The Journal of Forensic Psychiatry & Psychology

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/rjfp20

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To cite this article: Katherine Perryman, Leanne Heathcote, Katrina Forsyth, Jane Senior, Rachel Domone & Jenny Shaw (2023): Dementia and mild cognitive impairment in the older prison population in England and Wales (DECISION): developing a dementia care training package for use in prisons, The Journal of Forensic Psychiatry & Psychology, DOI: 10.1080/14789949.2023.2223194

To link to this article: https://doi.org/10.1080/14789949.2023.2223194

Published online: 30 Jun 2023.

THE JOURNAL OF FORENSIC PSYCHIATRY & PSYCHOLOGY
https://doi.org/10.1080/14789949.2023.2223194

Dementia and mild cognitive impairment in the older prison population in England and Wales (DECISION): developing a dementia care training package for use in prisons

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ABSTRACT

The rising prevalence of dementia in the UK presents a public health and economic challenge. People over the age of 60 are the fastest growing age group in prison and the number of people in prison who experience dementia is rising. There is a lack of research focused on improving management and support for people in prison who may experience dementia, but growing awareness of the need for staff training in prisons to identify and support people showing symptoms of dementia. This paper reports the development of a theory and evidence-based training package for prison staff and peer carers to identify and support people in prison with mild cognitive impairment or dementia. Training content and format was informed by the literature on dementia training in prisons and analysis of qualitative and quantitative data from semi-structured interviews with prison staff and a survey administered to prison governors and healthcare managers, both of which explored current provision of dementia training and training needs. A stakeholder working group reviewed and revised the training during two interactive meetings. Future research to evaluate the effectiveness of the training in practice is required.

ARTICLE HISTORY Received 22 January 2023; Accepted 1 June 2023

KEYWORDS Dementia; older prisoners; service development; prison training

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[NIHR Health Service and Delivery Research Programme 08270].
[NHR Research Ethics Committee for Wales 16/WA/0216]

Introduction

The number of older prisoners[1] has increased exponentially in most developed countries over recent years. In the UK, the number has trebled over the last two decades; in 2021, 17% (13,283) of the prison population were aged 50 or over (Prison Reform Trust, 2022). The increase in the number of older prisoners means it is likely that the prevalence of illness and disease common in older age is expected to rise, including the prevalence of dementia; the so-called 'hidden problem' (Cipriani et al., 2017). In a recent study by the authors (Forsyth et al., 2020), the prevalence of dementia was found to be 8% across the older prisoner population. Prisons are unprepared for this growing population of older prisoners, especially people with dementia. The built environment is unsuitable, there is no standardised pathway of dementia care and a lack of staff training opportunities to meet the needs of this vulnerable and growing prison population (Brooke et al., 2020; du Toit et al., 2019; Peacock et al., 2019).

Staff awareness of dementia and its care is variable across the prison estate (Brooke et al., 2020; du Toit et al., 2019; Peacock et al., 2019). In a 2018 survey; around a quarter (26%) of prisons in England reported that they had delivered training for prison staff whilst only 21% of healthcare departments had delivered training for prison healthcare staff (Forsyth et al., 2020). Current understanding and awareness of dementia and mild cognitive impairment (MCI) is low and prison staff lack the skills and knowledge needed to identify possible dementia with frequent misdiagnoses of early symptoms (for example, regressive and confusion behaviour) as 'bad behaviour'. Also, prisoners may not report any cognitive symptoms for fear of repercussions (Cipriani et al., 2017). The result of this means it is unlikely that referral into healthcare will take place. Furthermore, few establishments have routine dementia or MCI screening processes and so undiagnosed dementia will continue to go under the radar; thus, there is a need to develop training on dementia for prison staff (Brooke et al., 2020; du Toit et al., 2019; Peacock et al., 2019).

