Older persons with dementia in prison

Peacock, Shelley; Burles, Meridith; Hodson, Alexandra; Kumaran, Maha; MacRae, Rhoda; Peternelj-Taylor, Cindy; Holtslander, Lorraine

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Older Persons with Dementia in Prison: An Integrative Review

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Shelley Peacock*, Meridith Burles, Alexandra Hodson, Maha Kumaran, Rhoda MacRae, Cindy Peternelj-Taylor, & Lorraine Holtslander

*Corresponding author
Shelley Peacock, RN, PhD
Associate Professor
College of Nursing, University of Saskatchewan
Saskatoon, Canada
shelley.peacock@usask.ca

Meridith Burles, PhD
Post-doctoral Fellow
College of Nursing, University of Saskatchewan
Saskatoon, Canada
meridith.burles@usask.ca

Alexandra Hodson, RN, MN
Lecturer
College of Nursing, University of Regina
Saskatoon, Canada
alexandra.hodson@uregina.ca

Maha Kumaran
Head
Education and Music Library, University of Saskatchewan
Saskatoon, Canada
maha.kumaran@uasask.ca

Rhoda MacRae, RMN, MSc, PhD
Lecturer
School of Health and Life Sciences, University of the West of Scotland
Hamilton, United Kingdom
Rhoda.macrae@uws.ac.uk

Cindy Peternelj-Taylor, RN, BScN, MSc, DF-IAFN
Professor
College of Nursing, University of Saskatchewan
Saskatoon, Canada

cindy.peternelj-taylor@usask.ca

Lorraine Holtslander, RN, PhD, CHPCN(c)
Professor
College of Nursing, University of Saskatchewan
Saskatoon, Canada
Honorary Associate Professor, University of the Witwatersrand, South Africa
lorraine.holtslander@usask.ca
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 Whittemore 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a correctional context (correctional facility, prison, jail); (d) be derived from a published peer-reviewed journal or unpublished dissertation/thesis; and (e) be a qualitative, quantitative or mixed methods study.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.
Value: This paper identified and synthesizes the limited existing international research on the health and social care needs of older persons with dementia living in correctional settings. Although existing research is scant, this review highlights the need for increased awareness of dementia as a concern among older persons living in correctional settings. As well, the review findings emphasize that enhanced screening and interventions, particularly tailored approaches, are imperative to support those living with dementia in correctional settings.
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
with dementia are supported by enabling environments, interventions and care practices (Laver et al., 2016, Vreugdenhil et al., 2012). As brain health deteriorates and the damage progresses, people with dementia require increasing levels of support. Health care needs must be addressed in tandem with psychosocial and spiritual needs, and careful attention paid to the living environment and level of family caring where possible (Hanson et al., 2016, Tolson et al., 2016). Thus, emphasis must be placed on interventions, environments and approaches that enable and enhance quality of life. However, adopting a biopsychosocial-spiritual model of dementia care that places the person and caring relationships at the centre of health care practice during advanced stages of the condition remains a challenge in many community care settings across the globe (World Health Organization, 2017). This challenge may be even greater for those working in secure environments. Nevertheless, there is potential in all settings, including prisons, for staff to adopt approaches that enable and enhance quality of life.

Prisons and correctional facilities are among the most extreme, stressful environments known to society, and have not been built with an aging population in mind. The intensity of the physical and interpersonal environments, including the emphasis on authority, overcrowding, lack of privacy, architectural impediments, and threats of violence and exploitation, make prisons particularly challenging places for older persons (Human Rights Watch [HRW], 2012). Structurally, the design and layout of most prisons are also challenging for older persons, frequently requiring them to walk long distances for meals, medication, and health care services, while trying to keep pace with younger able-bodied peers. Many aging incarcerated persons are unable to readily climb stairs, navigate dimly lit corridors and uneven floors, pull themselves onto a top bunk, or easily complete toileting activities (Bedard et al., 2016; HRW, 2012).
(2012) concluded that accommodating older persons in prison is a “daily game of musical chairs that can shortchange individual elderly persons while it bedevils corrections officials” (p. 51).

