

Title

An exploration of the support provided by prison staff, education, health and social care professionals, and prisoners for prisoners with dementia

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Abstract

The prison population is aging, and older prisoners are at a higher risk of developing dementia than their community dwelling counterparts. Currently there is limited information on the support provided for prisoners with dementia. The aim of this study was to gain an understanding of the lived experience of prison staff, education, health and social care professionals and prisoners with a social care role who supported men with dementia in prison. The study was completed in a Category C male prison in England. Focus groups and interviews with each professional group and prisoners explored current experiences of supporting prisoners with dementia. This qualitative exploration highlighted diversity within: education and training received by participants; the development of participant's roles to support prisoners with dementia; and diversity within the prison regime which impacted on prisoners with dementia and those supporting them. Recommendations include the need for multidisciplinary training and development of both policies and guidelines to support staff and prisoners with a social care role to adequately support prisoners with dementia.

Key words

Dementia, prison, prisoners, phenomenology, education

Background

The prison population is aging and continues to age. In 2002 the population of prisoners over the age of 50 in England and Wales Prison Service was 7%, however by 2018 this had increased to 16%, whereas in 2002 prisoners under the age of 21 accounted for 16%, which decreased to 6% in 2018

(House of Commons, 2018). There are similar trends in the United States of America (Beck & Harrison, 2001; West, Sabol & Greenmans, 2010), and Australia (Australian Bureau of Statistics [ABS] 2000; ABS 2017). There are several 'types' of older prisoners those who are serving their first sentence, recidivist prisoners, and those who age within the prison system (Baidawi et al., 2011). Regardless of the type of prisoner, it is important for prison and, education staff, health and social care professionals and prisoners with a social care role to respond to the increasing numbers of older prisoners with complex age-related health needs, such as dementia.

Dementia is a chronic degenerative condition the risk of which increases with age (Corrada, Brookmeyer, Paganini-Hill, Berlau & Kawas, 2010). While younger people can also develop dementia, the risk of dementia in the general population, is said to increase two-fold every five years from the age of 65 (Corrada et al., 2010). In the prison setting dementia is an area of increasing concern, as the prevalence of dementia in this populations has been suggested to range from 0.8– 18.8% (Fazel et al. 2001; Shepherd et al. 2017; Kingston et al. 2011; Combalbert et al. 2018). The risk of prisoners developing dementia is also estimated to be higher than the general population (Maschi, Kwak, Ko & Morrissey, 2012; Williams, Stern, Mellow, Safer & Greifinger, 2012). Prisoners' risks of developing dementia include unhealthy lifestyles, poor engagement with healthcare, low educational attainment, higher rates of a mental health illness and traumatic brain injuries, and during a prison sentence poor nutrition and lack of exercise (Maschi et al. 2012).

Prisoners with dementia in a prison setting are vulnerable, due to two distinct cultures within this closed environment. Firstly, the need to follow the prison regime without causing any distractions or disruptions, responding both to the authority of the prison guards and prisoner leaders (Haney, 2001). This complex and challenging environment may be impossible for prisoners with dementia to navigate due to the impact of their dementia on their memory, reasoning skills, perceptual and language difficulties. Secondly, prison settings have a culture of violence and bullying, and prisoners with dementia may be victimised as less able to defend themselves, and be at risk of both physical

and sexual victimisation (Stojkovic, 2007). However, prisoners with moderate dementia may themselves disrupt the movement of prisoners with pacing and aggressive behaviour, for which the punishment would be solitary confinement, and as a result a deterioration in their physical and mental health (Wilson and Barboza, 2010).

Prisoners with dementia create unique challenges and burdens for prison staff, education, health and social care professionals and fellow prisoners (Wangmo, et al. 2015). Challenges include supporting prisoners with dementia in a regime that is restrictive (Gaston, 2018), and in an environment which prisoners with dementia have difficulty navigating (Brown, 2014). A further challenge for prison staff is identifying behaviours of prisoners that may be due to dementia. Prison staff, and health and social care professionals continue to identify the need to understand which behaviours are attributable to cognitive decline rather than a mental health condition or an episode of psychosis to illegal drug consumption (Gaston, 2018; Dillon, Vinter, Winder, & Finch, 2018). Behaviours attributable to cognitive decline may include pacing of the wing, repetitive asking of the same question, being unable to follow prison rules, agitation due to a lack of understanding their current environment, which may lead to aggression in the form of verbal or physical abuse.