Training provision specific to dementia and MCI remains *ad hoc* across England and Wales (Brooke 2020; Peacock et al., 2019; du Toit 2019). There have been a few local initiatives often supported by third-sector organisations. For instance, in the UK, the Alzheimer's Society has delivered tailored Dementia awareness training to prison staff as well as Dementia Friends sessions in prisons. This type of training has been shown to be acceptable to staff and can increase knowledge of dementia, but engagement with dementia-friendly community principles was constrained by contextual barriers including de-prioritisation in prisons with low numbers of older prisoners (Treacy et al., 2019). Also in the UK, the charity RECOOP have developed peer led buddy support training in several UK prisons, and this includes awareness of dementia (Recoop, 2023). Brooke and Rybacka (2020)

developed and conducted a brief evaluation of a dementia training package in prison. They found that all types of staff were able to gain a basic knowledge of dementia and participate in meaningful discussion around this topic. They struggled with conducting multi-disciplinary training, due to practical issues and highlighted the need for training to be accompanied by regime and environmental changes.

In response to care quality concerns which included skills and knowledge deficiencies within the healthcare workforce (Surr et al., 2017); policy strategies have since addressed such gaps in dementia training provision in the community. A national framework: The Dementia Training Standards Framework was developed (Skills for Health, 2018), which outlines fundamental topics and learning objectives in order to support workforces with sufficient skills and knowledge. The Dementia Training Standards Framework, updated by Skills for Health, Health Education England (HEE) and Skills for Care in (2018), provides a guide on what essential skills and knowledge about dementia and MCI are needed across the health and social care sector. The framework describes three tiers of training: awareness, which everyone should have (tier 1); basic skills that are relevant to all staff in settings where people with dementia are likely to attend (tier 2); and training for leadership (tier 3). In the UK, there is an obligation to provide the same standard of care inside prisons as that provided for the general population. With the principles of equivalence in mind, this framework should also guide the format of training interventions in the prison setting. Previous studies have indicated that the following should be included in such training: 1) early warning signs of dementia (2) increasing awareness of the impact of dementia on a prisoner's ability to function, thereby reducing the potential for conflict arising from misunderstandings and (3) developing interpersonal and communication skills amongst prison staff (Brooke et al., 2020; du Toit et al., 2019; Peacock et al., 2019). Moll (2013) and du Toit et al. (2019) further recommended the need to explore and clarify the role of peer carers in prison and provide them with appropriate training. This is particularly important considering the vulnerability of people in prison with symptoms of dementia and the risk of abuse they face.

There is a clear need for research that can inform the development of dementia services in prison, including improved identification and care pathways. The Dementia and Cognitive Impairment in the Older Prison Population in England and Wales (DECISION) study (Forsyth et al., 2020), funded by the NIHR Health Services and Delivery Research programme, aimed to address this. It was a mixed methods study aiming to firstly estimate the prevalence of dementia and MCI in people aged 50+ in prisons in England and Wales. The study explored what pathways of care, service provision and staff training packages should be provided to appropriately support these prisoners. This paper reports on the

development of training packages for staff and peer carers in prisons to identify and support people in prison who are showing signs of dementia/MCI or are already diagnosed with the condition.

Methods

In order to develop evidence and theory-based training for prison staff to identify and support people in prison showing signs of dementia; the process of development of the training package involved analysis of data relevant to training that was collected as part of the DECISION study (Forsyth et al., 2020). This included questionnaire data and qualitative interview data (see further detail below). Interim analysis of this data (descriptive data on the data available at that time (December 2018) was then presented to a stakeholder working group (see below), alongside existing literature on training for the identification of dementia and support provided in the prison setting and proposed training content and format. Stakeholder views were then incorporated into the development of the training package.

