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### Older persons with dementia in prison

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*Published in:*  
International Journal of Prisoner Health

*DOI:*  
[10.1108/IJPH-01-2019-0007](https://doi.org/10.1108/IJPH-01-2019-0007)

Published: 07/08/2019

*Document Version*  
Peer reviewed version

[Link to publication on the UWS Academic Portal](#)

*Citation for published version (APA):*  
Peacock, S., Burles, M., Hodson, A., Kumaran, M., MacRae, R., Peternej-Taylor, C., & Holtslander, L. (2019). Older persons with dementia in prison: an integrative review. *International Journal of Prisoner Health*, 16(1), 1-16. <https://doi.org/10.1108/IJPH-01-2019-0007>

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**Older Persons with Dementia in Prison: An Integrative Review**

Journal:	<i>International Journal of Prisoner Health</i>
Manuscript ID	IJPH-01-2019-0007.R3
Manuscript Type:	Practitioner Paper
Keywords:	Integrative review, older adults, dementia, Prison, health care, social care

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Manuscripts

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8 Older Persons with Dementia in Prison: An Integrative Review9  
10 Manuscript accepted by the *International Journal of Prisoner Health*11  
12 June 26, 201913  
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## Older Persons with Dementia in Prison: An Integrative Review

### Abstract

**Purpose:** The number of prisoners over 55 years is increasing and many are at risk of developing dementia. This has generated new responsibilities for prisons to provide health and social care for older persons. The aim of this paper is to synthesize the existing research literature regarding the phenomenon of the health and social care needs of older persons living with dementia in correctional settings.

**Approach:** Using an integrative review method based on Whitemore and Knafl, the inclusion criteria for the review are: (a) articles written in English; (b) a focus on some form of dementia and/or older persons with discussion of dementia; (c) to be set in a correctional context (correctional facility, prison, jail); (d) be derived from a published peer-reviewed journal or unpublished dissertation/thesis; and (e) be a qualitative, quantitative or mixed methods study.

Based on those criteria a search strategy was developed and executed by a health sciences librarian in the following databases: Medline, CINAHL, Embase, PsychINFO, Proquest Nursing and Allied Health, and Web of Science; searches were completed of up to April 2019. After data were extracted from included studies, synthesis of findings involved an iterative process where thematic analysis was facilitated by Braun and Clarke's approach.

**Findings:** Eight studies met the inclusion criteria. Key findings of the eight studies include (a) recognition of dementia as a concern for correctional populations, (b) dementia-related screening and programming for older persons, and (c) recommendations for improved screening and care practices. Most significant is the paucity of research available on this topic. Implications for research are discussed.

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3 **Value:** This paper identified and synthesizes the limited existing international research on the  
4 health and social care needs of older persons with dementia living in correctional settings.  
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7 Although existing research is scant, this review highlights the need for increased awareness of  
8 dementia as a concern among older persons living in correctional settings. As well, the review  
9 findings emphasize that enhanced screening and interventions, particularly tailored approaches,  
10 are imperative to support those living with dementia in correctional settings.  
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## Introduction

Internationally, the number of prisoners over 55 years is increasing disproportionately among correctional populations (Moll, 2013). Reasons are multifactorial and include population ageing, longer sentences, and recent sexual abuse convictions for historical offences (Moll, 2013). Many of these older persons may be at risk of developing dementia while incarcerated (Christodoulou, 2012; Gaston, 2018) due to factors such as unhealthy diets, inactivity, smoking, social isolation, depression, substance abuse, head injury, and lower educational attainment (Maschi et al., 2012a). Increasing numbers of incarcerated persons with dementia has generated new responsibilities for correctional services to provide care for the aging population. For prison staff, the invisibility of challenges for persons with dementia-related challenges (such as changes in mood, depressive symptoms, confusion, disorderly behaviour) presumed levels of prisoner distress have been highlighted within prison inspection reports (HM Inspectorate of Prisons for Scotland, 2017). The consequences of not properly diagnosing dementia for the person include heightened fear and distress, denial of access to appropriate health care and potential violation of human rights. For staff, lack of understanding has led to conflict, inappropriate restraint, and segregation, therefore escalating dementia-related distress (Newcomen, 2016).

Dementia describes a collection of diseases that affect the brain and are usually chronic or progressive in nature (Alzheimer Society of Canada, 2017). Its prevalence shows a striking association with age, but dementia is not a normal part of ageing. Disease progression causes disturbance of memory and orientation uniquely in each person, shaped by underlying physical and psychological health, personality, biography and social context. People with dementia can experience greater difficulties than the level of impairment warrants because of disabling environments and relationships (Spector and Orrell, 2010), with negative social experiences prompting deterioration (Macaulay, 2018). Functional improvements can be achieved if people

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3 with dementia are supported by enabling environments, interventions and care practices (Laver  
4 et al., 2016, Vreugdenhill et al., 2012). As brain health deteriorates and the damage progresses,  
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6 people with dementia require increasing levels of support. Health care needs must be addressed  
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8 in tandem with psychosocial and spiritual needs, and careful attention paid to the living  
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10 environment and level of family caring where possible (Hanson et al., 2016, Tolson et al., 2016).  
11  
12 Thus, emphasis must be placed on interventions, environments and approaches that enable and  
13  
14 enhance quality of life. However, adopting a biopsychosocial-spiritual model of dementia care  
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16 that places the person and caring relationships at the centre of health care practice during  
17  
18 advanced stages of the condition remains a challenge in many community care settings across the  
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20 globe (World Health Organization, 2017). This challenge may be even greater for those working  
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22 in secure environments. Nevertheless, there is potential in all settings, including prisons, for  
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24 staff to adopt approaches that enable and enhance quality of life.  
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31 Prisons and correctional facilities are among the most extreme, stressful environments  
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33 known to society, and have not been built with an aging population in mind. The intensity of the  
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35 physical and interpersonal environments, including the emphasis on authority, overcrowding,  
36  
37 lack of privacy, architectural impediments, and threats of violence and exploitation, make  
38  
39 prisons particularly challenging places for older persons (Human Rights Watch [HRW], 2012).  
40  
41 Structurally, the design and layout of most prisons are also challenging for older persons,  
42  
43 frequently requiring them to walk long distances for meals, medication, and health care services,  
44  
45 while trying to keep pace with younger able-bodied peers. Many aging incarcerated persons are  
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47 unable to readily climb stairs, navigate dimly lit corridors and uneven floors, pull themselves  
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49 onto a top bunk, or easily complete toileting activities (Bedard et al., 2016; HRW, 2012). HRW  
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3 (2012) concluded that accommodating older persons in prison is a “daily game of musical chairs  
4 that can shortchange individual elderly persons while it bedevils corrections officials” (p. 51).

