Manual: source literature The management of patients with severe alcohol related brain damage (ARBD)

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Overview

Most patients, presenting acutely with alcohol related brain damage do so through general hospital settings or through critical clinical situations within community settings (Smith et al 1999, Elleswei 2000). The less obvious presentation is associated with an insidious onset, often presenting with dysexecutive syndrome and related frontal lobe symptoms. These patients may come to the attention of community service providers, including alcohol treatment services (Harper, et al, 1986; Torvik et al 1982). Concomitant cerebro-vascular disease and/or traumatic brain injury is common (Jones, 1989; Tarter & Edwards, 1986; Weinstein & Martin, 1995, Woodburn and Johnstone 1999).

In both situations, the initial psycho-social assessment of patients with alcohol related brain damage is usually conducted over a number of interviews over the first two to three months of abstinence. As the patients' conditions will change; rehabilitation plans will be informed by ongoing assessments over the following two to three years.

Patient identification

We have used a two stage process to screen for patients on acute medical wards for severe alcohol related brain damage, this includes an adaptation of Oslin's criteria (2003) as a preliminary screening tool; utilising demographic and hospital based data. We reviewed the first 19 patients accepted by the service in the Wirral and devised a simple check sheet for the use of nurses working on acute medical wards so as to facilitate referral of patients of high risk of experiencing ARBD. The preliminary screening instrument a consists of the following items

- 1. Probable history of heavy, long standing alcohol drinking: 35 units or more a week for at least five years.
- 2. Confusion, memory problems, doubt about capacity, concerns about risk on discharge, after withdrawal/physical stabilisation.
- 3. Thee or more admissions into hospital and/or A&E in one year probably associated either directly (withdrawal, unconscious, encephalopathy, delirium tremens) or indirectly (trauma, organ disease, etc.) with alcohol ingestion.

Or

One or more delayed discharges from general hospital (often GIT/Liver) wards in the last 12 months.

Exclude patients if main problem is non alcohol drug dependence. Exclude patients if aged 65 and over (if service is developed for working aged adults)

Diagnostic Assessment

Obviously, cognitive performance is likely to be compromised if there are significant blood levels of alcohol or psychotropic drugs. Likewise, in acute hospital settings, significant organ damage, infections and other physical illnesses may cause acute and sub-acute confusional states. Hence, it is necessary to undertake an initial assessment when the patient has been withdrawn from alcohol, is abstinent and physically stabilized. The window of opportunity to undertake an assessment is often curtailed by the expected rapid turn-over of patients on acute wards. At this stage; assessment should be carried out in the context of appropriate neuro-radio imagery and entail;

A simple cognitive assessment (e.g. MMSE or ACE-R)
Identification of concomitant mental illness
Occupational therapist/nursing assessment
Risk assessment
Assessment of capacity with reference to alcohol ingestion, discharge planning and associated arrangements
Preliminary social / financial assessment.

On-going assessment should be conducted over the 2-3 months following physical stabilisation and alcohol withdrawal (Oslin 2003). During this period of time the relatively acute affects of the alcohol insult and consequences of withdrawal and related medication are likely to settle (Cocchi & Chiavarini, 1997a, 1997b). This should culminate in the completion of a comprehensive psycho-social assessment which should include cognitive examination, nursing assessment, and occupational therapy assessment, financial and social review (MacRae & Cox 2003). Regular reviews of capacity in relationship to alcohol ingestion and behaviours associated with risk should be undertaken.

On-going Assessments

It is recommended that assessments are undertaken at least every six months, after the care plan has been devised and implemented at the three month stage (Smith and Hillman 1999) over at least two years (Bruce and Ritson 1998, Jacques and Stevenson 2000).

Instruments

The role of instrumentation in assessment should be considered with care. Very few instruments have been validated in the assessment of ARBD patients. A variety of ADL instruments are available. They can be used to rate improvement and inform specific rehabilitative techniques in facilitating improvement in targeted functional domains. However, many of the problems confronting patients with ARBD will include memory problems, higher order reasoning problems, difficulty in planning and understanding the implications of decisions. These issues are rarely identified through relatively simple ADL measuring instruments. Other more global instruments may play a significant role in informing care planning. The Camberwell Assessment of Need for the Elderly (CANE) has been adapted for younger people with dementia (Hammond 2004) and may play a role in identifying some of the psycho-social needs of ARBD patients. More specific instruments may be facilitate the identification of specific functional deficits and inform development of patient-specific rehabilitation programmes. None of these instruments take the place of a full clinical functional assessment.