Questionnaire data

As part of the DECISION study (Forsyth et al., 2020), two separate questionnaires were issued to governors and healthcare managers of all prisons housing men and women in England and Wales ($n = 109$ prisons). The questionnaires included free-text sections, single-response questions, and multiple-choice questions. The governor questionnaire included questions on service provision for people with dementia and MCI, including any modifications to the environment, training delivered and required, and social care provision. The healthcare questionnaire included questions on training provision, training needs, current health and social care provision, and future care pathway delivery. At the point of interim analysis; data was collected from 85 prison governors (78% of prisons) and 37 health-care managers (34% of prisons). The questionnaires analysed at this interim stage were completed between August 2017 and December 2018 (for the final survey results, see Forsyth et al., 2020)

Interim analysis of the 23 questions about training provision and training needs was conducted to inform the content and format of the training. The training specific data analysed included who should attend training on dementia and MCI, preferred mode of delivery, setting, length, group size and frequency of training, teaching methods and who should deliver training. For training content, data on gaps in knowledge or areas in which staff lack confidence in relation to identification and management of MCI and dementia, and what topics should be covered in training were analysed.

Qualitative interview data

The DECISION study (Forsyth et al., 2020) included qualitative interviews with prison staff (six healthcare staff, two social workers, one prison officer, one probation officer, three governors or deputy governors, two prisoners and two peer carer volunteers). A semistructured interview schedule was used based around several a priori themes and interviewees were given the opportunity to expand on any issues. Questions pertaining to training included: How much training have you received concerning identifying and supporting prisoners with memory problems? How confident do you feel in identifying and supporting these individuals? What further training/support do you feel you/your staff need (if any)?. The interview transcriptions were coded in NVIVO 12™ for data relevant to dementia training using the Framework Method (Ritchie et al., 2003) and the following deductive themes were used to analyse the data: attendees/recipients, barriers to training, content, format and experience of previous training. The data was summarised for each theme and was used to inform training design and content.

Training working group

Stakeholder views were obtained to inform training design. Eight people attended the first meeting, with the group consisting of a neuropsychologist, a patient carer, a lecturer in dementia, a prison social worker, three prison officers (including an older person lead) and a representative from Alzheimer's Society. To introduce the topic a presentation was delivered which outlined existing literature on content and format for dementia training in prison; discussed interim analysis of the survey and qualitative data; and explored the Dementia Training Standards Framework (DTSF) as a potential source to inform the content of the programme (Skills for Health, 2018). The group shared their views on proposed content and format throughout the presentation, and agreement on key training content and format issues was reached. Detailed notes of these discussions were taken by the researcher (KP). The feedback was incorporated into subsequent drafts of the training.

The people who attended the first meeting were invited to a second meeting to review the first completed draft of the dementia awareness training. The second meeting was attended by a patient carer, social worker and two prison officers where a presentation of the proposed training was given. The group was asked for their comments on each slide. The feedback was incorporated into the final drafts of the training packages.

Analysis

The above data sources and the feedback from the working group meetings were used to identify the training needs of prison staff in relation to dementia, including who needed training, what content should be included and how it should be delivered. The theoretical framework used to inform the content and format of the training packages was the Perceived Effectiveness of Training (PET) framework (see Figure 1) developed by the author KP for the design of optimal healthcare professional training (Perryman, 2014). The framework draws on several learning and behaviour change theories and was developed from qualitative analysis of what training components underpin effective healthcare professional training as perceived by healthcare professionals and experts in training and behaviour change (Perryman, 2014). Figure 1 illustrates how training design should be considered in terms of interpersonal (social), intrapersonal (individual) and system factors and should aim to address each of the five themes that underpin effective training (social interaction, credibility, relevance, information processing and practicalities).

In addition to this, a list of pre-defined training methods with evidence of their effectiveness, known as The Training Intervention Component (TIC) Taxonomy, was used to inform the design of the training packages (Perryman, 2014). This taxonomy consists of 171 defined training components and is divided into three phases and several groupings within each

