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Living with dementia in correctional settings: A case report

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Abstract

The prison population is aging at an alarming rate and many older persons have the potential to develop dementia while in prison. This case report aims to explore the needs of older people living with dementia in prison and discusses the interventions that exist to address these needs. As the condition progresses people with dementia become increasingly reliant on the support of others for their health and wellbeing due to the increasing complexity of physical health care and psychosocial needs. Very few interventions are cited in the research literature regarding the use, acceptability, and/or effectiveness of programming for people living with dementia in prison. To support the unique and complex needs of these persons, research is needed to guide the development of evidence-informed dementia programs and services, as well as consideration of interdisciplinary collaboration with community organizations.

Keywords:

Dementia; older adults; offenders; prisoners; correctional institution; prisons

Description of Case

In January 2017 the Canadian Broadcasting Corporation reported a story about Francis McLaughlin, a 79 year old man who although paroled and living in the community since 1989 had his parole revoked in 2016, after he failed to show up for regularly scheduled appointments. At that time his parole officers described him as "cantankerous" and his behaviour as unpredictable; related documents revealed he had dementia. The case management team involved recognized that his behaviours were "beyond his control" and attempted to find a community based long term care facility for him. Given his criminal history (convicted of second degree murder and sentenced to life in prison in 1978), alternate arrangements could not be made and he was returned to a federal prison where he died ten months later (Karstens-Smith, 2017).

In Canada, compassionate release, known as *Royal Prerogative of Mercy,* is allowed under the Corrections and Conditional Release Act. Ongoing fears however about community safety, bed shortages in long-term care facilities, and the stigma surrounding the circumstances of the offender's incarceration in the first place have an impact on decisions made by the Parole Board of Canada (Beckett, Peternelj-Taylor & Johnson, 2003; Human Rights Watch, 2012). In the 2014-2015 reporting period, the Parole Board of Canada denied all 28 formal requests for compassionate release (Office of the Correctional Investigator [OCI], 2016). Similar challenges around compassionate or early release exist in other parts of the world (Handtke, Wangmo, Elger, & Bretschneider, 2017). While Mr. McLaughlin's return to incarceration due to dementia is a somewhat unique situation, the presence of older incarcerated persons with dementia within correctional populations is not. This means prisons will need to consider how they will provide appropriate care for men like Mr. McLaughlin, when options for compassionate or early release are so limited.

The dramatic increase of older offenders in recent years has been negatively referred to as a "silver tsunami" by Human Rights Watch (2012, p.12). Throughout the world, adult offenders over the age of 55 years are increasingly represented in prison populations, for example in England and Wales (Ministry of Justice, 2015), the United States (Carson & Sabol, 2016), Japan (Yamaguchi, 2011), Australia (Gaston, in press) and Canada (OCI, 2016). Many of these older persons are at increased risk to develop dementia while incarcerated (Christodoulou, 2012; Gaston, in press; Maschi, Kwak, Ko, & Morrissey, 2012). The high-risk environment in correctional settings (e.g., poor nutrition, inactivity, physical violence, isolation, etc.) may impose additional risks on older persons in prison who may in fact already be predisposed to developing dementia due to high-risk lifestyles, low education level, previous poverty, having diabetes, or living with high blood pressure (Alzheimer Society of Canada, 2014; Maschi et al., 2012; Maschi, Viola, & Sun, 2013).

The potential for increasing numbers of incarcerated persons developing dementia has generated new responsibilities for correctional administration who must now adjust to providing care for aging offenders in prison. Dementia research has long focused on the value of quality of life for persons living with dementia (Alzheimer Society of Canada, 2012). However, the incarcerated population is often forgotten in this work (Feczko, 2014). This case report will explore the needs of older offenders living with dementia and discuss existing interventions that can be used to address these needs within correctional settings.

