

Dementia and mild cognitive impairment in prisoners aged over 50 years in England and Wales: a mixed-methods study

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Scientific summary

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Background

People aged ≥ 50 years constitute the fastest-growing group in the prison population of England and Wales. Their presence in a prison system that was designed to accommodate younger people, especially young men, has proven to be a challenge to front-line staff, managers and policy-makers. This increase in numbers of a population with complex health and social care needs has coincided with a sustained period of funding cuts to the prison service, which has made meeting the needs of this population even more problematic.

There is currently no national strategy to guide the development of the many-faceted services required for this vulnerable population. Therefore, prisons are responding to the issue with a range of local initiatives that are untested and often susceptible to failure if they are not fully embedded and securely funded within commissioned services.

The current research is designed to fill a number of knowledge gaps in this area.

Aims and objectives

This study aimed to:

- establish the prevalence of dementia and mild cognitive impairment in prisons in England and Wales (part 1)
- establish the degree and type of impairment, risk level, needs and social networks of those who screened positive on the Addenbrooke's Cognitive Examination – Third Revision (part 1)
- validate the six-item cognitive impairment test for routine use in prisons to aid early and consistent identification of older prisoners with possible mild cognitive impairment or dementia (part 1)
- identify gaps in current service provision (part 2)
- understand the first-hand experiences of prisoners living with dementia and mild cognitive impairment in prison (part 3)
- develop a prison-based care pathway for prisoners with dementia and mild cognitive impairment (part 4)
- develop training packages for staff and prisoners in the awareness, assessment and management of dementia and mild cognitive impairment (part 5)
- undertake health economic costings for the care pathway and training packages developed in parts 4 and 5 (part 6).

Methods and results

Part 1

We aimed to screen at least 860 older (aged ≥ 50 years) male and female prisoners using the Montreal Cognitive Assessment. Participants who tested positive on the Montreal Cognitive Assessment (score of ≤ 23 points) were interviewed using the Addenbrooke's Cognitive Examination – Third Revision and a range of standardised assessments to establish degree of impairment, risk of violence to self and others (victimisation), activities of daily living needs, mental health needs, history and symptoms of brain injury (if applicable), and social networks. The six-item cognitive impairment test was also used with a proportion of participants to assess the tool's validity in this population.

Data generated were used to estimate the current prevalence of mild cognitive impairment and dementia in the older prisoner prison population to inform the planning and costing of services.

In total, 869 participants were interviewed using the Montreal Cognitive Assessment. A total of 100 (12%) participants screened positive, and 74 (74%) of those participants completed the Addenbrooke's Cognitive Examination – Third Revision. Seventy (95%) of those participants screened positively for possible dementia or mild cognitive impairment, which equates to 8% of our total sample. When these results were weighted to represent the ages of the total older prisoner population in England and Wales, we estimated that 8% had suspected dementia or mild cognitive impairment. This equates to 1090 older prisoners with suspected dementia or mild cognitive impairment in England and Wales. It should be noted that these findings are based on validated cognitive impairment assessments and not on a clinical diagnosis.

Only two individuals (3% of those who were screened on the Addenbrooke's Cognitive Examination – Third Revision) had a diagnosis of dementia documented in their prison health-care notes, suggesting current under-recognition of this condition. The prevalence rate among our sample of older prisoners is approximately two times higher for individuals aged 60–69 years and four times higher for those aged ≥ 70 years than it is for those living in the community.

Of the 70 participants with possible dementia or mild cognitive impairment in our sample, 42 (60%) had symptoms of depression, indicating that further clinical investigation should take place. Seven (10%) participants scored ≥ 3 on PriSnQuest, warranting further exploration of their mental health. Thirty-two (46%) participants scored high or very high for risk of harm to self or others. Nineteen (27%) participants had activities of daily living needs and half had no friends they could turn to for help. Nineteen (27%) participants indicated that they had experienced a potential brain injury in the past.