Prison staff, education, health and social care professionals, as well as prisoners need to be able to identify and support prisoners who are at risk of developing and showing symptoms of dementia. However there is currently limited information on the lived-experiences of supporting prisoners with dementia by prison staff, education, health and social care professionals and prisoners with a social care role.

Aim

The aim of this study was to gain an understanding of the lived experience of prison staff, education, health and social care professionals, and prisoners with a social care role in supporting prisoners with dementia.

Methods

Design

An inductive phenomenological design was applied (Groenewald, 2004).

Qualitative data were collected via focus groups and interviews. Participants were provided with the choice of being involved in either a focus group or interview, this was to address the concern of maintaining anonymity within the closed prison environment and to, where possible, avoid any negative consequences of participating in this research (Silva, Matheson & Lavery, 2017). Therefore, interviews allowed staff or prisoners to discuss their beliefs and experiences confidentially with the research team.

Both the focus groups and interviews consisted of carefully planned group and individual discussions to understand staff and prisoners lived experiences of supporting prisoners with dementia (Krueger & Casey, 2009). Both focus groups and interviews followed the same semi-structured interview guide, although interview guides differed slightly depending on the participant's role within the prison. For example, open-ended questions explored health and social care professionals' experiences of cognitive screening and supporting a prisoner with dementia, whilst open-ended questions for prison staff and prisoners with a social care role focused on their experiences of supporting prisoners with dementia within the prison regime. Focus groups allowed small groups of participants with a similar shared culture, such as being a healthcare professional working in a prison setting or a prisoner to share their experiences (Kitzinger, 1994), whilst obtaining a wide range of experiences (Krueger & Casey, 2009). Focus group discussions would also allow participants to influence and be influenced by each other as they would in the prison setting (Hollander, 2004). Individual interviews were important due to the closed environment of the prison, to support participants to discuss their experiences without any concerns of possible repercussions from their peers.

Setting

This study was completed in one prison from within Her Majesty's Prison and Probation Service (HMPPS) in England. The prison holds a maximum of 640 male sentenced prisoners, of which a large percentage had been convicted of sex offences. Due to the prosecution of historical sex offenders, this prison had a high proportion of older inmates. The prison had implemented two initiatives to support prisoners over the age of 55, firstly an education initiative, which included both arts and crafts and activities in the gym, secondly a work stream/social group to support older prisoners to be productive, such as making and painting birdhouses. The security level of this prison is classified as a category c, which is defined as a closed prison for prisoners who cannot be trusted in open conditions but are unlikely to try and escape. Although this prison has been refurbished a lot of the existing buildings were built in the early nineteenth century. The study was only completed in one prison due to the exploratory nature and time constraints of the researchers.

Ethics

Ethical approval for this study was obtained from: the Faculty Research Ethics Committee at Oxford Brookes University (FREC 2016/41), who were the sponsors of the study, the Health Research Authority (18/HRA/0107), and the National Offender Management Service (2017-166). Audio recording of focus groups and interviews was specifically obtained as occurring within the prison. Since obtaining ethical approval the National Offender Management Service is now Her Majesty's Prison and Probation Service (HMPPS).

Participants

A purposive sampling technique was adopted, which supported the phenomenological design of this study and the aim of gaining an understanding of the lived experience of supporting prisoners with dementia (Githaiga 2014; Brown, 2015). All potential participants received a participant information sheet from a member of the prison staff. Interested potential participants were provided time to

discuss the study with the research team prior to the provision of written informed consent, which included consent for audio recording of the focus group or interview. All participants were informed the research team would keep their contributions anonymous, although due to the closed environment of the prison, staff and other prisoners may be aware of their participation. The voluntary nature of participating and the ability to withdraw at any time, without any reason was also reinforced. Prison staff, education, health and social care professionals were informed if any information was disclosed that identified either prisoners or staff at risk of harm this would be discussed with the appropriate authorities. Prisoners were informed that certain information, regarding prison security, illegal behaviour or risk to self, other prisoners or prison staff would also be discussed with appropriate authorities.

Only prisoners with a social care role, were invited to participate, these prisoners are referred to as 'buddies'. The Buddy model and training has been developed collaboratively between National Offenders Management Service (NOMS), National Health Service (NHS), a relevant County Council and Resettlement and Care for Older ex-Offenders and Prisoners (RECOOP). The training and support of buddies is provided by RECOOP. The existence of buddies is recognised to be limited to the England and Wales Prison Service.

