Dementia and the ageing prisoner

Out of sight is out of mind. Many will take this view of the prison population. Yet, the challenge of dementia care in prisons is growing as the ageing prison population rises. However, little is known about this group and the impact it will have on the prison community and the justice system. Monica Cations explores the issues.

Older people represent the fastest growing age group in Australia’s prison system. This fact brings an associated rise in cognitive impairment – straining a system that was set up primarily to support younger inmates. What do we know about the older prison population in Australia? How do dementia and prisons intersect, and what are the options for supporting prisoners with dementia as their illness progresses?

Why so many older prisoners?

Prisoners aged over 55 are the fastest growing group of inmates both here in Australia and overseas. While still outnumbered, the proportion of older inmates has grown from 2.2% and 4.7% of men and women, respectively, in 2002, to 10.2% and 12.5% in 2014 (ABS 2015). Among this group, the fastest growing are the ‘oldest-old’, aged 65 and over (Angus 2015).

This jump cannot be wholly explained by the ageing of the general population. After all, numbers of older prisoners have grown at a sharper rate (84%) than the older general population (36%) (Angus 2015). Harsher sentencing is a contributing factor, as offenders are being sent to prison for longer periods of time. In addition, advancements in technology have allowed for retrospective sentencing, wherein offenders are sentenced for crimes committed many years prior (Baldawi et al 2011).

Examples of this cross our media paths semi-regularly, such as the famous case of Rolf Harris. Having never been incarcerated before, Harris was sentenced to more than five years in prison at the age of 84 (Miller 2014).

Ageing, dementia and the prison system

Of course, anywhere that you have an ageing population you are sure to find cognitive impairment, and the prison system is no exception. Dementia and prisons cross paths in two primary ways.

Crime associated with dementia

In some cases, criminal behaviour is associated with an underlying dementia. Some types of dementia, like behavioural-variant frontotemporal dementia (bvFTD), can affect personality and impulse control, sometimes resulting in criminal behaviour. One study found that 37% of people with bvFTD in their sample had committed a criminal act, compared with 8% of people with Alzheimer’s disease (Liščígr 2015). Crimes committed by people with bvFTD are generally impulsive in nature, including sexual assaults, trespassing, theft and so on.

This offending is complicated for the justice system to manage. People with bvFTD are unable to ‘stop themselves’, but may or may not understand that the crime is illegal. This makes establishing their innocence difficult, even though they are arguably not responsible. Rehabilitation, part of the rationale for incarceration, is not a realistic outcome for people with dementia. Community diversion programs do not exist in Australia for these cases as they do for some psychiatric illness, so where are they to go?

Dementia emerges during incarceration

Dementia can, of course, also emerge during incarceration, and indeed the number of people with dementia in prisons may be much higher than in the general population. This is because prisoners are disproportionately exposed to a number of environmental and lifestyle risk factors for dementia. Prisoners are, for example, on average poorly educated compared to the general population. Many prisoners have experienced socioeconomic disadvantage, homelessness, trauma, head injury, drug and alcohol disorders and mental illness before even reaching prison (Atabay 2009).

Then, the prison environment itself exacerbates age-related illness with limited access to medical care and nutritious food, and high rates of smoking and infectious disease (Alzheimer’s Australia 2014). Combined, these factors are associated with a very high risk for cognitive decline and dementia.

Despite this, estimates of the prevalence of dementia in prisons are scarce and unreliable. As far as we know, no Australian study has been conducted to estimate the number of prisoners with dementia in Australia. Overseas studies are typically based on white samples who do not reflect the diversity of the prison population (Lemieux 2002).

There is also a very serious problem with under-diagnosis in this population. This is because screening for cognitive impairment in prisons is poor, sometimes
limited to a single question at entry along the lines of “Have you ever had a head injury?” Confusingly, younger inmates are more likely to be screened for mental or cognitive impairment than their older counterparts (Moll 2013; Uzoaba 1998), and there is no consistency across prisons in the response to cognitive complaints.

It is also unclear how to screen for dementia in prisoners. Traditional tests are validated in the general community, often on middle-class and educated participants. Prisoners may have a number of confounding conditions that all contribute to memory loss and thinking changes. In that context, it is very difficult to identify impairment specifically caused by neurodegenerative disease.

Further complicating matters is that the regimentation of prison life can mask early symptoms of dementia, and staff are not trained to identify changes in thinking. This leaves the prisoner responsible for recognising and reporting their symptoms, even though some are reluctant to tell anyone for fear of attracting victimisation (Moll 2013). When the person does not have insight into their condition and sees no need for support there is little chance that their problems will be identified.

In the community the lack of a diagnosis is known to have serious consequences in terms of accessing appropriate services. In prison this can be compounded by difficulties in socialising appropriately or following instructions and performing daily tasks, leading to a reprimand.

**Models of care**

Once a prisoner is diagnosed with dementia, how do we care for them? This is a difficult question to answer, given that the prison system is and has always been set up to cater to a younger ‘audience’, so to speak; being older in prison is already hard enough without cognitive impairment.

One option is to release the person with dementia back into the community on compassionate grounds. However, there are a number of reasons why this option is rarely offered: early release can pose a safety risk for the community, particularly if the person is prone to impulsive crimes like sexual assault.

Early release also draws criticism from victim advocacy groups and, while it is a cost-saving measure for the prison system, it effectively just moves the public health burden sideways, to another department. In some cases, release is not favoured by the prisoner themselves, particularly if they have been in prison for a long time.

They may not have friends and family to care for them, an understanding of how to care for their health problems, or the financial stability to support themselves (Baidawi et al 2011). However, it is important to note that in cases where early release is appropriate, it is still rarely offered for political reasons that are beyond the scope of this article (Howse 2003).