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8 For those with dementia, coping with these physical and structural challenges may  
9  
10 exacerbate stress, disability, and disruptive behaviours. Changes in behaviour, like shouting and  
11  
12 repetitive behaviour, usually happen when a person with dementia feels confused or distressed  
13  
14 and cannot make sense of their surroundings (Alzheimer Society of Canada, 2017; Bedard et al.,  
15  
16 2016). Such behaviours are poorly understood by those around them, leaving persons vulnerable  
17  
18 to disciplinary responses from correctional staff or victimization from peers. Accommodating  
19  
20 persons with dementia therefore requires adaptations and approaches based on understanding of  
21  
22 the condition, the person, and how distressed behaviour can present, enabling treatment that  
23  
24 extends beyond a custodial response (Williams et al., 2014).

### 25 26 27 28 *Previous Literature Reviews*

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31 Several literature reviews have been completed that are relevant in some way to the  
32  
33 phenomenon of older persons in correctional settings. These reviews adopt diverse foci related  
34  
35 to mental and cognitive health in the prison population, and older persons who are incarcerated.  
36  
37 For example, some authors examine the prevalence of mental health disorders and cognitive  
38  
39 impairment across general prison populations (Brooke et al., 2018; Di Lorito et al., 2018;  
40  
41 Kakoulis et al., 2010), establishing dementia as one mental or cognitive health concern. Others  
42  
43 identify challenges facing older persons in general and specific to dementia across all phases of  
44  
45 corrections (Cipriani et al., 2017; Maschi et al., 2012b; Stojkovic, 2007), emphasizing the  
46  
47 detrimental outcomes associated with unmet dementia care and support needs. As well, issues  
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49 pertaining to dementia are discussed with regards to prison staff, health care providers, and  
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3 correctional services (Gaston, 2018, Brooke et al., 2018; Maschi et al., 2012b), although limited  
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5 research has been done in this area.  
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8 Through these reviews, it is apparent that greater awareness of this issue is needed, along  
9  
10 with better detection of dementia in older persons across the criminal justice system and  
11  
12 enhanced access to dementia-related services and supports within correctional settings.  
13

14 Although important correctional health issues are highlighted within these reviews, a more  
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16 specific focus is needed on older persons living with dementia in correctional settings to identify  
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18 evidence from research and strategies to inform sustainable efforts that can improve the  
19  
20 identification and care of this population. Through our review, we seek to highlight dementia as  
21  
22 a progressive neurodegenerative condition that recognizes the interplay between biological,  
23  
24 psychological, social, environmental and spiritual factors, and requires a multi-faceted approach  
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26 to care and support of this population. As such, our integrative review was thus guided by the  
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28 questions: “*What is the state of the research literature regarding living with dementia in*  
29  
30 *correctional settings?*” and “*How can the dementia-related issues faced by prisoners be*  
31  
32 *addressed through modifications to the social and physical environment?*”  
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### 38 **Methodology**

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40 Whittemore and Knafl’s (2005) integrative review method informed how the present  
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42 study was conducted. Our multidisciplinary team collaborated in all phases of the review,  
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44 including identifying the problem, terms, and key words to be utilized in searches, determining  
45  
46 inclusion criteria, and developing methods to synthesize the resulting empirical work. Two  
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48 authors independently (a) screened abstracts and titles, (b) assessed for inclusion or exclusion,  
49  
50 (c) extracted data from individual articles, and (d) completed thematic analysis. The entire team  
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53 met to discuss and deliberate on the themes resulting from analysis and collaborated on  
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3 preparation of this paper. Ethical approval was not required given the nature of the review  
4  
5 method.

### 6 7 8 *Search Strategies*

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10 Literature searches were developed and executed in collaboration with an experienced  
11 health sciences librarian. The Medline, CINAHL, Embase, PsychINFO, Proquest Nursing and  
12 Allied Health, and Web of Science databases were searched for all relevant publications.  
13  
14 Searches were done using a combination of controlled vocabulary and key words for major  
15 concepts such as ‘prison’, ‘older adults’, and ‘dementia’. Searches were conducted from  
16 inception of the databases searched to April 2019, and limited to peer-reviewed and scholarly  
17 research studies; no date or publication year restrictions were applied. Our initial intent was to  
18 explore experiences of living with dementia in correctional settings. However, a comprehensive  
19 search using key words and subject headings related to ‘dementia’ and ‘correctional settings’  
20 found no peer-reviewed research. To locate scholarly works that addressed dementia in  
21 correctional settings more broadly, we completed additional searches focused on ‘older adults’,  
22 as challenges for incarcerated older persons can relate to dementia (see Table 1 for search  
23 strategy used in Medline). This approach proved fruitful in identifying peer-reviewed research  
24 relevant to the review.  
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42 [Table 1]

### 43 44 45 *Selection of Relevant Sources*

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47 Selected studies were those that were: (a) written in English; (b) about some form of  
48 dementia and/or older persons (50+ years) with discussion of dementia; (c) relevant to a  
49 correctional context (secure facility, prison, jail); (d) a published peer-reviewed article or  
50 unpublished dissertation/thesis; and (e) a qualitative, quantitative or mixed methods study.  
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Articles were excluded if they lacked reporting on empirical evidence (for example, editorials), considered short-term correctional contexts (where those charged are held prior to trial and sentencing), or did not consider the dementia context sufficiently to inform the present review. Given the small number of studies meeting our inclusion criteria and variations in the research designs employed, no studies were excluded based on quality. However, only academic research was included, all of which was peer-reviewed (journal articles, dissertations). A summary of our selection process appears in Figure 1.

