Wernicke–Korsakoff syndrome: The hidden dementia in HIV? A case study

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Many of us will have some experience of caring for people with HIV who have issues with alcohol. Whether it's just noting alcohol use as a routine part of an initial assessment, or noting those who drink socially to those who feel they binge drink, or who have a recognised alcohol addiction, or who may have developed alcohol-related health issues such as chronic liver disease, chronic pancreatitis or alcohol-related dementias such as Wernicke–Korsakoff syndrome. For some living with HIV, alcohol use may go hand in hand with recreational or street drug use, poverty, anxiety and/or mental health issues. This article will look at the development of Wernicke–Korsakoff syndrome.

Society, as a whole, is becoming more knowledgeable and educated on what constitutes 'healthy', whether that is through stop-smoking campaigns, drives to increase our exercise levels, or evidence on the role of carbohydrates, fats, salt or sugar in our diets and their effects upon our health. Alcohol use, especially amongst the young, has received much press over the past decade via stories of binge drinking, cheap alcohol promotions, fetal alcohol syndrome, the closure of public houses and the rise in home drinking. It's a political issue costing the NHS billions of pounds in caring for those with alcohol-related issues or injuries. The recommended maximum alcohol intake per week is 21 units for men and 14 units for women, but does that mean anything to us? We may all have our own idea of what constitutes a measure or a glass. Due to public education campaigns in 2009, knowledge of daily benchmarks and measuring alcohol in units was shown to increase among both men and women, with the proportion of adults who had heard of daily benchmarks increasing from 69% in 2006 to 90% in 2009 [1]. However, there is now also a rise in binge drinking, primarily in the younger adult, and the risk for alcohol dependence increases with binge drinking. Binge drinking usually refers to drinking lots of alcohol in a short space of time or drinking to get drunk. Researchers define binge drinking as consuming eight or more units in a single session for men (three to four pints of beer) and six units (two large glasses of wine) or more for women. Alcohol misuse accounted for 1.5% of all premature deaths in England. The alcohol-related death rate is increasing, with 8,664 alcohol-related deaths in 2009, rising to 8,790 in 2010 [2]. The risk increases once intake exceeds three units per day [3]. Apart from increasing a person's risk of injury, alcohol consumption, particularly excessive drinking, significantly contributes to chronic disease. Around 25 chronic diseases and conditions can be attributed to alcohol consumption, including alcoholic liver disease, alcohol-induced acute and chronic pancreatitis, and fetal alcohol syndrome (FAS). In addition, alcohol consumption is causally linked to certain types of cancer, cardiovascular disease and liver disease. Consuming alcohol significantly increases a person's risk of cancers of the mouth, oesophagus, larynx, colon, rectum, liver and breast. That risk increases as the volume of alcohol consumed increases [4].

Heavy drinking is common among HIV-infected persons [5] and represents a serious public health threat, as there is a higher incidence of HIV infections among binge drinkers [6] and there is some evidence to suggest that alcohol has a causal impact on HIV infection [7]. Experimental studies appeared to show that excessive alcohol consumption led to a greater inclination to engage in unsafe sex, and indicated that there may be some causal relationship between alcohol and HIV infection [8,9]. For people living with HIV, excessive alcohol use can have a detrimental impact on the course of the disease by interfering with effective antiretroviral treatment as well as creating other health issues [10]. Problem drinking was associated with being less than half as likely to adhere to antiretroviral therapy (ART) guidelines [11]. Therefore, as the level of adherence to ART affects treatment success, excessive alcohol consumption is clearly associated with negative outcomes for people living with HIV. Korsakoff's dementia (an acute psychiatric disorder) has been linked with Wernicke's encephalopathy (an acute neurological illness) as Wernicke–Korsakoff syndrome; this condition involves brain cell damage that is further exacerbated by malnutrition brought on by poor eating habits. Wernicke's encephalopathy is a medical emergency. Untreated, it leads to death in up to 20% of cases, or to Korsakoff's syndrome in 85% of survivors. Up to 25% of the Korsakoff group will require long-term institutionalisation [12]. Korsakoff's dementia accounts for around 10% of all dementias but unlike most can be reversed. Vitamin supplements (thiamine and vitamin B complex) usually facilitate a return to 'normal' functioning, but there is no evidence to suggest that they can undo any brain damage [13]. One study suggested that the development of Korsakoff's syndrome may

depend on the degree of alcohol-related neurotoxicity that occurs before thiamine prevention is instituted [14].

What are the signs?