Summary of Key Findings

Dementia is a term used to describe a range of syndromes, usually of a chronic or progressive nature (often over 10 years or more); caused by a variety of diseases that affect the brain. Dementia can be a result of physical changes to the brain (e.g., accumulation of plaques

and tangles as in the case of Alzheimer's disease), socio-environmental factors (e.g., excessive exposure to air pollution or smoking, etc.), and/or genetic factors (as in the case of young-onset dementia) (Alzheimer Society of Canada, 2017). Unfortunately, causes are complex and not fully understood. As seen in Mr. McLaughlin's case, dementia imposes devastating physical and cognitive disability to those affected**.** Symptoms can include impaired memory, poor judgment and reasoning, difficulty communicating, and mood and behavioural changes (such as aggression), along with increased mobility concerns (Alzheimer Society of Canada, 2017). As the condition progresses people with dementia become increasingly reliant on the support of others for their health and wellbeing due to the increasing complexity of physical health care and psychosocial needs (Homerova et al., 2016).

Older prisoners with cognitive impairment can go unnoticed despite a growing body of research that suggests that older men in prison have serious health, social and custodial needs when compared to both older adults in the community, and younger men in prison (Crawley & Sparks, 2005; Hayes, Burns, Turnbull, & Shaw, 2012). As a result of these complex needs, persons living with dementia within correctional settings may struggle to comply with instructions, be prone to victimization, be exposed to unjustified discipline (Williams, Stern, Mellow, Safer, & Greifinger, 2012), and require considerable resources to support them over the trajectory of their illness (Maschi et al., 2012). This is alarming given that prisons were never designed to provide care to an aging, infirm, cognitively impaired population and most lack the necessary infrastructure and resources to meet their needs (Beckett et al., 2003; Loeb, Penrod, McGhan, Kitt-Lewis & Hollenbeak, 2014; Williams et al., 2012). These limitations result in a paucity of compassionate health care for incarcerated, vulnerable persons living with dementia

(Feczko, 2014), even though they are entitled to the same health care as the non-incarcerated population.

Interventions

The delivery of dementia care within the prison milieu is complex and poorly understood. In many cases, offenders with dementia are particularly vulnerable. Many may be left without access to appropriate medical and mental health services (Maschi et al., 2012; OCI, 2016). Given the case of Mr. McLaughlin, although we do not know about the care he may or may not have received in the last months of his life, it is imperative that health care delivery within prisons be re-considered to include an interdisciplinary team with knowledge of gerontology that would support the provision of basic health care, recognizing a chronic, long-term care model, including designating wards for older people where possible (OCI, 2015). Of particular importance is screening individuals at-risk (e.g., those 55 years and older) and diagnosing dementia earlier in the disease process (Williams et al., 2012). Nurses who work in correctional settings have opportunities to lead, participate in, and advocate for improved services for older adults who are incarcerated, including those living with dementia. Nurses may undertake collaborating with community organizations (e.g., local Alzheimer Society) and other interdisciplinary colleagues who have a more in-depth understanding of the biopsychosocial care needs of the condition and work together to advocate for more appropriate placement of older offenders with dementia, particularly when 24 hour care is required.

Internationally, the literature provides reference to specially-designed programs intended to meet the needs of persons living with dementia within prison systems (Maschi et al., 2012). An intervention of particular note is dementia caregiving training for volunteer offenders who are responsible for peers who are cognitively impaired. The responsibilities of these volunteers

include providing social support, ensuring aging offenders receive medical care, and providing protection from other offenders (Maschi et al., 2012). The literature makes mention of other interventions including alterations to the physical environment (Yamaguchi, 2011), and a prison-run rehabilitation center where people in prison can undergo assessment to develop an individualized plan of care (e.g., Baldwin & Leete, 2012; Hodel & Sanchez, 2012). Examples of specific interventions include Alzheimer Scotland which has worked with prison staff to engage prisoners and staff in dementia awareness sessions, as well as raise awareness amongst families at visiting times with the Alzheimer Scotland *Memory bus,* a mobile unit that visits communities and events to raise awareness, provide information, advice and support to people interested in and affected by dementia (Alzheimer Scotland, 2014). This work has led to the first dementia-friendly prison in Scotland (HMP Shotts, 2016). The project aims to support people with dementia to live well, address stigma, and improve inclusion. It is also supporting prison staff to create dementia-friendly environments within the prison and cells. The Alzheimer's Society runs a similar project in England (Alzheimer's Society, 2016). This intervention also works with the prison health care teams to introduce dementia screening tools that can be used on entry to prison and during follow-up assessments.