A wide range of cognitive assessment instruments may be used. However, it is evident that a significant number of patients present with frontal lobe disturbance. It is important to use instruments that capture the cognitive domains associated with this presentation as opposed to relying on less informative instruments such as the Mini Mental State Examination. The Addenbrook's Cognitive Examination (revised) (Mioshi et al 2006) is a fairly practical, time efficient example of such an instrument.

Global assessments of psychosocial function can be undertaken using by the Health of the Nation Outcome Scale –ABI version. This has the advantage of capturing clinical information relating to concomitant psychiatric and functional illness. It is designed to capture clinical information in patients with Acquired Brain Damage. It includes the following domains:

Cognitive problems Violence/Hostility Alcohol use Psychotic features

Other instruments/outcome measures that capture the patients' perspective are important and may include social outcome measures. A few instruments have been developed for people presenting to accident and emergency units and alcohol treatment services (Copersino et al 2012, Copersino 2003,2009, Gillan 1999).

Staged rehabilitation programme.

A review of the clinical management of 41 consecutive cases presenting through secondary care indicates that there are five, overlapping stages of rehabilitation in the context of abstinence.

- 1. Acute Physical Care; There is likely to be a period of acute confusion associated with acute stages of encephalopathy, delirium tremens, withdrawal and unstable physical illness. The duration of this will be informed by concomitant physical illness. It may last days or weeks. During this period of time the patient is being withdrawn from alcohol, being treated with thiamine as recommended by guidelines (NICE 2010) and treated medically/surgically as appropriately. As with other delirious states, patients may be aggressive, have significant and fluctuating cognitive profile and may manifest significant psychiatric and behavioural problems. During the acute phase of presentation it is difficult to determine cause and Wernicke's encephalopathy should be considered as a possible diagnosis in these high-risk patients (Smith & Hillman 1999). The physical manifestations of Wernicke encephalopathy improve more rapidly than the cognitive deficits (Day et al 2008). Provided the patient is physically stabilised, priority should be placed on transfer of the patient to a more conducive environment which offers a calm setting (Kopleman 2009) in which early stages of recovery can be facilitated.
- 2. Assessment and Stabilisation: The cognitive state is likely to improve in a few weeks (Cocchi & Chiavarini, 1997a, 1997b;). This period is reflected in Oslin's Criteria (2003) in which there is a period of approximately two months (of abstinence) after which the patient should be assessed in order to evaluate more long-standing cognitive deficits. Patients may be rehabilitated in their domestic environment but this is dependent on appropriate community facilities as patients rehabilitated through institutions may have a better outcome than patients rehabilitated through outpatient service provision (Rychtarik et al., 2000). If considering a community institution in which to rehabilitate the patient; the evidence suggests that specialised institutions (either residential or nursing care) promote better outcomes than non specialised (Fals-Stewart and Schafer 1992, DeLeon 1984, DeLeon & Jainhill, 1981, Blansjaar et al 1992, Ganzelves et al.1994). Staff in non specialised homes might be vulnerable to stigmatising patients with alcohol problems (Cox et al 2004). It is also important to have transparent and agreed procedures relating to access to alcohol within community settings as these are likely to vary between institutions.

Principles of care include:

Organisational issues

- Introduction of care planning and key worker with specialisation and experience in working with people with ARBD (McRae & Cox 2003).
- Full assessment of capacity and employment of appropriate legal frame-work to provide the minimum restrictive environment consistent with the safe management of the patient.

 Introduction of multi-disciplinary on-going assessment undertaken by teams with specialist knowledge of rehabilitation and the particular needs of those with ARBD such as psychiatrists and specialist practitioners (McRae & Cox 2003).

Environmental issues

- Establishment of an appropriate environment and introduction of daily routine and structure
 - o Abstinence (Grant et al., 1986; Malloy et al 1990).
 - o Good nutrition (Grant et al., 1986; Malloy et al 1990).
 - Mood stabilisation (Grant et al., 1986; Malloy et al, 1990).
 - o Regularisation of sleep pattern (Grant et al., 1986; Malloy et al 1990).
 - o Calm, stable environment (Kopleman et al 2009)