[Figure 1]

Data were extracted (see Table 2) from each study on method, setting and sample characteristics, and key findings. Data extraction was followed by synthesis of the study findings, involving an iterative process whereby key themes were identified across the articles. Theme identification was facilitated by Braun and Clarke's (2006) steps for thematic analysis: immersion in the data, generation of initial codes, probing for themes, reviewing themes, and defining and naming the themes. This process was completed independently by two authors, with subsequent discussion among the team followed by narrative integration of the themes.

[Table 2]

Findings

The eight studies are from diverse countries (Australia [ $n=1$ ], France [ $n=1$ ], the United Kingdom [ $n=3$ ], and the United States [ $n=3$ ]) and employ differing methods. Participant data from five of the eight studies comes from either health records ( $n = 32$ ) or incarcerated persons (ranging from 14 to 309), while four studies gathered data from experts and prison staff ( $n = 90$ ). Most data from incarcerated persons pertained to men, with one study including a woman (Curtice, Parker, Wismayer, & Tomison, 2003) and another a transgender woman (Dillon,

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3 Vinter, Winder, & Finch, 2018). Screening for cognitive impairment and/or assessing dementia  
4 was discussed to some degree in the eight studies, and the *Mini-Mental Status Exam* (MMSE)  
5 was the most cited measure (see Table 3). Of note, three studies evaluated cognitive impairment,  
6 despite not being equivalent to, nor comprehensive of all dementia-related symptoms.  
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12 [Table 3]  
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15 Key findings regarding living with dementia in correctional settings fell within three  
16 main categories: (a) recognition of dementia as a concern for older persons in correctional  
17 settings; (b) dementia-related screening and care for older persons; and (c) recommendations for  
18 screening and care practices. A discussion of each category follows.  
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### 23 *Evidence of Dementia as a Concern for Correctional Populations*

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26 Although risk of mental and cognitive disorders is highlighted in the literature on the  
27 health of individuals living in correctional facilities, only a few studies have been conducted to  
28 establish the prevalence of dementia in the correctional population. Combalbert et al. (2018)  
29 compared 138 older men living in several correctional facilities in France to an equivalent  
30 sample of the general population in France, using standardized scales to assess cognitive  
31 performance, health, mental health and quality of life. Combalbert et al. (2018) established that  
32 those living in correctional settings exhibited higher rates of cognitive impairment compared  
33 with the general population, with approximately 19% satisfying the criteria for a dementia  
34 diagnosis. Furthermore, their findings suggest that those at risk within correctional settings  
35 might be significantly younger, as the mean age of the correctional sample (59.7 years) was eight  
36 years younger than the general population sample (68.4 years). Potential contributors to  
37 cognitive decline and dementia among those in correctional settings were also identified in these  
38 studies, including physical and psychosocial conditions (Combalbert et al., 2018).  
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3 Similarly, Kingston et al. (2011) examined the prevalence of psychiatric disorders in  
4 adult's aged 50 years and older living in correctional settings. Assessments were conducted with  
5 121 older men from four facilities using the Geriatric Mental State Examination (GMSE), the  
6 MMSE, Short Form 12, and prison records. The researchers found that 16 participants (13% of  
7 the sample) showed signs of cognitive impairment based on their MMSE scores, although only  
8 two were identified as having dementia according to the GMSE measure. While this meant less  
9 than 2% of the sample were deemed to have dementia, the MMSE may be a more encompassing  
10 measure for assessing dementia prevalence in older adult men living in corrections. Curtice et al.  
11 (2003) also sought to establish the prevalence of dementia in 'elderly' individuals referred to a  
12 forensic psychiatric service in the United Kingdom. Using health records and case notes over a  
13 12-year timespan, 32 incarcerated individuals aged 65 years or older were identified. Of these,  
14 19% had been diagnosed with dementia and 79% had a history of alcoholism, a known risk  
15 factor (Schwarzinger, et al., 2018). Interestingly, almost 60% of the sample had no prior history  
16 of offending, raising the possibility that they were currently incarcerated for an offense linked to  
17 declining cognitive or mental well-being (Curtice et al., 2003).  
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37 Together, these studies offer evidence that cognitive impairment and psychiatric  
38 disorders, including those within the scope of dementia, are indeed a concern within the older  
39 adult correctional population. Namely, 13 to 19% of participants in these studies met the criteria  
40 for, or had received a dementia diagnosis. Additionally, Curtice et al. (2003) and Kingston et al.  
41 (2011) identify aspects of the correctional environment that contribute the heightened risk,  
42 reinforcing the concern for dementia among this population.  
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51 *Dementia-related Screening and Programming for Older Persons*  
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Several articles discussed screening of older persons in correctional settings, while few identified existing programming for this population. Curtice et al. (2003) found that only 4 of 32 individuals in their study had been screened using the MMSE, which they believe is an effective diagnostic tool. Curtice et al. (2003) were perplexed by this low number and concluded that existing diagnostic tools are not necessarily used when persons are evaluated in correctional settings. In comparison, they noted that dementia assessment and management in collaboration with forensic and older adult psychiatric teams was more thorough. Issues related to screening and diagnosis were also raised by Kingston et al. (2011), based on data collected on psychiatric disorders in persons over 50 living in correctional settings. Comparing self-reported data collected through interviews and medical record data that included the GMSE and MMSE, their findings revealed discrepancies between self-reported mental health and actual diagnoses. Although the conditions identified were not exclusive to dementia, differences between data sources suggest that older persons living in corrections may not be adequately screened for diseases that compromise mental health. Furthermore, only two dementia diagnoses were identified, despite evidence that 13% of inmates received a MMSE score qualifying them for diagnosis. Together, these three studies suggest that improvements to dementia screening are needed to ensure that incarcerated older persons receive appropriate screening, diagnosis, and subsequent treatment and support.