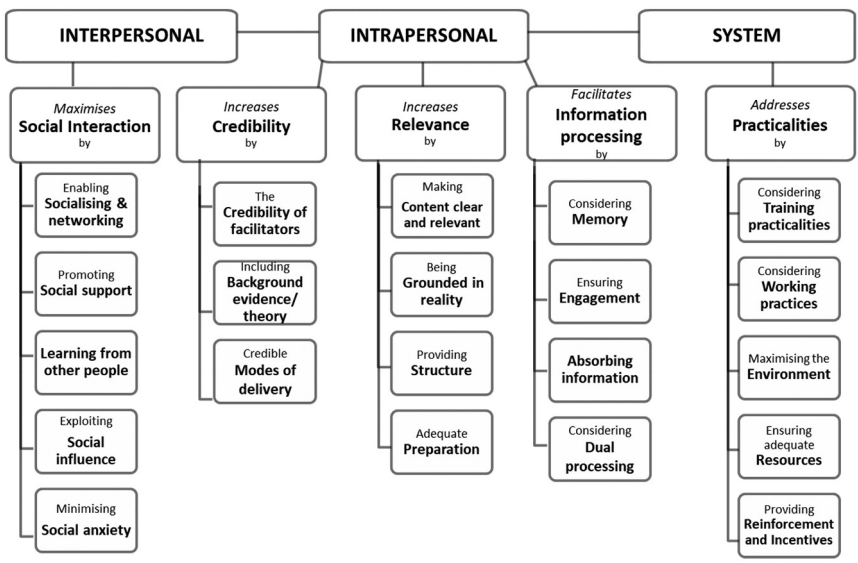

Figure 1. The perceived effectiveness of training framework (Perryman, 2014).

Box 1. Structure of the Training Intervention Component Taxonomy.

Phase	Groupings
Pre-training	Pre-training planning/preparation
	Incentives to attend training
Training delivery	Content
	Training methods
	Characteristics of the training provider/facilitator
	Characteristics of the recipients
	Length/duration
	Characteristics of the setting
Post-training	Evaluation
	Skills transfer techniques
	Leadership

phase which contain specific training components. Box 1 shows an overview of the structure of the taxonomy.

The TIC taxonomy has been mapped to the PET framework, so it is possible to identify which theme in the framework each training component was perceived to be effective in (Perryman, 2014)

A document designed to capture the training components identified to be relevant and important to include in the training packages was applied to the questionnaire data analysis, the qualitative interview analysis and the notes from the training working group meeting. This enabled the identification of specific training components that should be included in the training packages for them to have the potential to be effective, and how well our training packages mapped to the PET framework.

Results

The training needs analysis is presented below, showing the recommendations for training content and format for each data source.

Questionnaire data

The data from the full analysis of the questionnaire is published elsewhere (Forsyth et al., 2020). Interim analysis of the questionnaire data informed the proposed training content and format. To summarise, the following recommendations were presented to the training working group for discussion: (1) all prison and healthcare staff should receive awareness training, (2) training should be delivered in person, on site and in the format of a workshop to small or medium sized groups, (3) training should be no longer than one half day or shorter, modular sessions, (4) training should be interactive and use case studies, group discussion and small group tasks to achieve learning objectives, (5) sessions should be facilitated by an external clinician with

prison experience, a forensic psychiatrist or a mental health nurse, and (6) training should increase awareness by covering early warning signs, impact on functioning, communication, causes, local assessment (and referral) processes.

Qualitative data

Several recommendations for the training design were obtained from interim analysis of the qualitative data. These were (1) train all staff in dementia awareness, offering more detailed and in-depth training as needed, (2) train peers to support other prisoners, (3) have a well-trained dementia champion (prison and healthcare staff)), (4) training sessions to be no longer than two hours (modular training if any longer), (5) Face-to-face, interactive workshop training, (6) training methods to include case studies, discussion and role modelling, (7) small group training (e.g. 10–12 people), (8) a train-the-trainer approach is the most practical (9) on-site (at the prison) training is best, (10) it is more important for the facilitator to have dementia expertise than prison expertise and (11) training should offer a certificate of competence to recipients.

Training working group recommendations

The training working group was presented with a synthesis of data from the scoping review, interim analysis of questionnaire data, semi structured interviews and a review of the Dementia Core Skills Education and Training Framework (later renamed the Dementia Training Standards Framework (Skills for Health, 2018), which outlines the skills that should be covered in dementia training for health and social care staff, including discussion on its applicability to the prison setting. It was agreed that due to a lack of existing training to inform the content of the training packages, the Dementia Training Standards Framework would be the primary source of content. We therefore obtained permission from HEE to adapt their training resources based on the framework and aimed at health and social care staff, to the prison setting.