In that case, alternate models have been proposed to continue caring for the person as their dementia progresses while still in prison.

**Segregation**

In separation models, prisoners with cognitive impairment are moved to a special unit with staff trained to support their needs. Such a system can reduce their risk of victimisation and inappropriate reprimand, and increase social support among the prisoners with associated positive effects on mental health (Moll 2013; Maschi et al; Davies 2011).

However, these units are costly and are not feasible for many prisons, so the prisoner may be moved a long way from where they were previously housed. Being moved away may not be favoured by the prisoner themselves, and can have negative effects on the population they leave behind. Older prisoners can have an authoritative and calming influence on younger inmates, and the prison’s social balance can be disrupted when they are removed (Atabay 2009; Uzoaba 1998).

**Mainstreaming**

Another option is to leave prisoners with dementia where they are, and train staff and cognitively-healthy inmates to care for them. This approach has shown positive results for inmates with and without dementia in trials overseas (Hodel & Sánchez 2012) and is a relatively cheaper option than specialised units. However, care provision may not be tailored enough, particularly for people with complex behavioural and psychological symptoms of dementia.

There is no consensus about which model is most appropriate, and ultimately most prisoners with dementia want the freedom to choose where they want to live and where they want to die (just like any other older person) (Hill et al 2006).

**How is the Australian system responding?**

As you can see, dementia in the prison system presents a complex public policy situation. In late 2015, the Federal Senate commissioned its Community Affairs References Committee for an inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia. The inquiry is intended to determine how many people with cognitive and psychiatric impairment are detained in Australia, their needs and experiences, their access to human rights and justice, and how the system must change to better meet their needs (Parliament of Australia 2016).

In May 2016, Alzheimer’s Australia entered a submission to this inquiry, recommending that all people aged 55 and over living in prison are screened for cognitive impairment, that corrections staff are trained to identify and respond to signs of cognitive impairment, and that specialised support services are available at the time of release and resettlement. In addition, diversion programs were recommended for crimes committed after the onset of dementia, similar to those in place for people with psychiatric illness (Alzheimer’s Australia 2016).

At present, very little ‘system’ exists to screen and manage cognitive impairment in prisons. Policy changes are accordingly urgent, and interdisciplinary amendments to the system are needed to cope with increasing demand.

**Why care?**

Identifying and responding to dementia during incarceration is a worthwhile aim for a number of reasons. Early intervention and treatment while in prison reduces the burden on the health care system once released. Improved health and quality of life also reduces the chance of reoffending and rearrest, which is obviously good for the community. In addition, the prison community is an excellent access point for vulnerable groups that can be difficult to engage via community health care services.

Providing services there may be more cost-effective than after release (Maschi et al 2013).

Still, some might argue that quality health and functional care for prisoners with dementia is a privilege that was given up during offending. This view is misguided in the context of the fundamental right of prisoners to protection from cruel and unusual punishment, and as such the current system of no system just won’t do.

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The author’s March 2016 guest lecture presentation on this topic, hosted by the NSW/ACT DTSC, is available as a free webinar on the DTSC’s website at: http://www.dtscc.org.au/2016/03/14/dementia-and-the-ageing-prisoner/
Dementia in people with Down syndrome

Up to 70% of people with Down syndrome over the age of 60 exhibit the clinical symptoms of dementia. However, there is presently little research on the effects of ageing for people with other forms of intellectual disability. In the articles on these pages, Elizabeth Evans, Clancy Black and Julian Trollor outline what is known about dementia in people with intellectual disability from any cause, and describe their current research which aims to improve care and identify risk factors and tools for screening and assessment.

About 1–2% of Australians have an intellectual disability (ID). In recent years, the life expectancy of people with ID increased dramatically (Patja et al 2000), reflecting advances in medical care and societal opportunities. Although people with ID are at increased risk for a range of age-related health conditions, there is presently little research on the effects of ageing for this group. This article outlines what is known about dementia in people with ID and the article below describes our team’s current research in this area.

What we know about dementia in people with ID

It is now well-established that one particular form of ID, Down syndrome, is

The Successful Ageing in

In response to the issues outlined in the article above, Elizabeth Evans, Clancy Black, Julian Trollor and their team at UNSW Australia are investigating the factors associated with good health versus dementia as a person with ID ages.

The Successful Ageing in Intellectual Disability (SAge-ID) study aims to investigate the correlates of dementia in ID, including potentially modifiable risk factors, and to identify appropriate instruments for screening and assessment. A further aim is to identify factors associated with positive mental health for family carers of older adults with ID, including those who develop dementia.

Participants

The SAge-ID study is recruiting adults with ID and their family members. So far the study has collected information about 117 adults with ID and 72 of their family carers. This sample was drawn from selected metropolitan, regional, and rural areas in NSW and Victoria.

Participants were follow-uped with a second questionnaire approximately 2.5 years after baseline. This part of the study was funded by the Dementia Collaborative Research Centres and Ageing, Disability and Home Care.

The study is now expanding with new funding from the National Health and Medical Research Council and the Australian Research Council.

Additional participants will be recruited Australia-wide, from mid-2016 until mid-2018. Participants are currently being sought from two streams: firstly, a sample is drawn from community organisations such as disability or aged-care services. These participants may or may not show signs of decline. Secondly, a sample already identified as being at high risk and/or showing signs of decline will be recruited via clinicians and aged-care assessment teams.

People are eligible to participate if they are aged over 40 years, have an ID, and have a family member, friend, or key worker who can assist with completing questionnaires.

Recruiting people age 40 upwards is designed to ensure that a portion of the sample can be assessed prior to the onset of declines. Commencing

References


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