There is a rich evidence base that illustrates how the environment can be enabling and disabling, stress reducing and stress inducing for people with dementia. There exists evidence-based design principles and toolkits that can support caregivers and organizations to make low-cost enabling changes to the micro and macro built environment of the home, hospital care home, leisure facilities and community for older people with physical and cognitive impairments (e.g., Alzheimer's Society, 2014). Many of these principles can be applied in the prison environment. Hodel and Sanchez (2012) suggest that incarcerated persons with dementia would

benefit from adaptations to their physical environment including coloured nametags on cell doors, colour painted arrows to distinguish the toilet area from the sleeping area within a cell, as well as pictures above the sink to guide hand-washing. Verbeek et al. (2014) studied the effects of the physical environment on dementia and found that living with a smaller group of people decreased the development of the number of aggressive responses that required physical or chemical interventions. Carefully considered low-cost enabling changes to the micro and macro prison environment could be provided while continuing to adhere to prison rules.

It is important to note that very few interventions are cited in the research literature regarding the use, acceptability and/or effectiveness of programming for persons living with dementia in correctional settings (those indicated above are based on reports within *grey-literature*, such newspaper articles). This is alarming in that either very little programming currently exists or it is not being evaluated for its effectiveness. Far more remains to be done to address the needs of the vulnerable, older offender living with dementia.

Discussion

A search of the literature suggests that services within corrections are not meeting the needs of older persons living with dementia (e.g., see Loeb et al., 2014; OCI, 2015; 2016). It may be that supportive programs in fact exist in some correctional settings and they are simply not being researched to evaluate their effectiveness or outcomes; one wonders then if, and how, particular programs have been chosen and what evidence served as a basis for such choices.

The correctional system has often been referred to in the literature as a *warehouse* for prisoners (Canadian Center for Policy Alternative, 2014). This is concerning for all offenders, but is especially worrisome for those living with dementia. Persons living with dementia manage better in calming, predictable, enabling and open environments, therefore the

overcrowding and segregation that is typical of prison environments is likely leading to increased incidences of agitation or withdrawal. Recognizing that the environment within the prison system might be overwhelming to a person with dementia, it would be important for practitioners to identify that if an offender appears to be choosing not to participate in an activity, it may not be an act of defiance but instead a symptom of dementia (Feczko, 2014). There is little information about how people with dementia in prisons are recognised and supported; however, researchers, clinicians, advocates**,** and prison authorities alike are beginning to understand the consequences for failing to recognise and diagnose people with dementia in prison and the need to equip prison staff to appropriately and compassionately respond to their needs. For example, fatal incidents investigations into prisoners in the United Kingdom found that people with dementia had been subjected to inappropriate physical restraint, lacked access to mental capacity assessments, their wishes had not been documented**,** and care planning had been inadequate resulting in neglectful treatment (Prisons and Probation Ombudsman, 2016).

In addition to the human cost there may also be a financial one; keeping an older person in prison costs three times as much as a younger person largely due to health care costs (Moll, 2013). This is likely to be higher for prisoners with dementia given inappropriate management and comorbidities. In short, persons living with dementia, especially those with advanced dementia or at the end of life who require 24 hour care may be better served in supportive long-term care homes in the community. Such a consideration could be achieved with a better application of the compassionate or early release program and providing persons like Mr. McLaughlin with more appropriate options than having to return to prison where his complex health care needs may not be best addressed.

Conclusions

To support the unique and complex needs of persons living with dementia in the prison system, research is needed to guide the development of evidence-informed dementia programs and services; further, consideration of providing those with advanced dementia who require 24 hour care the option of being cared for in a long-term care home in the community is also of importance. It is important that the health care team and correctional staff, work together to identify offenders exhibiting symptoms of dementia and advocate for increased assessment, treatment planning, and support for this vulnerable group. Offenders are at an increased risk of dementia and early diagnosis and intervention can improve their quality of life. When developing new programs, or adapting existing programs, particular attention should be paid to the set-up of the physical environment as this has the potential to greatly influence behaviour. Interdisciplinary collaboration with community organizations may be beneficial to advocate for and identify ways to support persons living with dementia in prisons. Nurses are ideally situated to demonstrate leadership in this area.

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