The training working group felt that the dementia awareness (tier 1) training did not need to be delivered by a clinician and should be delivered by a prison officer or a member of the healthcare team. Ideally, they would be involved in dementia in some capacity in either a specialist role or as a dementia champion within the prison. The training working group provided several recommendations for the training. Prison representatives indicated that prison staff do not often respond well to role-play techniques in training. Therefore, it was decided not to include this method in our training packages. Furthermore, as the HEE training case study presentations are not relevant to

the prison setting, the training working group felt that we should not include them as proposed. As a result, the research team filmed case study presentations to supplement the training using actors to portray prison officers, and prisoners showing signs of dementia. Eight film clips were developed demonstrating (1) signs and symptoms of dementia; (2) the likely impact of prison on someone with dementia; and (3) good and poor communication skills.

Outline of training packages

Three training packages were developed based on the findings from the qualitative interviews, survey data and the training working group. Tier one is provided to all staff to enhance their awareness of signs and symptoms of dementia and how to address them. Tier two provides more in-depth training to those who provide direct health and social care support to individuals with dementia or MCI living in prison. The final package is training specifically adapted for peer carers.

Tier 1: dementia awareness in the prison setting

The basis of content for the dementia awareness training presentation was taken from the Tier 1 dementia awareness training developed by HEE.[2] Adaptations were subsequently made for the prison setting in terms of style, delivery, literacy and knowledge, and prison-relevant content. In addition, existing training on dementia awareness in prisons developed by the Alzheimer's Society was reviewed, and some slides were adapted with the organisation's permission. The working group felt this first package should provide a comprehensive understanding and be suitable for those with little or no understanding of dementia and MCI. Figure 2 shows the recommended training format and content.

Tier 2: dementia care and support in the prison setting

In addition to tier 1 training, to be delivered to all staff in the prison setting, we decided in conjunction with the training working group to develop a more in depth, tier 2 training resource for prison and healthcare staff who support people in prison with dementia or who have a role that involves responsibility for the health and social care needs of prisoners (see Figure 2). We used the resources on the HEE website to inform this training (Dementia Education and Learning Through Simulation 2) and also the e-learning developed by HEE [URL: www.e-lfh.org.uk/programmes/dementia/ (accessed 1 April 2020)]. As with tier 1 training, these resources were also adapted to the prison setting. Due to the more specialist content, tier 2 training was reviewed by the neuropsychologist in the working group (RD) and received