Procedure

All interviews and focus groups were held in private rooms within the prison setting. The first author facilitated all focus groups (n=7) and interviews (n=3), which were held between September and December 2017, with a total of 29 participants (refer to Table 1).

INSERT Table 1 here

Analysis

All focus groups and interviews were audio recorded and transcribed verbatim. Data were analysed from an inductive phenomenological approach to explore the lived experience of participants and

followed the six phases of inductive thematic analysis as described by Braun and Clarke (2006), which included: familiarisation with the data, coding, searching for themes, reviewing themes, defining and naming themes, and finally the writing of the analytic narrative. This process was completed by both authors who followed a reflexive and iterative process where any differences were discussed and agreement obtained by referring back to the original data (Clarke & Braun, 2013).

Findings

The inductive phenomenological thematic analysis identified three themes: diversity of education and training in dementia provided to prison staff, health and social care professionals and to the prisoners with a social care role (buddies); diversity within roles of prison staff, education, health and social care professionals and buddies to support prisoners with dementia; and, diversity that occurred within the prison regime which impacted on prison staff, health and social care professionals, buddies and prisoners with dementia.

Diversity of education and training

Education and training provided to prison and probation staff, health and social care professionals, and buddies was diverse. Prison and probation staff reported a lack of dementia education and training, whilst buddies reported comprehensive training, and insight into supporting fellow prisoners with dementia. Mental health and primary care nurses, and prisoner officers identified difficulties in differentiating between dementia, mental health and drug induced conditions. Two subthemes were identified within this theme: *need for staff training in dementia; and comprehensive training of buddies.*

“Need to understand... we haven’t had any training”: Need for staff training in dementia

Prison staff, education, health and social care professionals identified the need for education and training to support them to work as a multi-disciplinary team to support prisoners with dementia. An

important element of training was to enable staff to differentiate between dementia, mental health and drug induced conditions. This was particularly important for prison officers as they wanted to support rather than reprimand a prisoner with dementia.

“Sometimes we have problems identifying whether it is mental health or dementia or learnt behaviour, because we are not trained in that type of stuff... we don’t know, with the older guys, is it because they have been in prison for years or is it drug induced, or alcohol induced, or an illness, we don’t know...” (FG4 – prison staff)

The need of training all staff was identified, including current staff, and within the recruitment programmes for new prison officers and undergraduate programmes for probation staff.

“I was quite surprised that during my training, I didn’t get anything on dementia, I didn’t hear the word dementia once...”. (FG1 – prison staff)

“I have certainly not done anything here (prison) on dementia...” (FG2 – probation staff)

A further aspect of training discussed by prison officers was the need to be able to recognise the signs and symptoms of dementia, and to communicate important and relevant information to the mental health team. Prison officers believed this was essential and necessary to validate their concerns and support a holistic assessment of the prisoner.

“I would love more training, because you work so closely with these guys, and invariably you see them more than the mental health team, so if you can see what needs to be seen and can get across what needs to be got across to the experts, then that is only going to help everyone.” (FG1 – prison staff)

“There were 14 different modules we had to cover”: comprehensive training of buddies

Prisoners with a social care role, known in this prison as ‘buddies’, undertook comprehensive training and support to enable them to provide social care for prisoners with extra needs, including

those with dementia. The training was a two-week full time programme, which included 14 modules, including one on dementia. Following the training a probation period was completed prior to the prisoner becoming a buddy.

“There is a probation period where they (trainers) do come out and check you are doing it right, I had to get a written statement from one of my clients (fellow prisoner), and from one of the officers, so you are supervised for the first couple of months.” (Buddy 3)

Buddies training and support was on-going as they attended monthly meetings, to discuss concerns, difficulties and best practice. This support enabled buddies to discuss the care and support of each client (fellow prisoner), with other buddies and prison staff, which was viewed as essential as they were a changing group of prisoners.

“It is about best practice; we tell each other what we have been doing, what is working well for us because at the end of the day if I get shipped out to a different jail they have got to step in, it kind of alleviates the teething problems.” (Buddy 1)

Buddies provided an insight into person-centred care and discussed when to step in and help and when to stand back to support the prisoner’s independence with respect and dignity.