Turner (2018) also sought to understand best practices in correctional settings for screening, assessment, and managing the needs of persons living with dementia from the perspectives of correctional mental health employees ( $n = 7$ ) from three facilities in Ohio, United States. A key finding is the lack of training staff receive to identify and assess dementia. Mental health staff were identified as needing better training in dementia, along with other staff who

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3 work closely with persons living in corrections (such as correctional officers and unit managers).

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5 Similarly, in response to Governor-identified needs to inform recommendations for meaningful  
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7 change in two prisons in the United Kingdom, Dillon and colleagues (2018) undertook a  
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9 qualitative study to understand the experience of dementia through interviews with persons  
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11 living in corrections and staff. Participants indicated challenges in recognizing signs of dementia  
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13 in persons and stressed the importance of early screening so that persons could access supportive  
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15 care as soon as possible. This can begin to be addressed with increasing the availability of  
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17 dementia-specific training. Lack of training in this area, however, has implications for if, when,  
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19 and how screening for dementia is completed.  
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24         Appropriate screening can facilitate access to care and programming for those with  
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26 dementia. Harrison (2015) highlights the importance of screening and provision of support for  
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28 those with dementia through evaluation of the “True Grit” program, a specialized program  
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30 implemented in a correctional setting in Nevada (United States). This enriched program for  
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32 older adult men integrates human rights principles by offering a safe, healthy and structured  
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34 living environment. Harrison compared the cognitive and physical abilities of 153 participants in  
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36 the program to a comparable sample of those living in regular correctional environments.  
37  
38 Analysis revealed that members of the True Grit program fared better on 13 of 14 measures, with  
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40 significant differences reported for executive function, intellectual ability, visual perception, and  
41  
42 physical mobility, among others (Harrison, 2015). The specialized care accessed through the  
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44 True Grit program was found to benefit persons with cognitive impairment, but this program is  
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46 only accessible if appropriate screening occurs to identify those in most need of such services.  
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51         Across these studies, evidence suggests that efforts toward screening and programming  
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53 for older persons at risk for dementia varied across setting. Foremost, Curtice et al. (2003),  
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Kingston et al. (2011), and Turner's (2018) studies highlighted the need to enhance screening, either through increased use of the MMSE or referral for further assessment when a low MMSE score is noted. While Kingston et al. (2011) did not identify a recommended approach to dementia diagnosis, Curtice et al. (2003) emphasized the value of old age psychiatric services to screening and diagnosis. Additional funding for and integration of specialized services could also include efforts to assist older persons in managing dementia-related symptoms within correctional settings (Turner, 2018). The specialized program described by Harrison (2015) is one example of how better care can support older persons' cognitive functioning within correctional settings. Namely, the reported outcomes demonstrate the potential that exists to enhance support through modification of psychosocial-environmental conditions.

#### *Recommendations for Improved Screening and Care Practices*

Further to the discussion of screening as summarized in the above section, suggestions for improving existing screening and care practices were made by several authors. A salient recommendation was to improve the training of frontline correctional staff (Dillon et al., 2018; Turner, 2018). Furthermore, along with increasing awareness of dementia through training, Kingston et al. (2011) emphasized the need for increased understanding of older persons' mental health needs when living in correctional settings. These authors recognized that the proportion of dementia diagnoses in correctional populations is likely higher than the recorded cases in their sample (less than 2%). Accordingly, they proposed a focus on improved screening and early diagnosis of dementia in correctional populations. Similarly, Turner (2018) recommended the need for a standard process to screen and assess persons living in corrections upon entry to the system and for those displaying symptoms of dementia.

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3 Patterson et al. (2016) also made screening recommendations based on the findings of a  
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5 Delphi study. They found that of the registered nurses who participated in the first round,  
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7 approximately 64% perceived the Reception Screening tool administered to individuals newly  
8  
9 admitted to the correctional system as 'sometimes unsuitable' or 'very unsuitable' for identifying  
10  
11 dementia. The tool was deemed inadequate because it did not evaluate cognitive function or  
12  
13 memory, contained no section that prompts assessor if there are suspicions of dementia, was only  
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15 sensitive to advanced dementia, and relied on nurse experience with dementia. Survey  
16  
17 respondents thus advocated for inclusion of the MMSE and other indicators of cognitive  
18  
19 function, memory and daily activities into the assessment tool (Patterson et al., 2016). In  
20  
21 subsequent discussion groups with health care providers, use of simple memory and cognition  
22  
23 tests was recommended. This could allow identification of concerns and individuals needing  
24  
25 further assessment from a dementia care team; depending on these results, referral could then be  
26  
27 made for screening using the MMSE or Rowland Universal Dementia Assessment. Participants  
28  
29 also deemed the Global Deterioration Scale to be suitable for evaluating older persons living in  
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31 corrections for dementia, but indicated the need for validation to ensure that it was context-  
32  
33 appropriate (Patterson et al., 2016). Overall, participants outlined an appropriate assessment  
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35 pathway for older persons that involved initial assessment, referral for further screening by a  
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37 specialized multidisciplinary team if necessary, followed by further assessment and treatment by  
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39 a dementia care team.  
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47 Williams et al. (2012) recommended that all individuals aged 55 and older, or with  
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49 traumatic brain injury, be screened for dementia upon entry into correctional settings and  
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51 annually if dementia is identified. Similarly, Combalbert et al. (2018) emphasized the  
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53 importance of systematic screening of men over 50 years of age for cognitive disorders. Curtice  
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3 et al. (2003) developed specific assessment guidelines based on their finding that screening was  
4 often inadequate, and recommended the use of appropriate screening tools for cognitive  
5 impairment, depression, and physical well-being. While these authors agree on the need for  
6 improved screening, Patterson et al. (2016) recognized barriers to effective dementia screening  
7 within correctional settings, including time limitations, nurses' lack of familiarity with cognitive  
8 screening, and ineffectiveness of screening individuals under the influence of illicit substances.  
9 This process may therefore require access to health care providers with relevant experience who  
10 can perform in-depth assessments. Establishment of multidisciplinary teams is imperative,  
11 similar to Curtice et al.'s (2003) advocacy for the inclusion of old age psychiatric services in  
12 forensic settings. Such teams can provide ongoing support, share knowledge with teams based at  
13 other facilities, and collaborate with correctional staff.  
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28 Finally, the experts who participated in Patterson et al.'s (2016) Delphi study advocated  
29 for adaptation of existing prisons, rather than moving older persons living with dementia to  
30 specialized units. Their recommendations included advanced care planning for individuals with  
31 cognitive deficits and supportive programs. Similar to Turner (2013), Patterson et al. suggested  
32 a peer-buddying system, greater education/training for correctional staff, and enhanced screening  
33 and care pathways. The enriched programming described by Harrison (2015) appears to have  
34 the potential to provide various benefits to incarcerated older persons, although its  
35 implementation may require increased resources.  
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## 47 Discussion