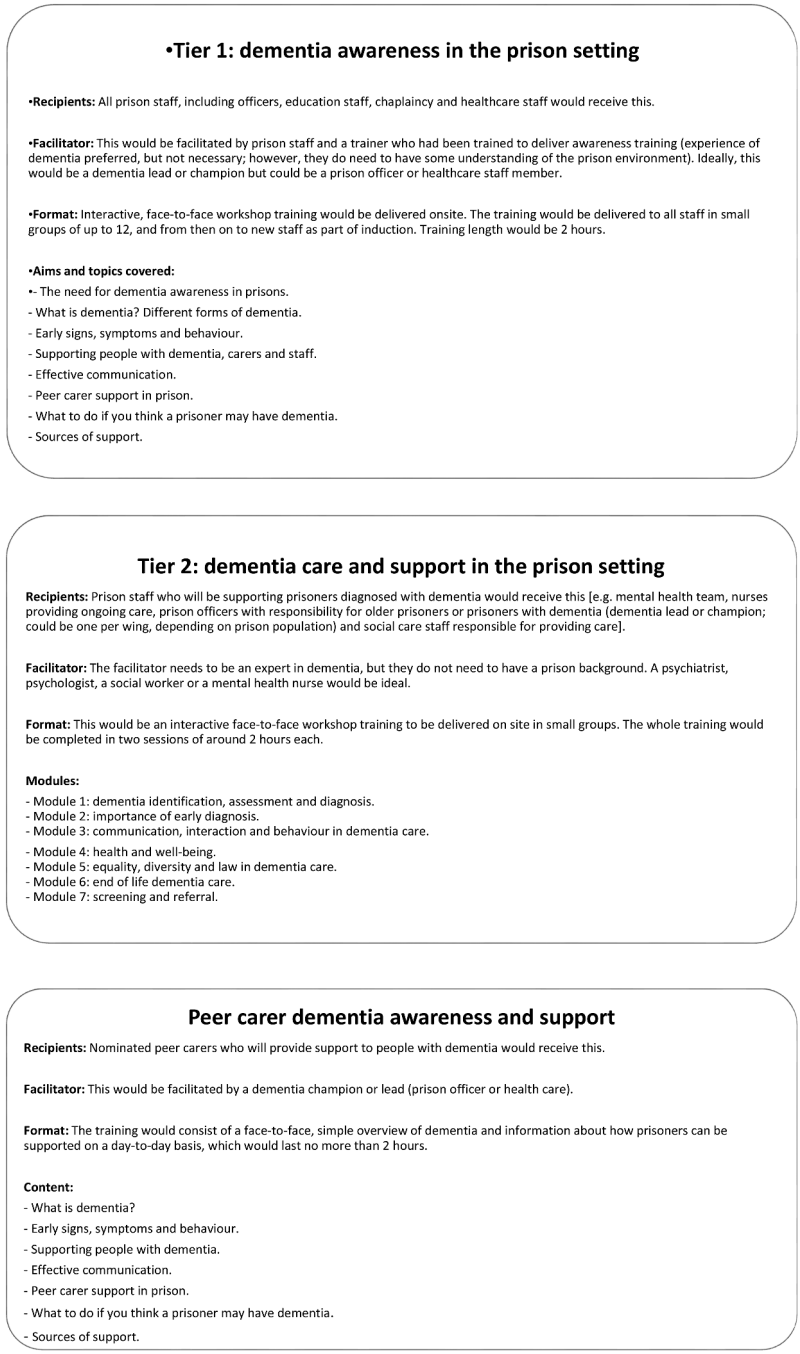

Figure 2. Outline of the DECISION training package.

specialist forensic psychiatric input from the principal investigator (JS). Drawing on their experience of conducting research and clinical work, the project team reviewed all drafts of the training, so that the training could be further adapted to the prison setting.

Peer carer dementia awareness and support

The training working group was very receptive to the development of separate training for peer carers to help them to look out for signs of dementia among older prisoners and to provide day-to-day care and support. Tier 1 training was adapted to be more appropriate for the targeted recipients, with the content and language presented in a more accessible way. It was recommended that this session should also be delivered in person and last for no longer than two hours. The training includes clear descriptions of the peer carer role and outlines the limits and expectations of the role.

A full description of the training components that should be implemented when delivering the DECISION training packages with definitions and associated theory can be seen in appendix 1. This outlines pre-training preparation work that needs to take place before the training can be delivered (in conjunction with discussions on implementing the care pathway), training delivery components (content, training methods, characteristics of the facilitator, characteristics of the recipients, length/duration, characteristics of the setting) and post training components (leadership). It is possible to see in the table which training components have been linked to each theme in the framework. If the training is implemented in the way we recommend using these training components; then it should maximise social interaction, increase credibility and relevance, facilitate information processing and address practicalities related to delivering optimal training. If the training was rolled out to prisons, it would be accompanied by a training manual that outlines how the training should be delivered with detailed guidance for the facilitator.

