DEMENTIA IN UK PRISONS

HOW SIGNIFICANT IS THE PROBLEM AND HOW MIGHT IT SHAPE FUTURE PRACTICE?

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Name: Ramandeep Purewal
Institution: University of Nottingham
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Introduction

“The government is failing in its duty of care towards people detained in England’s prisons. Too many prisoners remain in unsafe, unsanitary and outdated establishments.”

(House of Commons Health and Social Care Committee, 2018)

Prison is a place built for the young, fit offender (Newcomen, 2016a), yet elderly people are the fastest growing demographic in UK prisons (O’Moore et al., 2018). Prison services were not built to be well-equipped for the needs of the older prisoner, and therefore still struggle to provide for them (Munday, Leaman & O’Moore, 2017). Dementia is one of the most pressing healthcare issues in the UK (Moll, 2013), and so it is unsurprising that facing dementia is one particular need that has arisen amongst older prisoners. Both forensic psychiatrists and old age psychiatrists play a role in the management of offenders with dementia, with the exact combination varying between different health trusts (Royal College of Psychiatrists, 2007).

Issues that arise around the older prisoner with dementia and the extent of the problems unique to this prison setting will be explored in this essay, as well as the impact on our future practice, for which I will look to existing good practice and official recommendations by governing bodies.

Prison’s Ageing Population

The general population in the UK has been steadily getting older, a trend which looks set to continue. In 2016, over-65s made up 18% of the total population, and are projected to increase to over a quarter of the population in the next 40 years (Storey, 2018). This trend is driven by two enduring factors: a longer life expectancy, and declining birth rate (Storey, 2018).

This increase in older people as a proportion of the population translates over to the prison population too. In December 2017, 16% of the adult prison population was over 50 years old (HMI Prisons & the CQC, 2018). This is due to a mix of factors including general increased life expectancy, an increase in sexual offence and historical offence proceedings, and longer prison sentences (Di Lorito, Vollm & Dening, 2017, Munday, Leaman & O’Moore, 2017 & Ministry of Justice, 2018). To compound this, what is considered to be ‘old’ in prison is around 10-15 years younger than the general population, as prisoners’ mental and physical health deteriorates more rapidly, thus ageing them more quickly (Enggist et al., 2014, Di Lorito, Vollm & Dening, 2017 & Munday, Leaman & O’Moore, 2017). This is attributed to reasons such as poverty, diet, inadequate access to healthcare, alcohol, smoking, substance misuse, as well as exacerbating psychological factors including familial separation and the contemplation of long periods of time in
incarceration (Moll, 2013). Therefore, a widely used figure to demarcate ‘old age’ in prison is 50 years old (Enggist et al., 2014 & Munday, Leaman & O’Moore, 2017).

Just like any other older patient, older prisoners have large and complex physical and mental health needs (Enggist et al., 2014 & Di Lorito, Vollm & Dening, 2017). A vast majority of older prisoners have at least one medical condition affecting them, and 50% of them have more than three (Munday, Leaman & O’Moore, 2017). Navigating the possible comorbid challenges of the older patient, which include a range of vascular problems, memory issues, sensory impairments, mood disorders, alcohol abuse, mobility limitations, diabetes and dental issues to name a few, are only complicated by the addition of a prison environment (Enggist et al., 2014 & Di Lorito, Vollm & Dening, 2017).

**Dementia**

Dementia is characterised as a group of symptoms that come about due to a decline in brain function, often involving problems with memory, thinking skills, disorientation, and mood and personality changes (NHS, 2017 & Age UK, 2019). Dementia is an umbrella term for many diseases, the most prevalent being Alzheimer’s disease and vascular dementia (Age UK, 2019). It is a disease commonly associated with old age; 1 in 6 people over the age of 80 in the UK have dementia (NHS, 2017 & Age UK, 2019). Although dementia cannot currently be cured, its progressive worsening can be slowed in most cases with a combination of medication, such as acetylcholinesterase inhibitors or memantine, and adjunct therapies, such as cognitive stimulation therapy, cognitive rehabilitation and reminiscence therapy (NHS, 2017).