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49 Across much of the developed world, the number of older persons living in corrections is  
50 rising, compounded further by the complex health care needs, including those living with  
51 dementia (Moll, 2013). Our review found that robust research exists that identifies dementia as a  
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3 concern within the correctional population, albeit far more is needed. Combalbert et al. (2018)  
4 and Kingston et al. (2011) collected data from relatively large samples of older persons living in  
5 correctional settings and reported similar rates of dementia as Curtice et al.'s (2003) smaller  
6 study; these studies suggest that as many as one in five incarcerated older persons have received  
7 or meet the criteria for a dementia diagnosis. The reported rates fall around the middle of the  
8 estimated prevalence range (1-44%) for older persons in American correctional settings (Maschi  
9 et al., 2012a). Thus, there is evidence that a substantial number of older persons are living with  
10 dementia in correctional settings.  
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21 Awareness of dementia as an important correctional health issue is evident in efforts to  
22 improve dementia screening and care (Turner, 2013) by bringing stakeholders and experts  
23 together to generate recommendations (Patterson et al., 2016; Williams et al., 2012). One such  
24 recommendation is that all persons who are 55 years and older be screened for dementia,  
25 followed by annual assessment for those screening positive. Such measures can increase the  
26 detection of dementia, which has potential benefits for affected individuals and the correctional  
27 environment. However, effective screening can be difficult when correctional health care staff  
28 lack knowledge about dementia or the use of screening measures, emphasizing the need for  
29 appropriate education and training (Dillon et al., 2018; Turner, 2013). Multidisciplinary teams  
30 that include older person specialists have also been a focus of advocacy (Curtice et al., 2003;  
31 Maschi et al., 2012a).  
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47 Along with improved screening, several authors highlight the need to create formal  
48 recommendations that support and guide care for persons with dementia living in correctional  
49 settings. Such recommendations should emphasize a focus on supporting persons with dementia  
50 by modifying the social and physical environment, rather than considering dementia as a mental  
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3 disorder and individual concern that can be treated pharmaceutically. For example, Dillon et al.  
4 (2018), Harrison (2015) and Patterson et al. (2016) emphasize the importance of social-  
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6 (2018), Harrison (2015) and Patterson et al. (2016) emphasize the importance of social-  
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8 environmental adjustments, because disabling environments will increase levels of disability and  
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10 stress. One way to guide formal recommendations for improving the environment is by way of  
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12 incorporation of *Dementia-Friendly* environmental principles (Mitchell and Burton, 2010), as  
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14 these are beneficial for overcoming some disabling aspects of correctional settings. Adopting  
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16 design principles for persons with dementia can ease decision-making, reduce agitation and  
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18 distress, encourage independence and social interaction, promote safety, and enable activities of  
19  
20 daily living (Hodel and Sanchez, 2012). Such adaptations have the potential to reduce the  
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22 inappropriate pharmacological management of dementia (Macaulay, 2018), and supports  
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24 practices that enables persons with dementia to maintain identity and dignity. Accordingly,  
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26 greater awareness of specific challenges, improved screening practices, and translation of  
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28 guidelines into programming aimed at addressing psychosocial-environmental barriers to well-  
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30 being can support successful management of dementia-related symptoms in older persons who  
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32 are incarcerated.