Korsakoff's syndrome is caused by lack of thiamine (vitamin B1), which affects the brain and nervous system. People who drink excessive amounts of alcohol are often thiamine deficient. This is because many heavy drinkers have poor eating habits and their diet does not contain essential vitamins; alcohol can interfere with the conversion of thiamine into the active form of the vitamin (thiamine pyrophosphate) and alcohol can inflame the stomach lining, cause frequent vomiting and make it difficult for the body to absorb the key vitamins it receives. Alcohol also makes it harder for the liver to store vitamins.

To diagnose Wernicke's encephalopathy in a heavy drinker, a person must have at least two of the following four groups of symptoms:

- evidence of under-nutrition (they are very underweight)
- involuntary, jerky eye movements or paralysis of the muscles that move the eyes
- poor balance or unsteadiness, or other signs of damage to the cerebellum (a region of the brain involved in coordinating movement)
- disorientation, confusion or mild memory loss

The main symptom of Korsakoff's syndrome is memory loss – particularly of events that occur after the onset of the condition. (The term 'alcohol amnesic syndrome' may sometimes be used). Memories of the more distant past can also be affected in some cases. The typical person with Korsakoff's syndrome appears fairly normal on first impression. Intelligence is intact, and individuals with the syndrome can carry on a conversation quite naturally. They are usually able to recall and talk about incidents that took place before the onset of the disorder and recognise family members and old friends without much difficulty. Symptoms may include:

Difficulty in acquiring new information — or learning new skills.

Change in personality — they may show apathy (a lack of concern or emotional reaction), or may be talkative with repetitive behaviour.

Lack of insight into the condition — they may believe that their memory is functioning normally.

Confabulation — they may invent events to fill the gaps in memory; falsification of memory in clear consciousness is very characteristic of the syndrome – patients can answer questions promptly with inaccurate and sometimes bizarre answers.

Case study: James

James is a 54-year-old man who lives alone with three cats in a basement flat in central London. He was diagnosed with HIV 18 years ago and has been on and off ART for 10 years; he states that he has neglected his HIV care as he has been too busy with friends and work. He was referred to the Community HIV Clinical Nurse Specialist (CNS) after he had been admitted to hospital following a fall that was thought to be due to a heavy drinking session. James had also failed to attend the last four appointments at his HIV clinic (his HIV centre is two train journeys away from his home, taking 45 minutes, despite his living near a large hospital just a 5-minute bus journey away). The clinic has been unable to contact him. On assessment at home he is well dressed, his home is tidy but needs some cleaning, and his cats look well fed and happy. He is very friendly and talkative about everything except his HIV. When asked about this he appears to be embarrassed by his HIV status ('that virus', 'the thing', 'that bug') and is reluctant to talk about it, although he expresses a wish to go back onto ART. When it is suggested that he moves to a closer clinic for ease, he agrees and a referral is made. He felt embarrassed to have missed so many appointments and was anxious that his CD4 would have fallen. 'Do you think I'm really ill?' He was given ART on the ward and the Community HIV CNS continued to monitor his adherence. He refused a dosette (medicine dosage) box and explained that he could manage without. He also takes thiamine, vitamin B complex and septrin. He stated that he took his medications every day but sometimes he forgot, or forgot if he'd taken them. On discussing his alcohol intake he describes himself as a 'social drinker', admits to drinking alone, at home, most days, but feels that this is perhaps more for medicinal purposes (Guinness for the iron content and red wine with his evening meal because he's heard it's good for him). He also smokes between 15 and 20 cigarettes a day.

Over the next few weeks James does not answer the phone and fails to answer the door to visitors. Despite text and written reminders he fails to attend a follow-up at the HIV clinic. He is next seen in hospital following another fall down the concrete steps to his flat. He had a capacity assessment on the ward as the ward team felt he was too unwell to go home; however, he passed the assessment and was discharged home with a package of care, and a referral to the local drug and alcohol agency as he admitted to drinking excessively and blacking out at times. On joint assessment with the drug and alcohol worker he states he has 'about four cans of Guinness and two to four bottles of wine' a day but says that he only drinks from early afternoon onwards, even though he had an open can of strong lager at 10.30am (a friend had left it there for him). He listened to what the drug and

alcohol agency had to offer but refused group support and cognitive behavioural therapy ("it's not for me"). He did agree to further joint visits with the Community HIV CNS and a 'floating support worker' to look at the housing and financial issues he was having. A dosette box was commenced, and refilled weekly to enable the Community HIV CNS to monitor his adherence and general health. The flat was now dirty and untidy, with a stack of wine boxes hidden behind the sofa. James looked unkempt, unwashed and emaciated. He was drinking Ensure supplement and eating mostly soup, toast and biscuits. He stated that he knew he looked a mess and was going to have a bath, change his clothes and get his hair cut later that day. Again he was keen to accept help and promised to answer the door.