It is also important to support people with dementia at home by making it a quiet, well-lit environment with possible adaptations, such as labelled household cupboards and storage, assistive technology (for example, large LCD clocks with the date as well as the time), and safe outdoor spaces (NHS, 2017 & Age UK, 2019). People with dementia will, at some point in the progression of the disease, begin to require support with everyday activities such as eating and drinking, and so eventually require high-level care often provided by a combination of carers and professional healthcare staff (NHS, 2017).

**Problems With Dementia in Prison**

**The Sheer Prevalence**

Approximations have been made as to the prevalence of dementia in prison, but it is made challenging by the fact that dementia is underdiagnosed in prisons (Newcomen, 2017 & Munday, Leaman & O’Moore, 2017). Current estimations are that approximately 5% of prisoners over 50 years old are suffering with dementia (Munday, Leaman & O’Moore, 2017), which is comparable to the prevalence in the general population in which it affects 7% of over-65 (NHS, 2017). There is a possibility that the prevalence of dementia may be far higher than initially projected; when HMP Bronzefield undertook a pilot cognitive
screening test (Addenbrooke’s Cognitive Examination-III) on their over-55s, a quarter received a provisional diagnosis of dementia for the first time (Munday, Leaman & O’Moore, 2017 & Chao, 2019).

Although age and genetics play a large part in the development of dementia, there are other more modifiable risk factors too, such as obesity, alcohol and depression (NHS, 2017).

Obesity is one of these aforementioned factors. Being obese can itself be a risk factor for dementia, as well as obesity increasing your likelihood of type 2 diabetes which is an additional risk factor, particularly for Alzheimer’s and vascular dementia (NHS, 2017). In the general UK population, 29% of adults are obese (NHS, 2019), and prisoners in the UK have similar, if not lower, levels of obesity (Chaudry, Armstrong & Dregan, 2018).

However when it comes to alcohol abuse, prisoners are at an increased risk. Heavy alcohol consumption can lead to reduction in the brain’s white matter and therefore negatively affect brain function, increasing the risk of dementia (Alzheimer’s Society, 2019). The harmful use of alcohol is a struggle for many prisoners; heavy alcohol use and alcohol dependence is estimated to be around 18-30% for male prisoners and 10-24% in female prisoners (Enggist et al., 2014). This is a great deal larger than the 9% of men and 3% of women in the general population that struggle with alcohol dependence (Drinkaware, 2019).

Depression has a complex relationship with dementia. Whilst depression can be a common comorbidity along with dementia, there is emerging evidence that depression or depressive symptoms, particularly in earlier life, have an association with at least a doubled risk of dementia (Byers & Yaffe, 2011). The studies on later life depression have been inconclusive due to it being difficult to tell whether the depression was indeed a risk factor, a prodrome, or a co-occurrence (Byers & Yaffe, 2011). Whilst the exact relationship between depression and dementia is unclear, there is certainly an association (Li et al., 2011); some possible explanations have been offered involving factors such as vascular changes, increased glucocorticoid levels, amyloid plaque formation, inflammatory changes, and alterations in nerve growth over long periods of depression (Byers & Yaffe, 2011). This is relevant to the question of prevalence of dementia in our prisons, because whilst the national occurrence of depression in the UK is around 3.3% (Mind, 2017), the prevalence of depression in UK prisons is estimated to be around ten-fold greater (Moll, 2013 & Newcomen, 2016b), which may mean more prisoners are at risk of developing dementia.

The prevalence of dementia in prison is at least the same as in the general population, and there is a distinct possibility that it is higher(Sindano, 2016, Newcomen, 2017 & Munday, Leaman & O’Moore, 2017). Dealing with any large scale health problem is a challenge even in the public sphere, but this is intensified in prisons when the system was not designed with it in mind and is therefore no longer fit for purpose.
Spotting the Signs

Common early signs and symptoms of dementia are memory loss, difficulty concentrating, struggling to carry out familiar tasks, having difficulty with following and contributing to conversation, not being orientated to time and place, and mood changes (NHS, 2017). These are the kind of changes that friends and family members would typically look out for in their elderly loved one, and bring it to the attention of their GP.