### 33 34 35 36 37 *Gaps in knowledge and areas for future research*

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40 There are several significant gaps in knowledge on this topic. While the paucity of  
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42 research may suggest little concern for this vulnerable population, the growing body of academic  
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44 literature emphasizes an increasing need for dementia care within corrections (Brooke et al.,  
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46 2018; Feczko, 2014; Maschi et al., 2012a). We join their voices in highlighting the need for  
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48 improved understanding of living with dementia in correctional settings. This is apparent in the  
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50 few scholarly empirical works identified that focus on living with dementia in correctional  
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52 settings, and the general focus on older persons rather than on dementia specifically. There is no  
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3 research from the perspective of incarcerated individuals that qualitatively addresses what it is  
4 like to live with dementia in correctional settings, although Dillon et al. (2018) interviewed  
5 persons who had an experience with dementia. We recognize potential barriers to research with  
6 this population, including restrictive policies and challenges accessing individuals with dementia  
7 for research. However, creative efforts to enhance research in this area are imperative to guide  
8 evidence-based support and care for older persons living with dementia in correctional settings.  
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12 The studies reviewed were largely conducted with men, highlighting an absence of  
13 research on women's experiences of living in correctional settings (Kingston et al., 2011). In  
14 particular, implementation and evaluation of enriched structured living programs with women  
15 could determine benefits for their cognitive functioning and well-being (Harrison, 2015). Along  
16 with the need for programming and research with women, attention should be paid to the  
17 experiences of diverse cultural groups and their unique needs related to living with dementia  
18 while incarcerated.  
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33 While some correctional settings have made adaptations to address dementia, it is unclear  
34 how broadly such interventions have been implemented, if other interventions are also in place,  
35 and, if so, how they were chosen. Thus, there is an immense need for research on existing efforts  
36 toward management of dementia-related symptoms and whether interventions effectively meet  
37 the needs of older persons in corrections (Peacock et al., 2018). Given the increasing number of  
38 older persons in corrections and their risk for developing dementia, these issues must be  
39 addressed. It is essential to implement quasi-experimental evaluation of dementia-related  
40 programs, as this would facilitate optimal program choices that are evidence-based and cost-  
41 effective, and ensure that older persons with dementia in corrections receive appropriate long-  
42 term, sustainable support (Williams et al., 2012).  
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3 Additional research is needed with an explicit focus on older persons living with  
4 dementia in correctional settings. To date, existing studies that have included incarcerated older  
5 persons only address dementia as a secondary concern (for example, relative to the notion of  
6 safety). For example, Dawes (2009) identified dementia as a focus with respect to its potential to  
7 affect adherence to prison rules/regulations and health care decision-making for older persons in  
8 corrections. Also, research could be further conducted with correctional health care providers  
9 and staff members to explore their understandings of dementia prevalence and related symptoms  
10 in older persons living in correctional settings, perceptions of existing screening tools and current  
11 programming, and experiences of interacting with members of this population.  
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24 Future research must also consider that a general focus on cognitive abilities (Combalbert  
25 et al., 2018; Harrison, 2015) is not necessarily useful for generating evidence regarding  
26 dementia, given that compromised cognitive abilities can result from various conditions.  
27 Similarly, research about psychiatric disorders can reveal findings pertinent to dementia (Coid et  
28 al., 2002; Kingston et al., 2011), but these findings may not be specific enough to guide  
29 dementia-related policy and practice. Cognitive impairment and psychiatric disorders are not  
30 synonymous with dementia. Such equation reflects a narrow lens indicative of the medical  
31 model, and neglects the interaction of dementia-related impairments with social-environmental  
32 conditions (Alzheimer Society of Canada, 2017). Therefore, additional research is needed with  
33 an explicit focus on dementia and its various forms that incorporates standardized tools to ensure  
34 valid screening and determination of prevalence rates, and generation of accurate information  
35 about older persons' experiences of living with dementia in corrections. The MMSE is the most  
36 cited screening tool in this review, yet it can be challenging to use for screening and diagnosing  
37 dementia. Furthermore, several tools exist beyond the MMSE (Tsoi et al., 2015). Efforts should  
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3 thus be made to validate existing dementia screening tools, like the MMSE, in correctional  
4 settings to ensure relevancy (Brooke et al., 2018; Kingston et al., 2011).  
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### 7 8 *Limitations*

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10 Although all stages of the review were conducted systematically by two independent  
11 reviewers, limitations exist. Firstly, some of the included studies were not predominantly  
12 focused on dementia, but rather on older persons. Secondly, while attempts were made to  
13 identify all relevant studies, it is possible that some studies were not identified or not yet  
14 published; publication bias may also have contributed to the limited available research.  
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### 21 22 **Conclusions**

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24 Our review demonstrates that dementia is a concern for correctional services and staff,  
25 which is likely to increase as our population ages. Increasing numbers of persons living with  
26 dementia may find themselves in contact with the criminal justice system if awareness and care  
27 are not improved within the community. Increased attention to, and implementation of,  
28 recommendations gleaned from existing research is essential. Namely, adaptation of correctional  
29 settings is imperative to create social and physical environments more conducive to supporting  
30 older persons living with dementia (Patterson et al., 2016). Physical environments can be  
31 altered, as can safety measures, programming, and support services. While existing research  
32 offers preliminary insights, further research is imperative to address significant gaps in  
33 knowledge. Most notably, there is a profound lack of understanding of the subjective experiences  
34 and care of women and men living with dementia in correctional settings.  
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Figure 1. Summary of Selection Process