“I will stand at the door and watch, yesterday he was trying to make his bed he got the sheet and the pillow done, but he put the orange blanket the wrong way round, and he was moving it up the bed and it was coming up and he was moving it down and it was going down, so I went in and said ‘do you want a hand with that’ and he let me finish it off, but maybe next time he might just get it right. It is so they don’t lose their dignity.” (Buddy 5)

Diversity within roles

Prison and education staff identified an emerging diversity to their role as they needed to support both young and old prisoners, who they believed had different needs, which required different

management strategies. Health and social care professionals highlighted the lack of relevant protocols and guidelines to support them as their practices changed to support prisoners with dementia. Two subthemes were identified within this theme: *changing role of prison officers; and, evolving and changing practice of education, health and social care professionals.*

“Our working day is so diverse”: changing role of prison officers

Prison officers discussed diversity in their role as they recognised the changing prison population. Officers divided prisoners into two groups: young and old, and each group were believed to have specific behaviours and needs.

“The issues between younger and older prisoners are huge, you have got the younger ones with ADHD and stuff, who can’t do their time behind the door and then you have got the other end of the spectrum where you have dementia and stuff like that, where they are forgetting stuff and don’t know what they are doing.” (FG4 – prison officer)

Prison officers discussed the need to change their approach and interaction with prisoners from one minute to the next, to ensure they supported each prisoner’s needs.

“I might be upstairs one minute with a young guy who wants to do smash his cell up, and then within a minute you are dealing with somebody downstairs who may be crying his eyes out because he can’t remember things. So, our working day it is so diverse it is unbelievable.” (FG1 – prison officer)

The experience of prison officers led them to believe prisoners with dementia were demanding and became fixated on certain activities, were a drain on resources, and their time.

“I mean a lot of the prisoners that we come across with dementia are very demanding, because they get focused on certain things like... we have one that is focused on medication

and he rings his bell all the time, 'is it meds yet? Is it meds yet? Is it meds yet?'"(FG4 – prison officer)

"You couldn't keep them (prisoners with dementia) all on one wing, you have to share the work load, you have to send them to other wings, he (prisoner with dementia) did end up going to another wing, just as a form of respite really, for the staff because he was that intensive." (FG1- prison officer)

"There aren't any protocols... we just do it": Evolving and changing practice of education, health and social care professionals

Education, health and social care professionals explored different elements of their roles and how they were developing and evolving to meet the needs of the changing prison population. Primary health nurses discussed a current lack of protocols or policies to guide them, for example they were unsure how to act on the information they gathered from cognitive screening of prisoners:

"There aren't any protocols with what we do with it (information from cognitive screening), we just do it, record it, and we don't actually do anything with it, you do a comparison in six months time, but to be honest there isn't anything further than that..." (FG10 – primary health nurse)

Social workers discussed the difficulty in assessing the needs of someone with dementia in the prison setting, as they viewed the prisoner as having no-one around them that could provide insight into their deteriorating cognition or needs.

"It can be quite difficult assessing people with cognitive impairment in custody, working in the community you tend to have people around them, and it is quite helpful to get an opinion of how somebody is functioning. In custody you don't have those people around." (FG 7 – social worker)

Educational staff discussed the different needs of older prisoners and how they had to adapt to their needs. For example, older prisoners were open that they would forget the work they had completed in a session and needed work outside of the classroom to support them, which was a new request for educational staff.

“It is a case of they have got the skills and ability, but if they are not using it all the time then they will forget, and they were quite open and honest about it. So, they were very keen to have work to do in their own time, which actually encourages the others as well. So, it wasn’t a bad thing it was just a different thing.” (FG 3 – educational staff)

Diversity within the prison regime

Prison officers admitted they did not understand how to support prisoners with dementia within the prison regime. Health and social care professionals believed the structured prison regime would support prisoners with dementia, but the prison officers and buddies disagreed as regular disruption to the regime impacted severely on prisoners with dementia. Two subthemes were identified within this theme: *restrictions due to the regime and impact of disruptions to the regime.*

“It is a bit of a minefield”: Restrictions due to the regime

Prison officers discussed the necessity of working within and maintaining the prison regime, and found it hard to understand how to simultaneously support a prisoner with dementia. This belief was reinforced by prison officers’ experience of family members with dementia.

“If the prison is going to admit someone with dementia, how are you going to treat them, because my mum has dementia and she is hard work, and how would you deal with that in a prison situation? She needs 24/7 care, we couldn’t deal with someone like that in prison.”
(FG4 – prison officer)

Due to a lack of understanding of how to support prisoners with dementia the prison officers' main aim was to keep the prisoner safe whilst keeping the prison regime running smoothly.