Therapeutic issues

- Introduction of psycho-social support
- Development of patient-staff collaborative relationships
- Development (where relevant) of relationships between institution staff and specialised team (McRae & Cox 2003)
- Early engagement of specialist alcohol treatment services (McRae & Cox 2003).
- Early engagement of family and other interested parties already involved with the patient (Ylvisaker & Feeney, 1998).
- Introduction of memory and orientation cues (Badderley et al 2002)
- 3. Functional Rehabilitation: As the acute presentation resolves, with stabilisation of the presenting confusional state, longer term residual cognitive, functional and behavioural problems become evident. This period is characterised by time-limited cognitive impairments (Bates et al 2002), which are prone to spontaneous recovery (in the context of an alcohol free environment) during which there is notable improvement in associated behavioural disturbance and functionality. This period may last up to three years. Controlled follow-up studies of abstinent alcoholics, using both structural and functional MRI have demonstrated structural and functional brain modification which can be relatively transient (Sullivan & Pfefferbaum 2005). Bartels et al (2007) describes a specific example of improvement in hippocampal function is in a two-year follow up 50 abstinent patients. Hippocampal dysfunction was associated with a lower long-term abstinence profile. However 50% of patients with hippocampal dysfunction returned to normal after two years and as would be expected; patients with additional hippocampal pathologies (such as concomitant vascular lesions) failed to show improvement. A large number of studies explored variance in cognitive improvement across time, with conflicting findings. Younger people tend to recover more speedily than older patients (Rourke & Grant, 1999). What little evidence there is indicated that verbal learning improves before other cognitive functions (Parsons & Leber, 1982). New learning, information processing, abstraction and perceptual motor skills may take longer Yohman, Parsons, & Leber, 1985).

Principles of rehabilitation include:

- The management of patients with ARBD draws on research conducted in patients with acquired brain injury and patients with ARBD (Mc Rae & Cox 2003, Bates et al 2002).
- The rehabilitative approach should be holistic (Prigatano et al 1996) and not merely focus on cognitive rehabilitation.
- The main purpose of rehabilitation is to enhance the individual's sense of internal control (Ylvisaker & Feeney, 1998). This involves the introduction of a programme of functional rehabilitation (defined as achieving positive psychosocial adaptations by means of collaborative interventions provided in real-world settings) (Ylvisaker and Feeney 1998).

- This is facilitated through a milieu based approach to rehabilitation of the individual (Heinssen 1996) in which increasing independence in relevant (Giles1994) life skills should be purposefully encouraged in real life settings (Ylvisaker & Feeney 1998).
- The environment (whether institutional or domestic) should be facilitative (one in which adaptations can be made to accommodate and optimise the changing cognitive profile of the individual) (Heinssen 1996, Bates 2002).

Assessment

This should be carried out by an experienced multidisciplinary team in the context of care planning. As it is an holistic assessment, it should include a comprehensive psycho-social and physical assessment of the individual. The patient's decision making capacity should be assessed in terms of all relevant aspects of life, including exposure to alcohol. The appropriate legal frame work should be established which will minimise the restriction to the patient.

Functional assessment:

The assessment should be conducted in a collaborative framework (Ylvisaker & Feeney 1998). It should be undertaken or supervised by a specialist with suitable skills and experience. It should be conducted with full collaboration of the patient and may include working closely with care staff and family members or friends. Not only does this facilitate continuity but also enables an easier generalisation of skills learned in one environment to other situations; making translation between an institution and more independent living easier (Ylvisaker & Feeney 1998). Such assessments should be on-going and regularly re-visited in the context of an evolving rehabilitative programme.

The assessment should furnish targeted, every-day behaviours and skills in which the patient is deficient. Re-skilling and the introduction of procedures to facilitate completion of the task will enhance a sense of self control, independence and confidence (Ylvisaker and Feeney 1998).

Rehabilitation process

Three sequential processes are recommended.

1. Diary keeping: (Arbias 2007)

Purpose:

- To provide memory and reminiscence material.
- To promote organisational awareness, a sense of predictability and routine.
- To facilitate patient responsibility and facilitate independence.
- To facilitate the building of collaborative relationships between caring staff, family and others involved in care.
- 2. <u>Planning</u>: (activity scheduling) A development of the diary in which future activities are planned with the patient. This is at first facilitated, then supervised and eventually the patient is enabled to take responsibility.

Purpose:

- To promote planning skills
- To promote predictability
- To reduce periods in which the patient maybe vulnerable to relapse
- To provide a vehicle by which increasing independence can be encouraged
- To promote social involvement
- 3. <u>Life skill development and problem solving (Arbias 2007)</u>: (Graded task assignment). This is a procedure by which the patient can be encouraged to become familiar with functional

skills which they may have lost or run into problems with. The functional assessment will inform the therapist and patient as to which areas should be focused on. Skills can range from simple to complex, depending on the degree of deficit.