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

**Previous Literature Reviews**

Several literature reviews have been completed that are relevant in some way to the phenomenon of older persons in correctional settings. These reviews adopt diverse foci related to mental and cognitive health in the prison population, and older persons who are incarcerated. For example, some authors examine the prevalence of mental health disorders and cognitive impairment across general prison populations (Brooke et al., 2018; Di Lorito et al., 2018; Kakoulis et al., 2010), establishing dementia as one mental or cognitive health concern. Others identify challenges facing older persons in general and specific to dementia across all phases of corrections (Cipriani et al., 2017; Maschi et al., 2012b; Stojkovic, 2007), emphasizing the detrimental outcomes associated with unmet dementia care and support needs. As well, issues pertaining to dementia are discussed with regards to prison staff, health care providers, and
correctional services (Gaston, 2018, Brooke et al., 2018; Maschi et al., 2012b), although limited research has been done in this area.

Through these reviews, it is apparent that greater awareness of this issue is needed, along with better detection of dementia in older persons across the criminal justice system and enhanced access to dementia-related services and supports within correctional settings.

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

**Methodology**

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

Search Strategies

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

[Table 1]

Selection of Relevant Sources

Selected studies were those that were: (a) written in English; (b) about some form of dementia and/or older persons (50+ years) with discussion of dementia; (c) relevant to a correctional context (secure facility, prison, jail); (d) a published peer-reviewed article or unpublished dissertation/thesis; and (e) a qualitative, quantitative or mixed methods study.
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.

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.

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,
Vinter, Winder, & Finch, 2018). Screening for cognitive impairment and/or assessing dementia was discussed to some degree in the eight studies, and the Mini-Mental Status Exam (MMSE) was the most cited measure (see Table 3). Of note, three studies evaluated cognitive impairment, despite not being equivalent to, nor comprehensive of all dementia-related symptoms.

Table 3

Key findings regarding living with dementia in correctional settings fell within three main categories: (a) recognition of dementia as a concern for older persons in correctional settings; (b) dementia-related screening and care for older persons; and (c) recommendations for screening and care practices. A discussion of each category follows.

Evidence of Dementia as a Concern for Correctional Populations

Although risk of mental and cognitive disorders is highlighted in the literature on the health of individuals living in correctional facilities, only a few studies have been conducted to establish the prevalence of dementia in the correctional population. Combalbert et al. (2018) compared 138 older men living in several correctional facilities in France to an equivalent sample of the general population in France, using standardized scales to assess cognitive performance, health, mental health and quality of life. Combalbert et al. (2018) established that those living in correctional settings exhibited higher rates of cognitive impairment compared with the general population, with approximately 19% satisfying the criteria for a dementia diagnosis. Furthermore, their findings suggest that those at risk within correctional settings might be significantly younger, as the mean age of the correctional sample (59.7 years) was eight years younger than the general population sample (68.4 years). Potential contributors to cognitive decline and dementia among those in correctional settings were also identified in these studies, including physical and psychosocial conditions (Combalbert et al., 2018).
Similarly, Kingston et al. (2011) examined the prevalence of psychiatric disorders in adult’s aged 50 years and older living in correctional settings. Assessments were conducted with 121 older men from four facilities using the Geriatric Mental State Examination (GMSE), the MMSE, Short Form 12, and prison records. The researchers found that 16 participants (13% of the sample) showed signs of cognitive impairment based on their MMSE scores, although only two were identified as having dementia according to the GMSE measure. While this meant less than 2% of the sample were deemed to have dementia, the MMSE may be a more encompassing measure for assessing dementia prevalence in older adult men living in corrections. Curtice et al. (2003) also sought to establish the prevalence of dementia in ‘elderly’ individuals referred to a forensic psychiatric service in the United Kingdom. Using health records and case notes over a 12-year timespan, 32 incarcerated individuals aged 65 years or older were identified. Of these, 19% had been diagnosed with dementia and 79% had a history of alcoholism, a known risk factor (Schwarzinger, et al., 2018). Interestingly, almost 60% of the sample had no prior history of offending, raising the possibility that they were currently incarcerated for an offense linked to declining cognitive or mental well-being (Curtice et al., 2003).

Together, these studies offer evidence that cognitive impairment and psychiatric disorders, including those within the scope of dementia, are indeed a concern within the older adult correctional population. Namely, 13 to 19% of participants in these studies met the criteria for, or had received a dementia diagnosis. Additionally, Curtice et al. (2003) and Kingston et al. (2011) identify aspects of the correctional environment that contribute the heightened risk, reinforcing the concern for dementia among this population.