“Our focus is just keeping them safe (prisoner’s with dementia), that is our main aim. Keep them safe, keep the regime running, it is a minefield, try and see that they are keeping their cells and themselves clean, and have a buddy to make sure that their needs are met, make sure they get food.” (FG4 – prison officer)

Primary care nurses and social workers believed the prison regime would support prisoners with dementia. The regime was viewed as structured, with clear routines supporting prisoners with dementia to cope with activities of daily living. The prison setting was also seen to remove the risks that occurred in the community.

“I think prisons are a good place for people with dementia, because there is generally a well-established routine, and you can get by in that context.” (FG10 – primary care nurse)

“All the things I really worried about working with people in the community with dementia I am not worried about in prison. The risks are managed by virtue of the fact they are in a custodial environment. It is a really odd perspective, but in terms of serious risk, it is easier to care for people with dementia in custody.” (FG7 – social worker)

“We end up having to fire fight”: Impact of regime disruptions

Prison officers discussed how disruption to the prison regime, with prisons spending extended periods of being locked in their cells, would affect prisoners with dementia. Disruptions occurred due to staff shortage over the weekends, and when incidents with other prisoners occurred. The impact of extended periods of being locked in cells over the weekend continued to affect prisoners with dementia on Monday and Tuesday the following week, until they were able to fall back into the prison regime.

“A major issue with the regime is the lack of staff, at the weekend prisoners don’t get out thir cells much time. So, when guys with cognitive impairment come out of their cells, everyone (staff and buddies) on Monday and Tuesday have to deal with the backlash of the weekend, when the routine was completely out of whack, then you are almost back at square one, instilling the routine it is the weekend again.” (FG1 – prison officer)

Buddies who worked most closely with prisoners with dementia and supported their social care needs experienced the impact of a regime disruption (red regime) and described how distressing this was for their clients.

“One of my guys, if he has been locked up on red regime, it fries his head, he finds it very hard, he kinds of just puts himself in his bed and when you open him up he will think it is the middle of the night, disorientated and everything.” (Buddy)

“There is a knock on effect of it (red regime), we end up having to fire fight, going in and trying to bring them back and put them on an even keel, bring them back to normality.” (Buddy)

A prison regime disruption did not only impact on the prisoners with dementia, but also the buddies that were supporting them, as they sometimes became targets of the aggression and confusion of prisoners with dementia.

“It has a knock on effect on our mental health, it is hard for us, but then as soon as we are let out we have to sort... deal with them... they can be quite aggressive and quite angry, and you are the first person they see, so you know it can come your way quite spectacularly, so that is where the training kicks in and you just reinforce your support and build that connection.” (Buddy)

Discussion

This research has begun to explore the impact of dementia in prison from the perspectives of prison staff, education, health and social care professionals and prisoners with a social care role (buddies). The central themes to emerge included diversity in training and education, diversity within roles and diversity within the prison regime, all of which impacted on prisoners with dementia and all staff within the prison.

In the current study prison officers reported a lack of training in dementia, and were unable to identify symptoms, onset or behaviours related to dementia. Training of prisoner officers is imperative as prisoners with dementia may be reprimanded for behaviours that occur due to their disease rather than intentional rule breaking (Carpenter & Dave, 2004; Dillon et al. 2018). This is further complicated as prison staff believed the prison regime may mask the onset of dementia and behaviours are therefore open to misinterpretation as disruptive, aggressive or due to a mental health condition (Dillion, et al. 2018). Health and social care professionals in the current study also discussed the difficulty differentiating dementia from other conditions, including mental health conditions and drug induced states, which has been identified previously (Gaston, 2018). An element that may contribute to this is the reduced independence of prisoners in activities of daily living within the prison setting, and inappropriate diagnostic criteria and cognitive screening tools (Dillion, et al. 2018; Feczko, 2014).

Our study also identified health and social care professionals held the view of the prison environment as supportive for prisoners with dementia, whereas prison officers and buddies discussed the negative impact of the prison regime. The differences of beliefs highlighted in our study are important to acknowledge, and may be accounted for as health and social care professionals are not involved in day-to-day provision of care. These differences need to be addressed and discussed in the provision of multidisciplinary prison specific dementia education, which includes prisoners (Dillon et al. 2018, Brooke and Rybacka, in press). In addition, health and

social care professionals require comprehensive clinical training to identify and screen for early symptoms of dementia (Maschi, et al. 2012).