It hasn’t always been this way. In 2011, the UK government launched a £2 million campaign to raise public awareness of the signs and symptoms of dementia in order to lead to more early diagnoses and more awareness of the support offered to people with the condition and their families (Department of Health & Social Care, 2011, Hitchcock, 2011 & Limb, 2011). This came about as a result of surveys from the Department of Health revealing the general public’s lack of awareness about most aspects of dementia. The surveys showed that two thirds of adults over the age of 40 didn’t understand the difference between normal ageing and signs of dementia, and nearly one third of adults over 40 thought that there was no support available for dementia (Department of Health & Social Care, 2011). The campaign involved television, radio and print adverts, showing a daughter becoming more aware of her elderly father’s dementia and getting him the help he needs to slow the progression of the disease (Hitchcock, 2011). It was aired over the Christmas season of 2011, and the following January the Alzheimer’s Society helpline had 43% more calls than the previous month (Department of Health & Social Care, 2011).

After the campaign, there was an increase in the number of people who said they would go to their GP if they saw any signs of dementia, and there was a significantly higher incidence of those over 40 years old knowing that the earlier dementia is diagnosed the easier it is to treat the symptoms and slow the progression of the disease (Department of Health & Social Care, 2011). Due to campaigns like this, the signs and symptoms are far more readily spotted by the general public when present in their loved ones.

The question then naturally arises: who is spotting these signs in older inmates? The nature of living in prison means that mental health conditions are largely missed or ignored if they aren’t causing the prisoner to pose a threat to security (Moll, 2013). Furthermore, the prison system is so large that often no single person is spending enough time with each prisoner, such that prisoners with mild dementia can go unnoticed with their short term coping mechanisms to cover forgetfulness and conversational difficulties (Moll, 2013). In UK prisons, 95% of inmates are male (Sturge, 2019), so another contributing factor could be the stoicism of the typical older male patient; older people and men are less likely to report their health difficulties or changes in mood than others (Moore et al., 2012) which furthers the problem of dementia in prisons because it could mean that not only are older prisoners going unnoticed due to the aforementioned reasons, but they are also less likely to actively seek help for any symptoms of dementia that they notice in themselves. Additionally, the strict day-to-day routine in prison may be beneficial to the prisoner with dementia, but it may also make it easier to cope to a level such that it means those with early dementia
are missed and not picked up until later in the course of the disease (Moll, 2013), thereby making it more difficult to slow the progression of the disease at a more independently functional stage.

The prison officers are arguably the most well-placed to flag up concerns about a cognitively declining inmate, but there is the concern that they lack the knowledge and skills to look for specific conditions and refer them on to the prison medical doctor or prison psychiatrist (Moll, 2013). The level of knowledge that prison officers hold regarding dementia is generally very low, and the symptoms are often not noticed or attributed to other conditions (Sindano, 2016). There has been an effort by the Alzheimer’s Society to improve the training of prison officers to solve this issue using e-learning techniques (Sindano, 2016), however more recent studies have still identified significant gaps in the knowledge and training of prison officers with regard to dementia (Brooke, Diaz-Gil & Jackson, 2018).

A possible solution may lie in the regular cognitive screening of older prisoners. The rigid prison structure means that healthcare appointments are typically no longer than ten minutes, which may be sufficient for small simple problems, but is insufficient time to thoroughly cognitively assess a patient (Sindano, 2016). Within the cognitive screening process, it can be difficult to ascertain whether the disorientation to time is due to dementia or the disorientating nature of being in prison (Brooke, Diaz-Gil & Jackson, 2018). It is for reasons like this that current screening tools that are valid in the usual non-incarcerated setting, such as the MMSE, are considered to be imperfect for a prison setting and have yet to be validated in such a setting (Brooke, Diaz-Gil & Jackson, 2018). There is currently no comprehensive screening policy for dementia in prison in the UK.