*Dementia-related Screening and Programming for Older Persons*
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
work closely with persons living in corrections (such as correctional officers and unit managers). Similarly, in response to Governor-identified needs to inform recommendations for meaningful change in two prisons in the United Kingdom, Dillon and colleagues (2018) undertook a qualitative study to understand the experience of dementia through interviews with persons living in corrections and staff. Participants indicated challenges in recognizing signs of dementia in persons and stressed the importance of early screening so that persons could access supportive care as soon as possible. This can begin to be addressed with increasing the availability of dementia-specific training. Lack of training in this area, however, has implications for if, when, and how screening for dementia is completed.

Appropriate screening can facilitate access to care and programming for those with dementia. Harrison (2015) highlights the importance of screening and provision of support for those with dementia through evaluation of the “True Grit” program, a specialized program implemented in a correctional setting in Nevada (United States). This enriched program for older adult men integrates human rights principles by offering a safe, healthy and structured living environment. Harrison compared the cognitive and physical abilities of 153 participants in the program to a comparable sample of those living in regular correctional environments. Analysis revealed that members of the True Grit program fared better on 13 of 14 measures, with significant differences reported for executive function, intellectual ability, visual perception, and physical mobility, among others (Harrison, 2015). The specialized care accessed through the True Grit program was found to benefit persons with cognitive impairment, but this program is only accessible if appropriate screening occurs to identify those in most need of such services.

Across these studies, evidence suggests that efforts toward screening and programming for older persons at risk for dementia varied across setting. Foremost, Curtice et al. (2003),
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.
Patterson et al. (2016) also made screening recommendations based on the findings of a Delphi study. They found that of the registered nurses who participated in the first round, approximately 64% perceived the Reception Screening tool administered to individuals newly admitted to the correctional system as ‘sometimes unsuitable’ or ‘very unsuitable’ for identifying dementia. The tool was deemed inadequate because it did not evaluate cognitive function or memory, contained no section that prompts assessor if there are suspicions of dementia, was only sensitive to advanced dementia, and relied on nurse experience with dementia. Survey respondents thus advocated for inclusion of the MMSE and other indicators of cognitive function, memory and daily activities into the assessment tool (Patterson et al., 2016). In subsequent discussion groups with health care providers, use of simple memory and cognition tests was recommended. This could allow identification of concerns and individuals needing further assessment from a dementia care team; depending on these results, referral could then be made for screening using the MMSE or Rowland Universal Dementia Assessment. Participants also deemed the Global Deterioration Scale to be suitable for evaluating older persons living in corrections for dementia, but indicated the need for validation to ensure that it was context-appropriate (Patterson et al., 2016). Overall, participants outlined an appropriate assessment pathway for older persons that involved initial assessment, referral for further screening by a specialized multidisciplinary team if necessary, followed by further assessment and treatment by a dementia care team.

Williams et al. (2012) recommended that all individuals aged 55 and older, or with traumatic brain injury, be screened for dementia upon entry into correctional settings and annually if dementia is identified. Similarly, Combalbert et al. (2018) emphasized the importance of systematic screening of men over 50 years of age for cognitive disorders. Curtice
et al. (2003) developed specific assessment guidelines based on their finding that screening was often inadequate, and recommended the use of appropriate screening tools for cognitive impairment, depression, and physical well-being. While these authors agree on the need for improved screening, Patterson et al. (2016) recognized barriers to effective dementia screening within correctional settings, including time limitations, nurses’ lack of familiarity with cognitive screening, and ineffectiveness of screening individuals under the influence of illicit substances. This process may therefore require access to health care providers with relevant experience who can perform in-depth assessments. Establishment of multidisciplinary teams is imperative, similar to Curtice et al.’s (2003) advocacy for the inclusion of old age psychiatric services in forensic settings. Such teams can provide ongoing support, share knowledge with teams based at other facilities, and collaborate with correctional staff.

Finally, the experts who participated in Patterson et al.’s (2016) Delphi study advocated for adaptation of existing prisons, rather than moving older persons living with dementia to specialized units. Their recommendations included advanced care planning for individuals with cognitive deficits and supportive programs. Similar to Turner (2013), Patterson et al. suggested a peer-buddying system, greater education/training for correctional staff, and enhanced screening and care pathways. The enriched programming described by Harrison (2015) appears to have the potential to provide various benefits to incarcerated older persons, although its implementation may require increased resources.