The six-item cognitive impairment test was completed by 495 of the participants, in addition to the Montreal Cognitive Assessment, for validation purposes. Forty-one individuals screened positive on the Montreal Cognitive Assessment but did not screen positive on the six-item cognitive impairment test ($\kappa = 0.39$; $p < 0.001$). Consequently, the six-item cognitive impairment test was not considered an effective tool for identifying potential mild cognitive impairment or dementia among the older prisoner population. The Montreal Cognitive Assessment appears more effective than the six-item cognitive impairment test for identifying incarcerated individuals aged ≥ 50 years with symptoms of dementia or mild cognitive impairment.

Part 2

To understand the current range of services operating to support older prisoners with dementia and mild cognitive impairment, we issued two separate questionnaires to governors and health-care managers of all prisons housing adult male and female prisoners in England and Wales ($n = 109$). The questionnaires comprised free-text sections, single-response questions and multiple-choice questions. The governor questionnaire included questions on service provision for people with dementia and mild cognitive impairment, including any modifications to the environment, training delivered and training required, and social care provision. The health-care manager questionnaire included questions on training provision, training needs, current health and social care provision, and future care pathway delivery.

We collected data from 85 prison governors (78%) and 77 health-care managers (71%). Cumulatively, across the 77 responding establishments, health-care managers estimated that a total of 198 prisoners had or were awaiting assessment for dementia or mild cognitive impairment. Most prisons (79%) had an identified older persons' lead. Around half of prisons surveyed (54% of governor responses) said that one or more modifications to the physical environment had been made for older people. Most (69% of health-care manager responses) did not have a defined care pathway for those with dementia or mild cognitive impairment. Very few (9% of health-care manager responses) used a standardised assessment tool to identify prisoners' social care needs, seemingly relying on needs being identified

as part of routine reception health screening. Sixty-nine per cent of health-care managers and 74% of prison governors felt that their local authority was meeting its social care responsibilities either very or fairly well.

When asked what day-to-day problems existed, staff indicated that delays in arranging assessment, establishing a diagnosis and, subsequently delivering care were common. Delays in local authority care staff being granted security clearance to work in prisons were also problematic, compounded by a high turnover of these staff. It was also noted that limited staff knowledge about the conditions led to problems identifying signs and symptoms, particularly in local prisons that have a high population turnover.

Peer carers appear to be becoming ubiquitous, with 87% of governors reporting their presence. However, only 61% of peer carers reported formal selection processes, such as security vetting, training and risk assessment. Only 26% of governors reported that they had received or provided staff training about dementia awareness, and this figure was even lower among health-care staff, at 21%.

Part 3

We undertook a focused, time-limited ethnographic study of older people in prison living with dementia and mild cognitive impairment. Observations of prisoners' daily lives were augmented by a series of interviews with those prisoners, their peers, peer carers and a range of staff members. In total, 16 observations were undertaken and 42 corroborating interviews were completed. A framework analysis technique was used to interpret the data gathered.

Four themes emerged from the data. First, the challenge faced by the prison system, generally, to cope, was further compounded by ever-increasing numbers of older prisoners. People spoke of the pressure the complex needs of these individuals placed on a system already under strain as a result of the reduction of resources during a sustained period of public service austerity. Prisons were described as often environmentally unsuitable for older prisoners, and complying with the regime was difficult for those with dementia. Health-care services often struggled to adequately identify and care for those with dementia.

Second, being an older person in prison was often an isolating experience, and prisons struggled to provide appropriate meaningful activity for older prisoners. Peer carers were considered a useful initiative, but the system needed to be monitored to ensure that appropriate services were being delivered and that older prisoners were not at risk of exploitation.

Third, although most prisons had a range of multiagency services available in-house, and links with complementary services in the community, such agencies often still worked in isolation, with no clear agreed or mutually understood lines of responsibility. As a result, services for older prisoners with dementia were not always seamless or joined up.

Fourth, training in dementia awareness is not widely available for staff or prisoners, and this lack of education can adversely affect people trying to fulfil their peer or professional caring duties.

Part 4

To identify service needs and develop an appropriate care pathway for older prisoners with dementia or mild cognitive impairment, we adopted a balance of care approach. Data from part 1 were used to create subgroups of people with similar care needs, from which we developed a series of representative case studies. Each case study was presented to multidisciplinary staff from prison and community settings at a series of workshops. Staff were asked to design an appropriate care package for each case study. Feedback notes from workshops were collated and summarised using a care plan template. Key themes were identified and these formed an initial draft of an assessment and treatment care pathway. A further workshop was held with professionals to adjust and further develop the final pathway.