Prisoners in this study with a social care role (buddies) reported receiving comprehensive training and ongoing support within clear formalised structures, which enabled them to provide person-centred care. The components of the buddies programme can be identified as addressing each of the different models for peer interventions, which include peer education, peer support, peer monitoring and peer bridging roles (South, et al. 2017). The current study and other initiatives of peer care have demonstrated the need for education, but also peer support and peer monitoring to address the needs of prisoners who have taken on a role that can be emotionally and physically draining (Moll, 2013; Stewart & Edmond, 2017). However there is currently a lack of robust evaluation or sufficient published information to evaluate the impact of these initiatives to support and improve the outcomes of the prisoners receiving care (Hodel & Sanchez, 2012; Stewart & Edmond, 2017).

Prison officers within the current study also discussed two distinct issues emerging within their role. Firstly, the difficulty in simultaneously supporting younger and older prisoners, as younger prisoners may become aggressive and disrupt the prison regime. An element also highlighted by prisoner officers was the inability to keep prisoners with dementia all on one wing, due to their care demands and lack of resources. However, this contradicts policies that include the segregation of older prisoners from younger prisoners, such as the introduction of geriatric housing units (Williams et al., 2010). Although, our results suggest prison officers support segregation, contemporary research indicates older prisoners' opinions of segregation remain divided, and the important element was the criteria for segregation beyond that of age (Wangmo et al. 2017).

The second issue emerging from prison officers' role was how to simultaneously support a prisoner with dementia and maintain the prison regime, therefore just aimed to 'keep them safe'. Research regarding mental illness, but not dementia, has identified difficulties associated with supporting a

prisoner with a mental health condition and maintaining the prison regime, which impacted negatively on the prison officers stress levels and mental wellbeing (Walker, Jackson, Egan & Tokin, 2015; Steiner & Wooldredge, 2015). However, the development of prison structures and values to support and enable prison officers to apply discretion and flexibility in their responses to the behaviours of prisoners with a mental health condition, has been identified to support the prison officer, prisoner and the prison regime (Galaneck, 2015). However, this work has not currently included a focus on prisoners with dementia.

Health and social care professionals within this study discussed their roles as evolving to support them to adapt to the changing needs of the prison population, which currently lacked clinical and operational protocols to support prisoners through assessment, diagnosis, treatment and support. In England and Wales in 2008, only three of the 29 inspected prisons had implemented a dementia guideline (HM Chief Inspector of Prisons, 2008), and in 2017 there remained no national strategy for dementia focused specifically on the prison setting (House of Commons, 2017). In Australia, the Department of Justice and Regulation (2015) produced a framework, which addresses four fundamental principles to support ageing prisoners, and dementia is mentioned in the challenges of managing older prisoners, but no specific guidance is provided. However, evidence-based guidance has been developed, but not widely implemented such as a clinical dementia protocol to support prisoners at risk of dementia (Feczko, 2014), which highlights the need for surveillance by all prison staff and routine cognitive screening by specifically trained healthcare professionals (Feczko, 2014).

One aspect that requires further development in the process of diagnosis of dementia within the prison setting is the use of advocates who know the prisoner; advocates can be drawn from both prison officers and fellow prisoners, who will know the prisoner, their declining cognition and increasing needs. This element has yet to be explored or developed. Finally, it is essential that prisoners with dementia have equity and support to access to all the opportunities and services within the prison setting. Currently only initiatives specifically for people with dementia are being

discussed in the literature (Harrison, 2006; Moll, 2013), rather than how to integrate prisoners with dementia in prison rehabilitation programmes.

Limitations

This study was completed in one male prison setting in England during a time of staff shortages and organisational change. Therefore, the results of this study need to be considered within these limitations, and if they are transferable to support female prisoners with dementia, or to prisons outside of the England and Wales Prison Service.

Conclusion

This explorative research highlights the changing needs of prisoners, and evolving roles of prison staff, education, health and social care professionals. The changing prison population challenges traditional roles and regimes, and demonstrates a need for training and education, alongside policies and guidelines to support prisoners with dementia by all within the prison environment. This is imperative to support prisoners with dementia to ensure they are not being reprimanded for their behaviours, receive appropriate care and support, alongside the acknowledgement of advocates within staff and fellow prisoners. Most importantly the need to challenge the perception of just keeping a prisoner with dementia 'safe', but enabling equity of access to rehabilitation programmes and prison activities.

References

Australian Bureau of Statistics (2000). Prisoners in Australia 2000. cat. no. 4517.0. Canberra: ABS.

Australian Bureau of Statistics (2017). Prisoners in Australia 2017. cat. no. 4517.0. Canberra: ABS.