- Skill development is designed to improve the independence and sense of control of the patient.
- Skill development is a natural progression of the 'planning phase' in which potential target skills are identified and rehearsed until an optimal level of independence is reached.
- It is collaborative
- It is planned with the patient
- Complex tasks are frequently broken down into stages, with each stage being mastered by the individual prior to moving on to the next stage.
- It is always best to focus on readily achievable skills in the early stages of rehabilitation and capitalise on the improving cognition and behaviour through introducing more complex skills as the patient progresses.
- Skill development may often include generalising learned skills into less dependent environments as the patient progresses.

Memory and orientation cues

Patients with ARBD can learn and recall new information. This is facilitated by provision of memory cues and encouraging patients not to guess answers (Badderly et al 2002). Simple diary keeping and planning activities can be facilitated by white boards in bedrooms or equivalent so as to facilitate memories and orientation. Updating these and the use of the diary and planner may be facilitating by the carer but with eventual responsibility being taken by the patient.

Psycho-social support

Kadden et al (1989) suggests that interactional group work is beneficial, when compared to CBT. It is certainly necessary to encourage the patient to build both informal and formal social networks in order to reduce likelihood of relapse (DoH 2006), facilitate on-going care and support as the patient improves and to facilitate the generalisation of newly acquired behaviour and skills into new environments (Ylvisaker and Feeney 1998)

- **4. Adaptation and Generalisation:** As cognition reaches an optimal level of improvement, compensatory mechanisms play a role in facilitating further independence. This stage is characterised by the purposeful acquisition of social, cognitive, behavioural and environmental adaptations (Bates et al 2002). It merges closely with the rehabilitative phase and is a critical component of the programme. The importance of a facilitative environment (Ylvisaker & Feeney 1998) is evident. Long-standing adaptations may have to be developed including memory and orientation cues. As the patient progresses, the physical and social environment should be adapted to provide the optimum level of support to achieve the maximum independence in the context of managing risk. This may involve a range of care plans that include complete independence in a domestic environment, domestic care plans based on personalised budgets combined with varying levels of day care and varying degrees of institutional care.
- **5. Socialisation and Relapse prevention:** The final stage of care planning and rehabilitative process is characterised by integration into a stable social environment and appropriate support structures so as to reduce the likelihood of relapse into alcohol abuse.

This phase requires on-going psycho-social management and is informed by the National Guidelines for the management of people with alcohol misuse (DoH 2006). It should be considered as integral to the care plan (DoH 2006). It includes a number of issues which should be considered:

Psychosocial therapies; designed to help individuals avoid or cope with high-risk drinking situations.

Social support; so as to facilitate life style changes. These may well include maintaining environmental and social adaptations to maintain optimum levels of independence. Examples may include financial help and advocacy, support in maintaining community living arrangements, on-going institutional care. Social networking is important and re-establishing family connections may be possible, however, many patients will have been socially isolated and may benefit from the development of new networks.

Structured programme of activities; this is a natural extension of the rehabilitative programme; (diary keeping, planning and skill development). This is designed to build on the individual's success, identify problems and overcome them through adapting the schedule, reinforce skills and behaviours and prevent relapse

Specific alcohol management; On-going engagement with specialist alcohol treatment services will depend on the relapse vulnerability of the individual and the nature of the local service provision. Any direct engagement must accommodate the residual cognitive and behavioural deficits of the individual. Patients with ARBD frequently find it difficult to engage with generic service provision (Weinstein & Shaffer, 1993). Cognitive dysfunction may contribute to the patient 'denying' that alcohol is a problem (Clifford, 1986; Fals-Stewart, et al 1995; Goldman, 1995; Gordon et al., 1988). This may be a result of the higher order reasoning problems associated with dysexecutive syndrome. Compliance issues may be compounded by memory problems and cognitive slowing. Mood control is often a problem; especially when the patient is confronted with tasks and problems that are too difficult (Fals-Stewart et al., 1995). This is not dissimilar to the catastrophic reaction frequently experienced by patients with stroke or organic brain disease when confronted with frustrating situations (Carota et al 2001). Any on-going alcohol treatment and management should be tailored to the individual's needs. On-going monitoring is essential and should be fully considered as part of the care planning process. This may include regular blood monitoring (alcohol related markers) and support.

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