The final pathway outlines the steps to be taken in prison and community services to streamline the diagnostic process. Additional guidance is provided about environmental modifications in prison, the development of adapted, specialist wings and the circumstances under which care out of the prison setting, for example release on temporary license or some type of secure nursing home or hospital accommodation, should be considered.

Part 5

A theory-based approach to the design and development of training was adopted. First, a scoping review of the literature was conducted to identify any existing studies around dementia training in prisons and the wider literature around training in health settings. Second, targeted analyses of the part 2 questionnaire data and part 3 qualitative data were undertaken, encompassing all data around training. Third, a draft set of training materials was produced and reviewed in a number of stakeholder workshops that included members of the study team, dementia experts, prison staff and experts by experience.

The literature review, combined with an analysis of the questionnaire and qualitative data, concluded that training should be available at two levels: (1) general awareness training for all staff and (2) a specialist health-care resource for those undertaking assessments and developing care plans. A discrete version of the tier 1 awareness training was indicated for prisoners and peer carers. Training was designed to be delivered face to face in sessions of around 2 hours. The desired format was facilitator led using a core set of slides, but with an emphasis on encouraging discussion, small group tasks and interaction between group members. Care and management skills were to be demonstrated using prison-specific examples shown on pre-prepared videos, rather than using role-play with group members.

The training materials produced are detailed in the full report and will be made freely available via the University of Manchester's online research resource repository.

Part 6

We undertook a costing exercise to estimate the resources needed to deliver the staff training packages developed and the care pathways for mild cognitive impairment.

Each of the three training packages would be delivered in separate 2-hour sessions facilitated by either a prison officer or a prison nurse. All costs would vary substantially by prison site, depending on a number of factors, including the local labour market conditions and the size of the prison population with mild cognitive impairment or dementia. For individuals who receive a diagnosis of dementia, a typical care pathway of diagnosis, assessments and standard dementia treatment is estimated to cost £5160 in year 1. For individuals who receive a diagnosis of mild cognitive impairment, a typical care pathway is estimated to cost £4052 in year 1.

It was possible to provide resource use and cost estimates for only those elements of the suggested care pathways that already exist in some form. Some of the suggested elements, such as secure nursing homes, are just ideas at this stage. Further research is required to investigate the cost of more ambitious options, such as the development of secure nursing homes.

Conclusions

We calculated that the prevalence of dementia and mild cognitive impairment in prisoners in England and Wales is 8%, equating to 1090 individuals. This is a much greater number than that estimated by prison staff in part 2 of the study. Prison staff outlined difficulties in caring for this group, including the challenges of delivering care in unsuitable environments and working with limited resources (e.g. inadequately staffed health and social care services). Prisons are routinely served by a range of professionals from different organisations, but issues remain in ensuring that care for vulnerable individuals is joined up and that equivalence of care between prison and community is achieved.

Implications for health care

We developed a care pathway and training materials to provide a framework that prison officers, prisoners, health and social care staff, and other statutory and third-sector organisations can adapt to fit local circumstances. We hypothesise that the implementation of this framework will improve care.

Recommendations for research

- A study examining the implementation of the assessment care pathway in prison and its adaptation for different types of prisons, with examination of process outcomes, including numbers of people with dementia and mild cognitive impairment identified, assessed and supported, and the impact on the pathway on meeting health and social care needs and improving quality of life.
- Evaluation of changes in staff members' and peer carers' knowledge and attitudes about dementia and mild cognitive impairment, and prisoners' health and social care needs and quality of life following the introduction of the three training packages on dementia and mild cognitive impairment.
- Evaluation of the impact of introducing 'dementia-friendly' environmental changes on prisoners' social care needs, well-being and orientation on prisoners with mild cognitive impairment and dementia.
- An exploratory study with health economics modelling of the service need, geographical location, environmental design, service development, philosophy of care and staffing structure of regional prison specialist units, secure nursing homes and older people services in forensic hospitals.
- A cohort study to establish health, social care and criminological outcomes of a sample of Addenbrooke's Cognitive Examination – Third Revision-positive individuals over a period of 3–5 years.

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