Baidawi S, Turner S, Trotter C, Browning C, Collier P, O'Connor D. & Sheehan R. (2011). Older prisoners—A challenge for Australian corrections. *Trends & Issues in Crime and Criminal Justice*, Australian Government Department of Criminology.

Beck, A.J., & Harrison, P.M. (2001). Prisoners in 2000. Washington, DC: US Department of Justice, Office of Justice Programs. NCJ 188207. Retrieved from <https://www.bjs.gov/content/pub/pdf/p00.pdf>

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Brown, J.A. (2014). Dementia in prison, discussion paper #9. North Ryde, NSW. Alzheimer's Australia. Retrieved from <https://www.dementia.org.au/sites/default/files/20140318-NSW-REP-DementiaInPrison.pdf>
- Brown, S. (2015). Using focus groups in naturally occurring settings. *Qualitative Research*, 15(1), 86-97.
- Carpenter, B., & Dave, J. (2004). Disclosing dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *Gerontologist*, 44(2), 149-158.
- Clarke, V., & Braun, V. (2013) Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, 26 (2), 120-123.
- Combalbert, N., Pennequin, V., Ferrand, C., Armand, M., Anselme, M., & Geffray, B. (2018). Cognitive impairment, self-perceived health and quality of life of older prisoners. *Criminal Behaviour and Mental Health*, 28 (1), 36-49.
- Corrada, M., Brookmeyer, R., Paganini-Hill, A., Berlau, D., & Kawas, C. (2010). Dementia incidence continues to increase with age in the oldest old: the 90+ study. *Annals of Neurology*, 67(1), 114-121.
- Department of Justice and Regulations (2015). Corrections Ageing Prisoner and Offender Policy Framework 2015-20. Retrieved from https://www.corrections.vic.gov.au/sites/default/files/embridge_cache/emshare/original/public/2019/04/ae/09d2abf69/cv_ageing_prisoner%26offender_policyframework15.pdf.
- Dillon, G. Vinter, L.P., Winder, B., & Finch, L. (2018). 'The guy might not even be able to remember why he's here and what he is in prison for and why he's locked in': residents and prison staff experiences of living and working with people with dementia who are serving prison sentences for a sexual offence. *Psychology, Crime and Law*, DOI: 10.1080/1068316x.2018.1535063.
- Fazel, S., Hope, T., O'Donnell, I., & Jacoby, R. (2001). Hidden psychiatric morbidity in elderly prisoners. *British Journal of Psychiatry*, 179, 535-539.
- Feczko, A. (2014). Dementia in the incarcerated elderly adult: Innovative solutions to promote quality care. *Journal of the American Association of Nurse Practitioners*, 26, 640–648.
- Galanek, J.D. (2015). Correctional officers the incarcerated mentally ill: responses to psychiatric illness in prison. *Medical Anthropology Quarterly*, 29(1), 116-136.
- Gaston, S. (2018). Vulnerable prisoners: Dementia and the impact on prisoners, staff and the correctional setting. *Collegian*, 25, 241-246.

- Githaiga, J.N. (2014). Methodological considerations in utilization of focus groups in an IPA study of bereaved parental cancer caregivers in Nairobi. *Qualitative Research in Psychology*, 11(4), 400-419.
- Groenewald, T. (2004). A Phenomenological Research Design Illustrated. *International Journal of Qualitative Methods*, 42–55. <https://doi.org/10.1177/160940690400300104>.
- Haney, C. (2001). The psychological impact of incarceration. Retrieved from <https://aspe.hhs.gov/basic-report/psychological-impact-incarceration-implications-post-prison-adjustment>
- Harrison, M.T. (2006). True Grit: An innovative programme for elderly inmates. *Corrections Today*, December 2006, 46-49.
- Her Majesty's Chief Inspector of Prisons (2008). Older prisoners in England and Wales: a follow-up to the 2004 thematic review. Retrieved from <https://www.justiceinspectrates.gov.uk/hmiprison/inspections/older-prisoners-in-england-and-wales-a-follow-up-to-the-2004-thematic-review/>
- Hodel, B., & Sanchez, H.G. (2012). The Special Needs Program for Inmate-Patients with Dementia (SNPID): A psychosocial program provided in the prison system. *Dementia International Journal of Social Research and Practice*, 12(5), 654–660.
- Hollander, J. A. (2004). The social contexts of focus groups. *Journal of Contemporary Ethnography*, 33(5), 602-637.
- House of Commons. (2017). Mental Health in prisons. Eighth Report of Session 2017-19. Retrieved from <https://publications.parliament.uk/pa/cm201719/cmselect/cmpubacc/400/400.pdf>
- House of Commons. (2018). Briefing paper: UK Prison Population Statistics. Retrieved from [file:///C:/Users/id127162/Downloads/SN04334%20\(1\).pdf](file:///C:/Users/id127162/Downloads/SN04334%20(1).pdf)
- Kingston, P., Le Mesurier, N., Yorston, G., Wardle, S., & Heath, L. (2011). Psychiatric morbidity in older prisoners: unrecognised and undertreated. *International Psychogeriatrics*, 23 (8), 1354–1360.
- Kitzinger, J. (1994). The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health and Illness*, 16(1), 103-121.
- Krueger, R.A., & Casey, M.A. (2009). (4th Edition) Focus Groups: A practical guide for applied research. London, UK: Sage.
- Maschi, T., Kwak, J., Ko, E., & Morrissey, M. (2012). Forget me not: Dementia in prison. *The Gerontologist*, 52(4), 441-451.
- Moll, A. (2013). Losing track of time. Dementia and the ageing prison population: treatment challenges and examples of good practice. Mental Health Foundation. Retrieved from: <https://www.mentalhealth.org.uk/sites/default/files/losing-track-of-time-2013.pdf>