**Discussion**

Across much of the developed world, the number of older persons living in corrections is rising, compounded further by the complex health care needs, including those living with dementia (Moll, 2013). Our review found that robust research exists that identifies dementia as a
concern within the correctional population, albeit far more is needed. Combalbert et al. (2018) and Kingston et al. (2011) collected data from relatively large samples of older persons living in correctional settings and reported similar rates of dementia as Curtice et al.’s (2003) smaller study; these studies suggest that as many as one in five incarcerated older persons have received or meet the criteria for a dementia diagnosis. The reported rates fall around the middle of the estimated prevalence range (1-44%) for older persons in American correctional settings (Maschi et al., 2012a). Thus, there is evidence that a substantial number of older persons are living with dementia in correctional settings.

Awareness of dementia as an important correctional health issue is evident in efforts to improve dementia screening and care (Turner, 2013) by bringing stakeholders and experts together to generate recommendations (Patterson et al., 2016; Williams et al., 2012). One such recommendation is that all persons who are 55 years and older be screened for dementia, followed by annual assessment for those screening positive. Such measures can increase the detection of dementia, which has potential benefits for affected individuals and the correctional environment. However, effective screening can be difficult when correctional health care staff lack knowledge about dementia or the use of screening measures, emphasizing the need for appropriate education and training (Dillon et al., 2018; Turner, 2013). Multidisciplinary teams that include older person specialists have also been a focus of advocacy (Curtice et al., 2003; Maschi et al., 2012a).

Along with improved screening, several authors highlight the need to create formal recommendations that support and guide care for persons with dementia living in correctional settings. Such recommendations should emphasize a focus on supporting persons with dementia by modifying the social and physical environment, rather than considering dementia as a mental
disorder and individual concern that can be treated pharmaceutically. For example, Dillon et al. (2018), Harrison (2015) and Patterson et al. (2016) emphasize the importance of social-environmental adjustments, because disabling environments will increase levels of disability and stress. One way to guide formal recommendations for improving the environment is by way of incorporation of Dementia-Friendly environmental principles (Mitchell and Burton, 2010), as these are beneficial for overcoming some disabling aspects of correctional settings. Adopting design principles for persons with dementia can ease decision-making, reduce agitation and distress, encourage independence and social interaction, promote safety, and enable activities of daily living (Hodel and Sanchez, 2012). Such adaptations have the potential to reduce the inappropriate pharmacological management of dementia (Macaulay, 2018), and supports practices that enables persons with dementia to maintain identity and dignity. Accordingly, greater awareness of specific challenges, improved screening practices, and translation of guidelines into programming aimed at addressing psychosocial-environmental barriers to well-being can support successful management of dementia-related symptoms in older persons who are incarcerated.

Gaps in knowledge and areas for future research

There are several significant gaps in knowledge on this topic. While the paucity of research may suggest little concern for this vulnerable population, the growing body of academic literature emphasizes an increasing need for dementia care within corrections (Brooke et al., 2018; Feczko, 2014; Maschi et al., 2012a). We join their voices in highlighting the need for improved understanding of living with dementia in correctional settings. This is apparent in the few scholarly empirical works identified that focus on living with dementia in correctional settings, and the general focus on older persons rather than on dementia specifically. There is no
research from the perspective of incarcerated individuals that qualitatively addresses what it is like to live with dementia in correctional settings, although Dillon et al. (2018) interviewed persons who had an experience with dementia. We recognize potential barriers to research with this population, including restrictive policies and challenges accessing individuals with dementia for research. However, creative efforts to enhance research in this area are imperative to guide evidence-based support and care for older persons living with dementia in correctional settings.

The studies reviewed were largely conducted with men, highlighting an absence of research on women’s experiences of living in correctional settings (Kingston et al., 2011). In particular, implementation and evaluation of enriched structured living programs with women could determine benefits for their cognitive functioning and well-being (Harrison, 2015). Along with the need for programming and research with women, attention should be paid to the experiences of diverse cultural groups and their unique needs related to living with dementia while incarcerated.

While some correctional settings have made adaptations to address dementia, it is unclear how broadly such interventions have been implemented, if other interventions are also in place, and, if so, how they were chosen. Thus, there is an immense need for research on existing efforts toward management of dementia-related symptoms and whether interventions effectively meet the needs of older persons in corrections (Peacock et al., 2018). Given the increasing number of older persons in corrections and their risk for developing dementia, these issues must be addressed. It is essential to implement quasi-experimental evaluation of dementia-related programs, as this would facilitate optimal program choices that are evidence-based and cost-effective, and ensure that older persons with dementia in corrections receive appropriate long-term, sustainable support (Williams et al., 2012).
Additional research is needed with an explicit focus on older persons living with dementia in correctional settings. To date, existing studies that have included incarcerated older persons only address dementia as a secondary concern (for example, relative to the notion of safety). For example, Dawes (2009) identified dementia as a focus with respect to its potential to affect adherence to prison rules/regulations and health care decision-making for older persons in corrections. Also, research could be further conducted with correctional health care providers and staff members to explore their understandings of dementia prevalence and related symptoms in older persons living in correctional settings, perceptions of existing screening tools and current programming, and experiences of interacting with members of this population.