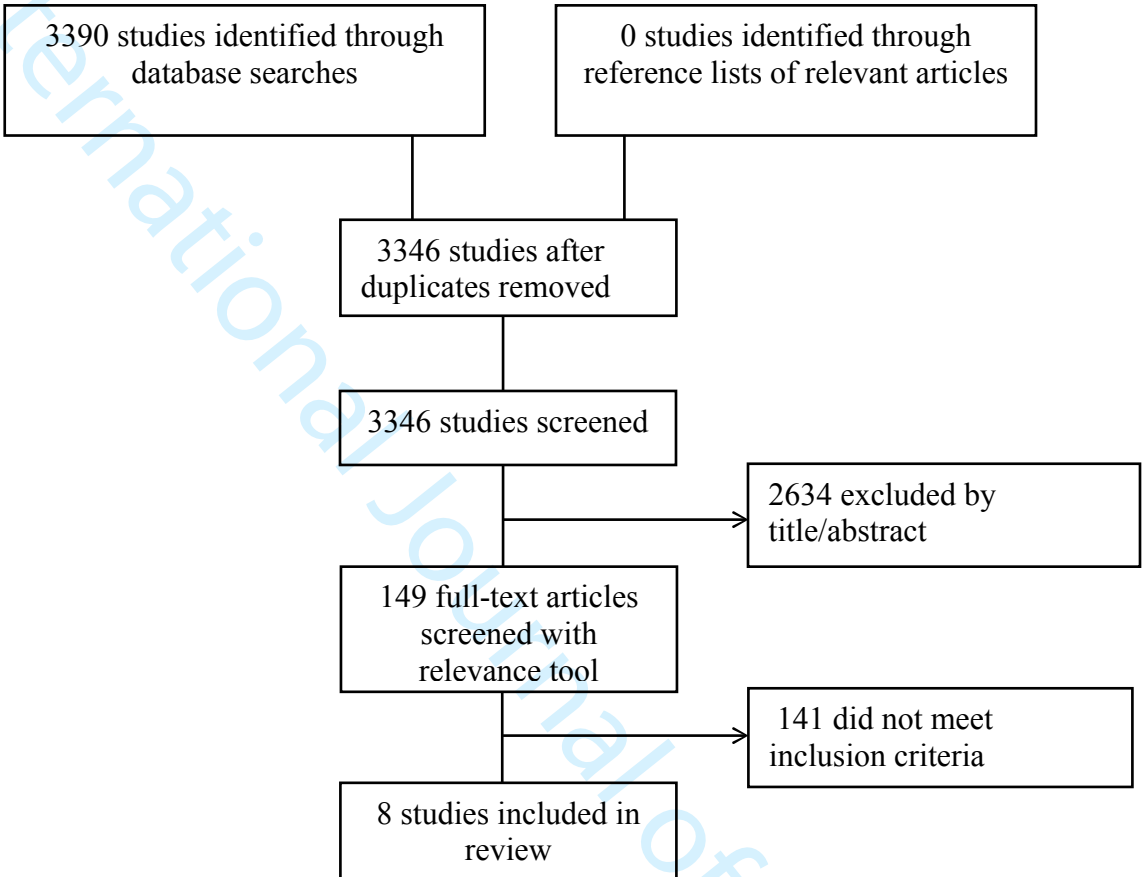


Table 1 Search Strategy Medline

1. Prisons/
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5. (prisoner or "prison-inmate*" or incarcerat* or corrections or prison* or "prison system*" or "prison population*" or jail* or "imprisoned individual" or "prison hospital* forensic hospital* medical prison*" or "prison population*" or inmat* or offender* or prison*).ab. /freq=2
6. ("correctional healthcare" or "correctional health care" or "prison based" or confine* or "lock up" or "locked up" or jailhouse* or "detention centre*" or "detention center*" or detain*).ab. /freq=2
7. ("reform school*" or "criminal justice system" or incarcerat*).tw.
8. (Penal* or Penolog*).tw.
9. (correction* adj2 (center or centre or facilit* or service* or system*)).tw.
10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11. exp aged/ or middle aged/
12. (Elderly or elderliness or older or senior or aged or aging or senile or senility).tw.
13. (senior and (adult* or person* or citizen*)).tw.
14. 11 or 12 or 13
15. exp Dementia/
16. exp Cognition Disorders/
17. *Decision Making/
18. (sundowning or dement* or alzheimer* or "cognit* impair*" or "functional impairment*" or "frontotemporal lobar degeneration" or "primary progressive aphasia" or "vascular cognitive impair*").ab. /freq=2
19. ((cereb* or Cognit* or memory or mental*) adj2 (deteriorat* or declin* or impair* or los* or degenerat* or complain* or disorder* or disturb*OR insufficen* or function*)).tw.
20. ("benign senescent forgetfulness" or binswanger or CARASIL).tw.
21. exp Cerebral Infarction/
22. exp *Memory Disorders/
23. *Problem Solving/
24. 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25. 10 and 14 and 24
26. limit 25 to english language
27. remove duplicates from 26



Table 2: Data Extraction Table of Included Articles

Sources/ Country	Study Objective(s)	Methods	Population, Setting, Context	Key Findings	Strength and Weaknesses
Combalbert et al., 2018  France	To examine the executive and cognitive function among older men who live in prison.  Compare older men in prison to the older men in the community.	Quantitative; Semi-structured interviews.	Experimental group: men aged >50 yrs living in prison for at least 1 year ( <i>n</i> = 138); mean age 59.7 yrs  Control group: men living in community ( <i>n</i> =138), mean age 68.4 yrs	Experimental group showed higher levels of cognitive impairment compared to control group.  Perceived health and quality of life scores were lower for experimental group.  Suggested 20% of experimental group sample reached threshold for dementia.  No association between cognitive impairment and perceived quality of life; researchers suggest men with cognitive deficits may not be reporting scores accurately.	Not dementia-focused.  Included various prisons across France.  Groups statistically different according to age, education, and MMSE scores.  No findings reported from open-ended questions.
Curtice et al., 2003  United Kingdom	To generate data describing the characteristics of older adults who are incarcerated.  To determine whether older adults in	Quantitative; Data from record databases and case-notes.	Persons aged > 65 yrs referred to regional medium security forensic facility between 1988-1999  ( <i>n</i> = 32; 1 woman)  Age range: 65-84 yrs	Dementia most common diagnosis with 6 (19%) cases; 4/6 persons with dementia had not had a MMSE completed.  Persons with dementia offences: arson, attempted wounding, rape, and inappropriate sexual behaviour.	Not dementia-focused.  “Holistic” assessment not clearly defined.  Age set at 65 years rather than younger age (i.e., 50 or 55 yrs).

Table 2: Data Extraction Table of Included Articles

Sources/ Country	Study Objective(s)	Methods	Population, Setting, Context	Key Findings	Strength and Weaknesses
	forensic settings were assessed from a holistic perspective.		All <i>white-European</i>		Unclear if dementia diagnosed at time of admission or developed after.
Dillon et al., 2018  United Kingdom	To explore understanding and experiences of dementia in response to Governor- identified needs in prisons.	Qualitative; Semi-structured interviews with prison staff and adults living in one of two prisons.	Persons incarcerated related to sexual offences ( <i>n</i> =14; one transgender woman) and direct contact staff employed in two UK prisons ( <i>n</i> =17; 10 women)	Four themes resulted: (a) <i>balancing act</i> (to encourage autonomy and provide appropriate support to a person living with dementia; (b) <i>challenges and confusion</i> (difficulties in identifying dementia-related behaviours); (c) <i>what works, what doesn't</i> (finding appropriate modes of support and identifying what doesn't work); and (d) <i>who to tell?</i> (making decisions about when to communicate dementia diagnosis and subsequent needs).  Importance of increased awareness and training to ensure support offered to those living with dementia; support can include modifications to the physical environment. Researchers suggest that it is unsuitable to detain men with dementia in prison given the lack of appropriate supports to meet their needs.	Participants living in the prisons either had personal experience or interest with dementia or no experience/unders tanding of dementia; besides gender no other participant characteristics reported.