- Shepherd, S.M., Ogloff, J.R.P., Shea, D., Pfeifer, J.E., & Paradies, Y. (2017). Shepherd Aboriginal prisoners and cognitive impairment: the impact of dual disadvantage on Social and Emotional Wellbeing. *Journal of Intellectual Disability Research*, 61 (4), 385–397.
- Silva, D.S., Matheson, F.I., & Lavery, J.V. (2017). Ethics of health research with prisoners in Canada. *BMC Medical Ethics*, 18:31.
- Smith, J.A., Flower, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London, UK: Sage.
- South, J., Bagnall, A.M., & Woodall, J. (2017). Developing a typology for peer education and support delivered by prisoners. *Journal of Correctional Health Care*, 23 (2), 214-229.
- Steiner, B., & Wooldredge, J. (2015). Individual and environmental sources of work stress among prison officers. *Criminal Justice and Behavior*, 42(8), 800–818.
- Stewart, W., & Edmond, N. (2017). Prisoner peer caregiving: A literature review. *Nursing Standard*, 31(32), 44–51.
- Stojkovic, S. (2007). Elderly prisoners: A growing and forgotten group within correctional systems vulnerable to elder abuse. *Journal of Elder Abuse and Neglect*, 19, 97–117.
- Walker, E.J., Jackson, C.A., Egan, H.H., & Tonkin, M. (2015). Workability and mental wellbeing among therapeutic prison officers. *Occupational Medicine*, 65(1), 549-551.
- Walsh, E., & Freshwater, D. (2009). The mental wellbeing of prison nurses in England and Wales. *Journal of Research in Nursing*, 14(6), 553-564.
- Wangmo, T., Handtke, V., Bretschneider, W., Elger, B.S., (2017). Prisons should mirror society: the debate on age-segregated housing for older prisoners. *Ageing and Society*, 37(4), 675-694.
- Wangmo, T., Meyer, A.H., Bretschneider, W., Handtke, V., Kressig, R.W., Gravier, B.,... Elger, B.S. (2015). Ageing prisoners' disease burden: Is being old a better predictor than time serviced in prison? *Gerontology* 61, 116-123.
- West, H.C., Sabol, W.J., & Greenmans, S.J. (2010). *Prisoners in 2009*. Washington, DC: US Department of Justice Programs. NCJ 231675. Retrieved from <https://www.bjs.gov/content/pub/pdf/p09.pdf>
- Williams, B.A., Lindquist, K., Hill, T., Baillargeon, J., Mellow, J., ... Walter, L.C. (2009). Caregiving Behind Bars: Correctional Officer Reports of Disability in Geriatric Prisoners. *Journal of American Geriatric Society*, 57, 1286–1292.
- Williams, B.A., Stern, M.F., Mellow, J., Safer, M., & Greifinger, R.B. (2012). Aging in correctional custody: Setting a policy agenda for older prison health care. *Framing Health Matters*, 102 (8), 1475-1481.

Wilson, J., Barboza, S. (2010). The looming challenge of dementia in prisons. *Correct Care*, 24(2), 10–13.

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