As it currently stands, there is great difficulty in identifying possible prisoners with dementia as the knowledge around the disease is often lacking, not enough time is spent by any individual with the at-risk prisoners, and the screening tools are not yet validated for this unique setting.

Providing Support

Patients with dementia require progressively more support and modifications (NHS, 2017), ranging from mild help in the form of calm, bright environments and gentle reorientation, to more extensive assistance with communication, feeding and dressing (NHS, 2017). Such support is often provided by loved ones acting as unpaid carers which, as a collective, save the NHS £132 billion a year (Carers UK, 2015). In terms of the remaining costs outside of unpaid caring, £26 billion is spent on dementia care per year, two thirds of which is paid from by those affected and their families (Hutchings, Carter & Bennett, 2018). State-funded dementia care is heavily rationed in the UK (Hutchings, Carter & Bennett, 2018) and this translates over to prison care for dementia too.

One of the biggest challenges in providing adequate support for dementia in prison is the lack of money. The typical cost of dementia care for one person is £100,000 (Hutchings, Carter & Bennett, 2018). The NHS
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has been responsible for providing healthcare in prison and has been long suffering with budget pressures (The King’s Fund, 2019). Furthermore, the prison system has had their budget significantly cut since 2010, resulting in a loss of a quarter of the prison workforce (Treacy et al., 2019), which only exacerbates the problem.

The lack of specific support in prison for a condition as common as dementia has been described as institutional thoughtlessness (Di Lorito, Vollm & Dening, 2017). There are many risks to the prisoner with dementia in this situation. Due to the lack of support, prisoners with dementia are likely to fall to victimisation at the hands of the other prisoners or isolation (Treacy et al., 2019). Prisoners with undiagnosed dementia may actually be punished rather than supported, as some behaviours, such as forgetting to respond to verbal instructions, can lead to disciplinary action if viewed as willing insubordination rather than as a result of the disease (Brooke, Diaz-Gil & Jackson, 2018). Additionally, the very buildings are not suited for those with dementia, the cells are often small one-man spaces with two prisoners squeezed into them (Newcomen, 2016a), and prisons are becoming increasingly noisy and violent places as the UK prison system is experiencing an unprecedented crisis (Grierson, 2018) which together are far from painting a picture of a calm, therapeutic environment for those suffering with dementia.

There are some examples of good practice within the prison system in the UK in caring for dementia. The prisons leading the way in dementia care for the elderly inmate are mostly the ones which have a disproportionately large percentage of older prisoners, either due to geographic location or the nature of the crimes committed by the prisoners they incarcerate (Moll, 2013). Volunteer organisation provide a large part of the support currently given to older inmates with dementia, for example, dementia awareness training on offer to both prisoners and staff at HMP Dartmoor and HMP Exeter, and ‘memory café’ events hosted at other UK prisons (Moll, 2013 & Newcomen, 2016a). HMP Whatton, a prison that caters exclusively for sexual offenders where one third have no fixed release date and in which 20% of the prisoners are over 60, hold regular meetings to discuss elderly prisoners with a multi-disciplinary team of security staff, psychologists, social workers and doctors (Moll, 2013), which enables those at-risk prisoners to be flagged up to, assessed by and supported by health and social care services within the prison, as well as having a dementia-friendly cell although this can only accommodate a maximum of two inmates (Newcomen, 2016a & Munday, Leaman & O’Moore, 2017). HMP Leyhill also approached treatment from a multi-disciplinary angle, but focuses more on behavioural interventions so that the staff on the wings with the prisoners will better understand and relate to the therapeutic modifications (Moll, 2013). HMP Isle of Wight has set up a ‘Memory Services Prison Pathway’ to aid prison officers who may be concerned about an inmate’s memory or cognition in referring them onto medical or psychiatric clinics (Moll, 2013). At Whatton, Wakefield, Leyhill and Isle of Wight, there is the use of trained, younger, reliable prisoners to act as carers or support for older patients with dementia (Moll, 2013 & Newcomen, 2016a), which addresses some of the burden of care placed on the strained healthcare system in prison. HMP Leyhill goes
further to prevent the isolation aspect of the problem by having day centre activities geared towards older inmate, such as, painting, nature walks and creative writing, as well as dementia specific activities, like reminiscence sessions (Moll, 2013).