Future research must also consider that a general focus on cognitive abilities (Combalbert et al., 2018; Harrison, 2015) is not necessarily useful for generating evidence regarding dementia, given that compromised cognitive abilities can result from various conditions. Similarly, research about psychiatric disorders can reveal findings pertinent to dementia (Coid et al., 2002; Kingston et al., 2011), but these findings may not be specific enough to guide dementia-related policy and practice. Cognitive impairment and psychiatric disorders are not synonymous with dementia. Such equation reflects a narrow lens indicative of the medical model, and neglects the interaction of dementia-related impairments with social-environmental conditions (Alzheimer Society of Canada, 2017). Therefore, additional research is needed with an explicit focus on dementia and its various forms that incorporates standardized tools to ensure valid screening and determination of prevalence rates, and generation of accurate information about older persons’ experiences of living with dementia in corrections. The MMSE is the most cited screening tool in this review, yet it can be challenging to use for screening and diagnosing dementia. Furthermore, several tools exist beyond the MMSE (Tsoi et al., 2015). Efforts should
thus be made to validate existing dementia screening tools, like the MMSE, in correctional
settings to ensure relevancy (Brooke et al., 2018; Kingston et al., 2011).

Limitations

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

Conclusions

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


Dillon, G., Vinter, L. P., Winder, B. and Finch, L. (2018), “‘The guy might not even be able to remember why he’s here and what he’s in here for and why he’s locked in’: Residents and prison staff experiences of living and working alongside people with dementia who are serving prison sentences for a sexual offence”, *Psychology, Crime and Law*, Vol. 25, pp. 440-457.


Figure 1. Summary of Selection Process

3390 studies identified through database searches

0 studies identified through reference lists of relevant articles

3346 studies after duplicates removed

3346 studies screened

2634 excluded by title/abstract

149 full-text articles screened with relevance tool

141 did not meet inclusion criteria

8 studies included in review
Table 1 Search Strategy Medline

1. Prisons/
2. Prisoners/
3. "prison*".tw.
4. (prison adj3 (populat* or inmate* or offender* or cell* or system or hospital or centre or center)).tw.
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 facil* 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>
<thead>
<tr>
<th>Sources/Country</th>
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<th>Key Findings</th>
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</thead>
<tbody>
<tr>
<td>Combalbert et al., 2018</td>
<td>To examine the executive and cognitive function among older men who live in prison.</td>
<td>Quantitative; Semi-structured interviews.</td>
<td>Experimental group: men aged &gt;50 yrs living in prison for at least 1 year (n = 138); mean age 59.7 yrs</td>
<td>Experimental group showed higher levels of cognitive impairment compared to control group.</td>
<td>Not dementia-focused.</td>
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<tr>
<td>France</td>
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<td>Control group: men living in community (n=138), mean age 68.4 yrs</td>
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<td>Perceived health and quality of life scores were lower for experimental group.</td>
<td>Included various prisons across France.</td>
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<td>Groups statistically different according to age, education, and MMSE scores.</td>
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<td>No association between cognitive impairment and perceived quality of life; researchers suggest men with cognitive deficits may not be reporting scores accurately.</td>
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<td>No findings reported from open-ended questions.</td>
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<tr>
<td>Curtice et al., 2003</td>
<td>To generate data describing the characteristics of older adults who are incarcerated.</td>
<td>Quantitative; Data from record databases and case-notes.</td>
<td>Persons aged &gt; 65 yrs referred to regional medium security forensic facility between 1988-1999 (n= 32; 1 woman)</td>
<td>Dementia most common diagnosis with 6 (19%) cases; 4/6 persons with dementia had not had a MMSE completed.</td>
<td>Not dementia-focused.</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>To determine whether older adults in</td>
<td></td>
<td>Age range: 65-84 yrs</td>
<td>Persons with dementia offences: arson, attempted wounding, rape, and inappropriate sexual behaviour.</td>
<td>“Holistic” assessment not clearly defined.</td>
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<td>Age set at 65 years rather than younger age (i.e., 50 or 55 yrs).</td>
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<tr>
<td>United Kingdom</td>
<td>To explore understanding and experiences of dementia in response to Governor-identified needs in prisons.</td>
<td>Qualitative; Semi-structured interviews with prison staff and adults living in one of two prisons.</td>
<td>Persons incarcerated related to sexual offences ($n=14$; one transgender woman) and direct contact staff employed in two UK prisons ($n=17$; 10 women)</td>
<td>Four themes resulted: (a) <em>balancing act</em> (to encourage autonomy and provide appropriate support to a person living with dementia); (b) <em>challenges and confusion</em> (difficulties in identifying dementia-related behaviours); (c) <em>what works, what doesn’t</em> (finding appropriate modes of support and identifying what doesn’t work); and (d) <em>who to tell?</em> (making decisions about when to communicate dementia diagnosis and subsequent needs).</td>
<td>Unclear if dementia diagnosed at time of admission or developed after.</td>
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</table>

