and 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: Dementia Services Development Centre. Available at <http://www.scotland.gov.uk/health/alcoholproblems/meetingneeds.pdf>
- McIntosh, C. and Ritson, B. 2001. "Treating depression complicated by substance misuse" *Advances in Psychiatric Treatment* 7: 537-364
- National Statistics 2002. *Drinking: Adults' Behaviour and Knowledge in 2002* London: Office for National Statistics
- NHS Scotland 1998. *The Scottish Health Survey 1998* Available at: <http://www.show.scot.nhs.uk/scottishhealthsurvey/sh809-01.html>
- O'Connell, H., Chin, A., Cunningham, C. and Lawlor, B. 2003. "Alcohol use disorders in elderly people – redefining an age old problem in old age" *British Medical Journal* 327:664-7

- Oslin, D., Atkinson, R., Smith, D. and Hendrie, H. 1998. "Alcohol related dementia: a proposed clinical criteria" *International Journal of Geriatric Psychiatry* 13:203-212
- Parahoo, K., Campbell, A and Scoltock, C. 2002. "An evaluation of a domiciliary respite service for younger people with dementia" *Journal of Evaluation in Clinical Practice* 8(4): 377-385
- Price, J., Mitchell, S., Wiltshire, B., Graham, J. and 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
- Public Health Institute of Scotland 2002. *Scottish Needs Assessment Programme: Liaison Psychiatry and Psychology* Available at: <http://www.phis.org.uk/doc.pl?file=publications/liaison%20psych%20report.doc>
- Scottish Executive 2002a. *Plan for Action on Alcohol Problems* Edinburgh: Scottish Executive
- Scottish Executive 2002b *Towards a Plan for Action on Alcohol Misuse: Responses to the Written Consultation* Edinburgh: Scottish Executive Central Research Unit
- Simpson, M., Williams, B. and Kendrick, A. 1994. "Alcohol and elderly people: An Overview of the Literature for Social Work" *Ageing and Society* 14:575-587
- Smith, D. and Atkinson, R. 1995. "Alcoholism and Dementia" *The International Journal of Addictions* 30(13 &14):1843-1869
- Smith, I. and A. Hillman 1999. "Management of alcohol Korsakoff's syndrome" *Advances in Psychiatric Treatment* 5:271-278
- Thomas, V. and K. Rockwood. 2001. "Alcohol abuse, cognitive impairment and mortality among older people" *Journal of the American Geriatric Association* 49:415-420
- Wattis, J. P. and Seymour, J. 2001. "Alcohol Abuse in Elderly People: overview and Summary" In: *Alcohol and Coffee use in the aging* Watson, R. (Editor) London: CRC Press
- Woodburn, K. and Johnstone, E. 1999. "Ascertainment of a population if a people with early-onset dementia in Lothian, Scotland" *International Journal of Geriatric Psychiatry* 14: 362-367
- World Drink Trends 2004. WARC Published in association with Commissie Gedistilleerd



## Appendix A – The fieldsites

Home	Registration of home	Origin of specialism	Alcohol policy of home	Number of people with ARBD	Where people with ARBD referred from
A	Adults with mental health problems related to substance abuse problems	Specialism has developed over 15 years following first admission of a person with ARBD. By being willing to take people with ARBD now receive many referrals and have gained a good reputation for caring for this group	Written alcohol policy based round 'alcohol agreements' drawn up by residents and staff together. Policy appears to pursue aim of harm reduction, alcohol is managed by staff	15 out of 44 residents	Most referrals come through social work departments from across Scotland. Usually come from hospital where they will have undergone detoxification and had a rigorous assessment
B	Elderly care home but with specialist 6-bedded unit specifically for people with ARBD	A need was identified to move people with ARBD from large long stay health institutions back into their own community and so specialist unit set up	Clear written alcohol policy that states that none of the residents with ARBD are allowed alcohol. Residents may be given alcohol free lager. Residents unable to comply with policy usually move on	6 in small specialist unit within larger residential home for older people	Most referrals come from local social work teams but still some problems with misdiagnosis, referrals for people with alcohol problems but who do not have ARBD
C	Elderly mentally infirm nursing home	Current unit manager has an interest in people with ARBD and through word of mouth more referrals for people with ARBD are made. This is not a group that is widely accepted by other care homes in the area	No written alcohol policy for residents. Generally alcohol is discouraged but given on special occasions to those who do not have conditions that would be exacerbated by alcohol such as ARBD	15 out of 60 residents	Referrals come from acute health services following hospital admission for other reasons, through geriatric services, through psychiatric assessment team
D	Organic mental health problems nursing home	No specialism	No written policy but no tolerance policy promoted. This contradicts what some staff members reported in interviews.	Approximately 4-5 out of 63 residents although thought to be more but many do not have a formal diagnosis and case histories are incomplete	All referrals from local hospitals. Diagnosis of ARBD would be made by psychogeriatrician

## Appendix B – The interviewees

Interview number	Home	Gender	Age	Job title	Number of years in post	Qualifications
1	A	Female	29	Care assistant	11	SVQ II and III
2	A	Female	52	Team leader	14 – 8 as a team leader	SVQ III
3	A	Female	65	Unit assistant manager	1 but 23 in care industry	SVQ III
7	B	Male	49	Social care worker	10 – 6 years in specialist unit	None – currently planning to take SVQ III
8	B	Female	32	Social care worker	5	Waiting to start SVQ III
9	B	Female	54	Team leader responsible for specialist unit	15 – 6 years in specialist unit	SVQ III
4	C	Female	41	Care assistant	10	None – currently completing SVQ III
5	C	Male	56	Staff nurse	5	Nursing qualifications
6	C	Female	41	Deputy manger	Less than a year but nursing for 15	RMN
10	D	Female	58	Nursing assistant	7 – in care work for 32	none
11	D	Male	47	Enrolled nurse D grade	2 – in nursing work for 28 years	Nursing certificate
12	D	Female	39	Nursing assistant	12	none