The examples of emerging good practice with regard to dementia care in prisons is hopeful, yet the intense financial pressures mean that there isn’t currently enough of this standard-level healthcare to help the high number of prisoners with dementia, resulting in a ‘postcode lottery’ effect. According to the Prisons & Probation Ombudsman, whilst some prisons are beginning to move in the right direction when it comes to caring and providing for prisoners with dementia, prisons are still systemically ill-prepared (Newcomen, 2016a).

**Ethical Issues**

The purpose of prison has been commonly thought to be some combination of deterrence, punishment, rehabilitation, and incapacitation to protect the public, and there is a large amount of disagreement and discussion on the importance and efficacy of each of these functions (Scottish Centre for Crime & Justice Research, n.d.). The concept of imprisonment and longer sentences serving as a criminal deterrent is largely untrue (Burnett & Maruna, 2004, Robinson & Darley, 2004, National Institute of Justice, 2016 & Lufkin, 2018), and our prison systems are leaning heavily into the idea of rehabilitation instead (Ministry of Justice & Gauke, 2018).

How then do you punish somebody who has forgotten where or why they are in prison, and to what end? How do you rehabilitate someone who is inevitably cognitively declining until death? Is it legally or ethically defensible to keep people incarcerated in unfit conditions to protect the public if there are alternative options such as secure care homes where non-criminals with dementia are also kept from wandering?

Of course not all of these questions will be relevant to every prisoner with dementia, as it runs along a spectrum of severity, but it will certainly apply to some. It is true that dementia can cause disinhibition such that prisoners become more aggressive or violent, but that happens in non-criminals too and is adequately dealt with in the latter case in care homes, so there doesn’t seem to be a valid reason that prisoners with dementia should remain incarcerated to solely deal with the issue of aggression, if, for example, they are sufficiently frail that they no longer pose a criminal threat (Fazel, McMillan & O’Donnell, 2002). When it comes to issues of retribution and punishment, it requires, at the very least, a rational offender who is able to connect the crime they have committed with the imprisonment they are currently facing, which would become increasingly difficult in the context of dementia (Fazel, McMillan & O’Donnell, 2002).

Whichever reasons and opinions one personally has for imprisonment after crime, whether public safety, rehabilitation or punishment, or a combination of the three, it has to be acknowledged that at some point
during the natural course of dementia, these reasons will stop applying to the prisoner, at which point it seems unnecessary and unethical to continue with their incarceration. If even some of these prisoners with dementia go undiagnosed and ignored, they may eventually reach a stage of being unjustly imprisoned.

The imprisonment of patients with dementia raises a question to do with one of the core pillars of medical ethics: justice (Beauchamp & Childress, 2001). In order to be just with regards to health and social care, it is the UK government’s national policy that there is an obligation to provide the same standard of care inside prisons as there is provided in the general population (House of Commons Health and Social Care Committee, 2018). If the basic standard of care cannot be provided to prisoners with dementia as it is outside prison in the general population, then it is in frank discord with the principle of justice. Provisions for prisoners will never be high on the public’s list of political demands (Moll, 2013), but that doesn’t make it right. There is the same need, without fair distribution. Not only is it ethically unsound, it is arguably illegal; the lack of appropriate healthcare for ill prisoners has been declared to be in violation of Article 3 of the Human Rights Act 1998, that is to say, it is a form of inhuman or degrading treatment (Fazel, McMillan & O’Donnell, 2002).

**The Current Picture: A Summary**

As it stands, many aspects of dementia healthcare in prisons are less than ideal; there are problems along the full journey of the disease.