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/understanding of dementia; besides gender no other participant characteristics reported.
Table 2: Data Extraction Table of Included Articles

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<td>Harrison, 2015</td>
<td>To determine if an enriched prison environment contributes to cognitive abilities.</td>
<td>Quantitative; Comparison of cognitive function scores between men living in enriched environment (True Grit program) to control group with similar demographics living in a correctional facility.</td>
<td>Experimental group: men aged &gt;55 yrs; (True Grit, n=153) Control group: men general prison environment (n=156)</td>
<td>Significantly (p&lt;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 (p&lt;0.05) lower scores for experimental group on Timed Up and Go, Geriatric Depression.</td>
<td>Unclear if participants had previous dementia diagnosis. No baseline data; difficult to determine what is significant to cognitive functioning/dementia.</td>
</tr>
<tr>
<td>Kingston et al., 2011</td>
<td>Identify prevalence of psychiatric disorders in prison for persons over 50</td>
<td>Mixed methods; Interviews conducted in prisoner cells; Prison and Age breakdown n=74 50 – 59 yrs</td>
<td>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</td>
<td>Not dementia-focused. Section on “unanswered questions”</td>
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| Australia       | 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. | provides reflection on dementia cases. |
| Patterson et al., 2016 | 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 ($n=18$) | | Results related to treatment rates focused on psychiatric illness and psychotropic drugs. | 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. |

Round 1: 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.  
Round 2: 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.  
Round 3: suitability of the Global Deterioration Scale (GDS) determined useful for dementia screening (needs adapting for prison setting); process for referral when cognition/memory concerns
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<td>United States</td>
<td>To collect data to inform best-practice recommendations for recognizing and assessing dementia in the prison population.</td>
<td>Qualitative; Thematic analysis study using semi-structured interviews with prison staff from three correctional institutions.</td>
<td>Staff members (e.g., psychology assistant, psychiatrist, psychologist or nurse practitioner) from three Ohio correctional institutions (n=7)</td>
<td>The resulting 12 themes are summarized to include: (a) a lack of employee training; (b) need for better use of screening tools for assessing dementia; and (c) a lack of identified policies for dementia assessment.</td>
<td>Themes not supported with direct quotes of participants. Limited interpretive abstraction of included data.</td>
</tr>
<tr>
<td>Williams et al., 2012</td>
<td>Create list of suggestions for policy improvements for incarcerated older adults.</td>
<td>Roundtable approach; Invited experts required to come to consensus on action items, discuss state of</td>
<td>Experts in field (e.g., physicians, psychologists, lawyers and nurses) (n=29)</td>
<td>Nine priority areas identified related to older adults; one being specific to dementia.</td>
<td>Not dementia-focused. Description of research method lacking; no indication of ethical approval</td>
</tr>
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<td>knowledge and identify gaps.</td>
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<td>has history of traumatic brain injury; (c) yearly for progression of symptoms; (d) yearly for all persons aged &gt;55 yrs and/or (e) for all persons aged &gt;45 yrs referred for a disciplinary hearing.</td>
<td>(researcher did not return an answer to email request of same).</td>
</tr>
</tbody>
</table>

Use screening results to guide decisions about housing, programming, healthcare, and discharge planning. Research needed to evaluate adequacy and cost-effectiveness of recommendations.
Table 3 Screening Tools

<table>
<thead>
<tr>
<th>Author</th>
<th>Screening Tool Utilized/Discussed</th>
</tr>
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</table>
| 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                                                                     |