Table 2: Data Extraction Table of Included Articles

Sources/ Country	Study Objective(s)	Methods	Population, Setting, Context	Key Findings	Strength and Weaknesses
Harrison, 2015  United States	To determine if an enriched prison environment contributes to cognitive abilities.  Enriched environments includes cognitive, physical, and ecological activities.	Quantitative; Comparison of cognitive function scores between men living in enriched environment ( <i>True Grit</i> program) to control group with similar demographics living in a correctional facility.	Experimental group: men aged >55 yrs; ( <i>True Grit</i> , <i>n</i> =153) Control group: men general prison environment ( <i>n</i> =156)  Period of time living <i>True Grit</i> from 8 months to 7.25 yrs (mean= 2.75 yrs)	Significantly ( <i>p</i> <0.05) higher scores for experimental group on COWAT Letters, Victoria Stroop, Trails B, Street Completion, Symbol Search, WRAT4 Word Recognition/Sentence Comprehension, Clock Drawing.  Significantly ( <i>p</i> <0.05) lower scores for experimental group on Timed Up and Go, Geriatric Depression.  Overview: experimental group had higher scores in terms of memory and cognitive flexibility, verbal fluency, cortical functioning, and improved problem-solving ability compared to control.  Researcher proposes that older adult male prisoners benefit cognitively/physically when living in an enriched environment compared to general prison environment.	Unclear if participants had previous dementia diagnosis.  No baseline data; difficult to determine what is significant to cognitive functioning/dementia.
Kingston et al., 2011  United Kingdom	Identify prevalence of psychiatric disorders in prison for persons over 50	Mixed methods; Interviews conducted in prisoner cells; Prison and	Men in prison aged >50 yrs ( <i>n</i> =121)  <i>Age breakdown n</i> =74 50 – 59 yrs	Dementia noted in 2 cases; whereas 6 cases scored 26 or less on MMSE.  Self-reported psychiatric disorders higher than clinical diagnoses and treatment records report but dementia	Not dementia-focused.  Section on “unanswered questions”

Table 2: Data Extraction Table of Included Articles

Sources/ Country	Study Objective(s)	Methods	Population, Setting, Context	Key Findings	Strength and Weaknesses
	and determine availability of treatment; assess whether detection/treatment rates have improved over last 10 years.	medical records data.	$n=40$ 60 – 69 yrs $n= 7$ >70 yrs	as diagnosis not specifically mentioned in findings.  Results related to treatment rates focused on psychiatric illness and psychotropic drugs.	provides reflection on dementia cases.
Patterson et al., 2016  Australia	Generate ideas about improving care for persons with dementia who live in prison.  Improve treatment and support for persons with dementia in prison.	Delphi; Round 1: Online survey; Rounds 2, 3 and 4: discussion forums with experts.	Round 1 participants; registered nurses ( $n=36$ )  Rounds 2-4 forum participants: variety of disciplines ( $n=18$ )	<i>Round 1:</i> 64% of respondents felt Reception Screening Tool not appropriate for identifying dementia; improvements included integrating MMSE and/or adding questions related to cognitive function, memory loss and activities of daily living. <i>Round 2:</i> agreement that screening tool be improved; adaptations included addition of a memory/cognition test (e.g., MMSE or Rowlands Universal Dementia Assessment). Screening results should prompt additional assessments. <i>Round 3:</i> suitability of the Global Deterioration Scale (GDS) determined useful for dementia screening (needs adapting for prison setting); process for referral when cognition/memory concerns	Expert views sought and formed basis of data collected; no older adults living in corrections had their perspectives included.  Three discussion forums conducted in-person.

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Sources/ Country	Study Objective(s)	Methods	Population, Setting, Context	Key Findings	Strength and Weaknesses
				identified on screening. Agreement on effectiveness of multi-disciplinary approach. <i>Round 4:</i> expanded on the need for advanced care planning for persons with cognitive deficits; plan includes buddying with other offenders, referral to services, and implementation of safety measures.	
Turner, 2018  United States	To collect data to inform best-practice recommendations for recognizing and assessing dementia in the prison population.	Qualitative; Thematic analysis study using semi-structured interviews with prison staff from three correctional institutions.	Staff members (e.g., psychology assistant, psychiatrist, psychologist or nurse practitioner) from three Ohio correctional institutions ( <i>n</i> =7)	The resulting 12 themes are summarized to include: (a) <i>a lack of employee training</i> ; (b) <i>need for better use of screening tools for assessing dementia</i> ; and (c) <i>a lack of identified policies for dementia assessment</i> .  Researcher recommends providing more resources to increase staff training to identify/assess dementia and create a standardized process for diagnosing dementia in prison.	Themes not supported with direct quotes of participants.  Limited interpretive abstraction of included data.
Williams et al., 2012  United States	Create list of suggestions for policy improvements for incarcerated older adults.	Roundtable approach; Invited experts required to come to consensus on action items, discuss state of	Experts in field (e.g., physicians, psychologists, lawyers and nurses) ( <i>n</i> =29)	Nine priority areas identified related to older adults; one being specific to dementia.  Research need focus on optimal screening tools for cognitive impairment in prisoners; use (a) upon admission for those aged >55 yrs; (b)	Not dementia-focused.  Description of research method lacking; no indication of ethical approval

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Sources/ Country	Study Objective(s)	Methods	Population, Setting, Context	Key Findings	Strength and Weaknesses
		knowledge and identify gaps.		has history of traumatic brain injury; (c) yearly for progression of symptoms; (d) yearly for all persons aged >55 yrs and/or (e) for all persons aged >45 yrs referred for a disciplinary hearing.  Use screening results to guide decisions about housing, programming, healthcare, and discharge planning. Research needed to evaluate adequacy and cost- effectiveness of recommendations.	(researcher did not return an answer to email request of same).

Table 3 Screening Tools

Author	Screening Tool Utilized/Discussed
Combalbert et al., 2018	Mini-Mental State Exam (MMSE) Frontal Assessment Battery Nottingham Health Profile Scale of Subjective State of Mental Health World Health Organization Quality of Life Questionnaire
Curtice et al., 2003	MMSE
Harrison, 2015	Controlled Oral Word Association Test Trail Making Test A and B Twenty Questions Test Victoria Stroop Color Word Test Wide Range Achievement Test 4 Clock Test Instrumental Activities of Daily Living Timed Up-and-Go test Geriatric Depression Scale Street Completion Test Symbol Search
Kingston et al., 2011	Geriatric Mental State Exam MMSE Short Form 12
Patterson et al., 2016	Reception Screening Tool Global Deterioration Scale
Turner, 2018	Dementia Rating Scale MMSE Montreal Cognitive Assessment