It is likely that due to increased risk factors for dementia in the prison population, such as alcohol abuse and depression, that the prevalence of the disease is greater than that of the general population. To compound this, there are issues with under-diagnosis, including the absence of a diagnostic tool validated in the prison setting, the stigma around asking for help (especially amongst older men), and lack of education about the normal and the abnormal ageing processes amongst prisoners and prison staff. Prisoners with suspected dementia will often be ignored due to the underfunded, understaffed prison system, where prison officers only have the time to respond to other prisoners that are being actively disruptive, whereas prisoners with dementia are more likely to withdraw and become isolated.

Even within the cohort of successfully diagnosed prisoners, there often isn’t the right environment for them to be housed in, and only a select number of forward-thinking prisons have the provisions in place to adequately support them. The problem of the lack of money in the budget, which makes it harder to provide the necessary care, is unlikely to disappear.

Finally, there are several ethical issues raised by people with dementia being incarcerated, including a re-examination of the purpose of their imprisonment, which becomes more and more relevant, the more they cognitively decline. There is also the issue of justice with regard to healthcare provisions in such a stretched system, where it seems that prisoners are not receiving the same support for their dementia as they might if they were a free citizen in the UK.
Possibilities for the Future

When it comes to the future of healthcare for dementia in the UK, several recommendations have been made by the World Health Organisation (WHO), the Prison & Probation Ombudsman, and many published studies. Of course, an increase in funding and personnel would be immensely useful for prisons in the UK (Moll, 2013), and not just for dealing with dementia; however, this is unlikely to be provided so other improvements that work within the parameters of what is feasible are going to have to be considered first.

Although there may not be the perfect screening tools for dementia in prison, some screening would be better than none, so a possible recommendation made by the WHO, and supported by other studies, is to have a cognitive screen of every new elderly prisoner and regular annual screening for those growing old in prison (Moll, 2013, Enggist et al., 2014 & Brooke, Diaz-Gil & Jackson, 2018). This would allow more accurate figures on the prevalence of dementia to be collected, and would identify dementia earlier in more cases, which would lead to better outcomes for the prisoners.

Furthermore, it is of utmost importance that prison officers and other inmates are well-equipped to spot the signs of cognitive decline and are also able to pass those concerns on to a multi-disciplinary team (Brooke, Diaz-Gil & Jackson, 2018). One study found that this type of dementia symptom and signposting training was the most commonly requested improvement by prisons (Moll, 2013). The need for good care plans from multiple disciplines was echoed by the Prison & Probation Ombudsman (Newcomen, 2017).

Finally, whilst costly, improvements need to be made to the infrastructure of UK prisons so that they are more practical and sensitive to the needs of the older prisoner; larger, more spacious facilities are needed, so that older prisoners with and without dementia can live in dignity (Newcomen, 2016a). Low-cost changes could also be made, such as grab rails, extra lighting, signposted bathrooms, and door frames painted in contrasting colours (Moll, 2013). Along with these sorts of changes, there needs to be a greater number of accessible activities for the elderly and the cognitively impaired (Moll, 2013).

Conclusion

There is still no national strategy regarding dementia in prison, although it is desperately needed (Newcomen, 2016a). It’s a national policy that those in prison receive a standard of care that is the same as that in the community (House of Commons Health and Social Care Committee, 2018), but despite areas of good practice, the government is categorically not delivering on this with regard to dementia.

Prisoners with dementia are a very vulnerable, poorly-recognised, under-supported and rapidly-growing patient group. Without sufficient political and financial support, the pressing problem of dementia in our UK prisons is unlikely to be solved. Whilst the government appear to be keen to fund dementia services and deliver public health initiatives, the amount that translates over to the prison system is minimal.

Certain changes need to be put in place to support these prisoners more than they currently are, including more training for inmates and prison staff on picking up the symptoms of dementia, and pathways put in place for them to be able to pass their concern onto medical and psychiatric professionals. There also needs to be changes in the very structure of our prisons to make them more appropriate for the physical, social and mental needs of the elderly prisoner. Finally, there needs to be a consistent, regular cognitive screening...
programme in UK prisons to help fewer prisoners go unnoticed in their suffering, and increase the likelihood of early intervention.

There need to be a cohesive, national drive to put a plan in place for this ever-growing problem of dementia in our elderly prison population (Newcomen, 2016a).
References