Following a supervised HIV clinic appointment James' CD4 count had fallen to 54 cells/mm^3 and he had a rising viral load. Unfortunately he failed to answer the door to three more visits, claiming to have lost his phone and not hearing the doorbell, despite being seen inside the flat and hiding in plain sight on two occasions. He was eventually seen 3 weeks later and explained that he'd decided to go to France on holiday and gave a very detailed explanation of where he'd gone and with whom. However, he'd been seen in the flat by a neighbour (his GP) when he stated he was away, and he was still in the same clothes as during the previous visit; his hair hadn't been cut. He repeated that he knew he looked a mess and was going to have a bath, change his clothes and get his hair cut later that day, talking at length about his barber. James was very pleased to state that he hadn't forgotten his medications; however, there were only two out of the seven doses taken. He stated that he'd refilled the boxes but there was no spare medication to enable him to do this. Once confronted with this evidence he reluctantly agreed to allow access via a key safe and daily visits from the district nurse to supervise his medications. He now has daily visits and accepts care but continues to drink two cans of strong lager and up to three bottles of wine a day.

Discussion

Looking after someone with Korsakoff's syndrome is challenging and demands a multiagency approach to care. A multidisciplinary team should work to a common goal. In James' case the goal was to ensure that his HIV and other health needs were controlled by taking his medications, especially the ART, thiamine and vitamin B complex. Despite discussion and offers of support he didn't want to stop drinking; he felt it was his only pleasure. For a long time it was felt that he had capacity to make decisions around his health; he was keen to cut down his alcohol intake but refused interventions to do so. With regard to his ART he wanted to take it, but again his memory issues meant that he frequently forgot despite reminders, signage around his room and daily visits to supervise his adherence. He had confabulation where he described scenarios in huge detail that weren't true, such as going on holiday, refilling drug boxes, planning a fictional day out with friends etc. He had very little insight into his alcohol problem, romanticising what he drank as having a medicinal reason, or tales of drinking with friends in wine bars. The ability to retain information was poor but he could say what the medications were for and why they were important to him. James refused to stop drinking alcohol and as such he was supported at home with daily support until he became too unwell and was, after 12 months, transferred to a residential home for long-term care.

The role of alcohol, and its physical and mental effects, are well researched and understood, as is the effect of alcohol upon the development of Wernicke–Korsakoff's syndrome. Recognising the signs early is vital to allow therapy to be effective, but the prognosis for full recovery from Wernicke–Korsakoff syndrome is poor. Once chronic Korsakoff's amnesia ensues, approximately 80% of patients will never fully recover the ability to learn and remember new information. There are interventions that can help to allow some degree of independence:

- Encourage the patient to stop drinking alcohol to minimise the damage. This is easier said than done. Sometimes the dementia is too pronounced and unless there is a structured home support this may be difficult. More so if they are in a co-dependent relationship with another alcohol drinker, or live alone. For heavy drinkers alcohol reduction/cessation should always be carried out under supervision. Look to supported alcohol detoxification programmes available in your area. A local drug and alcohol agency should be able to offer advice.
- Team work – liaise and work closely with the patient's GP, district nurse, alcohol services and support agencies to ensure that the patient can live safely at home. The role of the dietician should not be overlooked as nutrition is often poor. This may also mean referral and assessment by community physiotherapy and occupational therapy services to assess for adaptations and hazards. Services need to be flexible and persistent, and communication between services is vital to ensure the patient is seen and is safe. If it's difficult to gain access, working with other teams may be a good 'way in', such as joint visits with housing support services to sort out repair issues or with social services to discuss benefits.
- Document – a detailed description of the patient, their life, routine and home will help. Sometimes the patient won't believe what you are telling them, and to be able to accurately recall what they said or what the problem was is useful.

Discuss and write down the plan for care even if you feel that they aren't taking your suggestions/advice at the time. It may be useful to check with them frequently about stopping alcohol or accessing support if they initially refused. Dealing with confabulation is difficult as the patient may sound so convincing and, in their minds, what they are telling you is completely true. Speaking to friends and family, if possible, may be useful, and compare notes with the other professionals involved.

- Try all the tools available to you. A soft approach at first and seeing what does or doesn't work may be needed. From an ART-adherence point of view, for example, the steps that can be taken range from simplifying medications, dosette monitoring to the setting of timers, text reminders or 'Have you taken your pills?' signage. Directly observed therapy by a district nurse team or a paid carer may be eventually needed.
- Capacity and the patient's ability to make informed decisions should be measured.
- Don't give up and don't feel defeated! From a Community HIV CNS viewpoint, trying to gain access can be difficult and a persistent, long-term approach may be needed. Unfortunately a hospital admission may be the only time you can pin the patient down but flexibility and patience is vital to allow any kind of intervention.

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Further reading

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