Discussion

This study addresses the need for the development of training for prison staff to improve the support for people in prison that may have dementia or MCI as identified in previous studies (Brooke et al., 2020; du Toit et al., 2019; Moll, 2013; Peacock et al., 2019). This need is especially pertinent considering the increasing number of older adults in prison, many of whom are likely to face structural barriers to receiving a formal diagnosis of dementia. There is also a risk that the structured environment of a prison makes it harder to identify symptoms of dementia/MCI in prisoners. A theory-based approach to the design and development of training was adopted. Three training packages were developed by adapting the

dementia awareness training for health and social care professionals and the dementia care eLearning programme developed by Health Education England to the prison setting. Training for dementia care in prisons should be available at two levels: (1) general awareness training for all staff and (2) a specialist healthcare resource for those undertaking assessments and developing care plans. Also, we developed a version of the tier 1 awareness training for prisoners and peer carers, as recommended in the literature (du Toit et al., 2019) and the stakeholder working group in this study.

All three training packages were designed to be delivered face-to-face in sessions of around 2 hours. We recommend face-to-face training because it enables social interaction and certain training components, such as group discussions, are easier to facilitate face to face. Participants have the chance to socialise and network, share their personal experiences of prisoners showing signs of cognitive impairment and dementia and learn from each other when training is delivered in person. The format is facilitator led using a core set of slides, but with an emphasis on encouraging discussion, small group tasks and interaction between group members. It may also be advantageous to involve trained peer carers in the delivery of the peer carer training to maximise peer learning. Communication skills are demonstrated using actors demonstrating prison-specific examples shown on pre-prepared videos, rather than using role-play with group members. This enables all trainees to observe the same skills they are being trained on thereby creating consistency in the demonstration role plays.

The study employed a robust methodology, which included input from a wide range of experts. The involvement of stakeholders including prison officers and experts in dementia is a key strength of this study. However, only two working groups were held, it may be that further working groups are delivered in the future to ensure the views incorporated into training materials reflect the wider workforce. Two members of the steering group for this study had previously lived in prison (one member experienced mild cognitive impairment). They both provided advise on the training package. Furthermore, the data that informed the training package was conducted between 2017 and 2018, therefore we are not able to say how the pandemic may have influenced people's perceptions of how people in prison with dementia could be best supported and how training should be delivered. At the time of writing, group training sessions on all topics across the prison estate had resumed; nonetheless, as there are currently no national, standardised dementia-specific training packages for prison use in operation across England and Wales, despite a rapidly increasing older prisoner population, the developed training packages provide a resource for improving the identification and support of people with dementia/MCI. The training materials produced are freely available via the University of Manchester's online research resource repository.

We argue that for successful implementation of the training, it is important that appropriate pre-training activities be conducted prior to training delivery. This includes meeting with policy leaders and prison management to ensure that there is managerial support and adequate resources to implement training, to plan implementation procedures and ensure that the working environment is amenable to change. We suggest that at least one dementia champion be identified in the prison to oversee the implementation of the training and wider DECISION Care Pathway (Forsyth et al., 2020), and to be involved in the delivery of the training as a facilitator. Large prisons with several wings containing older residents would benefit from more than one champion per wing. It is also important that a whole systems approach is taken, including consideration of how adaptations to the regime and environment could help support individuals with dementia in prison (Brooke & Rybacka, 2020).

In the coming years the number of older prisoners will continue to increase, and it is expected there will be a rise in age-related illnesses, including dementia. This will undoubtedly present a number of challenges for the prison estate. It is fundamental that prison and healthcare staff are equipped with the skills and knowledge to support this vulnerable and growing population. The potential benefits to prisoners would be substantial, including improved healthcare and access to a receiving formal diagnosis of dementia. It is quite possible that the routine-structured environment of a prison may in fact 'conceal' those living with dementia/MCI, meaning their status as vulnerable prisoners is not realised. Future research should seek to evaluate the training as implemented in practice and post evaluation; we recommend that training to improve the identification and support of people in prison showing signs of cognitive impairment and dementia becomes mandatory to support prison and healthcare staff, prisoners, establishments, and the wider criminal justice system.

Notes

1. In line with terminology used in establishments across England and Wales, any prisoner over the age of 50 is defined as an 'older prisoner'.
2. (www.hee.nhs.uk/our-work/dementia-awareness/resources-tier-one-two-three ;(accessed 1 April 2020)

Disclosure statement

No potential conflict of interest was reported by the authors.

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