End-of-life Care in the Prison Environment

Backgrounder Updated 09.15.2020





Photo Source: Lori Waselchuk, gracebeforedying.org http://bit.ly/30uttq8

n the following pages is a representative sample of articles, reports, etc., on hospice and palliative care in the prison environment noted over the past five years (2016-2020) in the weekly report Media Watch. Although a universal public health issue, it is in the United States that most interest and attention has been afforded the aging and the terminal ill prison population. This backgrounder begins with a selection of articles by way of a broad overview of the issue, followed by additional articles, etc., (in descending order of publication) that offer a national and (in the U.S.) state-by-state overview. This is followed by a list of articles, etc., from a variety of sources on end-of-life care in the prison systems in Canada, China, the U.K., France, Poland and Australia.

Contents

COVID-19 Pandemic Selected Studies on End-of-Life Care in the Prison Environment U.S.A. U.S.A. (State-by-State) Australia Canada China France Poland Russia Switzerland	2 3 11 14 18 19 20 21 21 22 22
Switzerland	22
United Kingdom	22

Compiled by Barry R. Ashpole, Media Watch (or a link to the weekly report) is posted on several websites that serve
the hospice and palliative care community-at-large, including the International Palliative Care Resource Center
(http://bit.ly/2ThijkC) and the Palliative Care Network-e (http://bit.ly/2Ujdk2S).

COVID-19 Pandemic

A cursory search of the literature yielded many articles on the potential impact of COVID-19 on prison populations. To date, however, none have addressed or given mention of the palliative and end-of-life care needs in the context of the pandemic. Below is a representative sample of recent articles:

The pandemic is boosting efforts to get the old out of prison

Page | 2

THE ECONOMIST - 7 September 2020 - Globally the number of old people behind bars is increasing at a phenomenal rate. In Britain, the number aged over 60

has jumped by 243% since 2002, to 5,176 in March 2020; they make up 6% of the prison population. Today 20% of Japan's inmates are 60 or older, double the proportion in 2002. The American Civil Liberties Union ... estimates that by 2030 one-third of all inmates in America will be older than 55. They already make up a larger share of the state-prison population than do people aged 18-24. Prisons were built for fit and healthy young men, not people who need handrails in the shower, bed hoists or escorting to the toilet. Old people have more health problems, often chronic, such as dementia, or incurable, like some cancers. Rich countries have started to acknowledge that their prisons now have to be nursing homes and hospices. But prison guards are trained in discipline and security, not nursing. In some cases prisons set up hospices on their grounds. HMP Whatton provides palliative care... Both Britain and America have acknowledged the growing number of elderly inmates and the associated problems. Yet neither country has a national strategy to deal with older offenders. That means provisions to deal with them are improvised and often depend on the prison – with varying results. https://econ.st/3bFnFjN

Prisons and COVID-19: A desperate call for gerontological expertise in correctional healthcare

THE GERONTOLOGIST – 24 July 2020 — The large and continued growth of the older adult population within U.S. prisons affects not only criminal justice policy and correctional health practice, but also gerontology. Amidst the COVID-19 crisis, associated know-ledge and skills surrounding older adulthood will be critical to assuring the needs of older adults incarcerated in prisons are met during their detention, while undergoing off-site intervention in community settings, and when preparing for release. The authors outline several key areas for which gerontologists and associated practitioners are especially well-suited in the effort to curtail morbidity and mortality driven by the disease caused by the novel Coronavirus. Critical gerontological knowledge and skills needed in prison healthcare include awareness regarding the unusual clinical presentations of COVID-19 among older adults, deconditioning among older adults due to immobility, challenges in prognostication, and advance care planning with older adults. Specific, targeted opportunities for gerontologists are identified to reduce growing risks for older adults incarcerated in prisons. Full text (click on pdf icon): https://bit.ly/2WUQ7YA

More people are dying in American prisons - here's how they face the end of their lives

THE CONVERSATION – 27 May 2020 – Outbreaks of coronavirus have hit prison populations particularly hard – but for many inmates in the U.S., illness and the prospect of dying behind bars already existed. Advocacy groups have flagged concerns about disease transmission, lack of medical care and deaths in custody as a result of COVID-19. But deaths in custody are not a new phenomena and the process of dying with dignity while incarcerated is complicated. Prisoners grow old faster and become sick earlier. By 2030 some experts believe that one in three prisoners will be over the age of 55, increasing the likely population of prisoners diagnosed with conditions such as cancer, heart disease, liver and kidney disease, high blood pressure and diabetes. A recent Bureau of Justice Statistics report revealed a startling increase in state prisoner mortality. Between 2006 and 2016, the last year for which the study provided data, there were more than 53,000 deaths in custody. More than half of the 3,739 deaths in custody in 2016 resulted from just two illnesses – cancer (30%) and heart disease (28%). The proportion of prisoners requiring end-of-life care is twice as high as the general population. https://bit.ly/2X8xpO0

1. 'Prevalence and characteristics of prisoners requiring end-of-life care: A prospective national survey,' *Palliative Medicine*, published online 8 August 2017. **Full text:** https://goo.gl/5pa3Jh



Search back issues of Media Watch for articles, etc., on COVID-19 in the context of palliative and end-of-life care: http://bit.ly/2ThijkC

Selected Articles, Reports, etc., on End-of-Life Care in the Prison Environment

2020

Barriers to and strategies for gaining entry to correctional settings for health research

NURSING LEADERSHIP, 2020;33(1):71-80. Challenges to gaining entry to correctional settings to conduct research can impede research productivity, delay the launch of studies and inhibit researchers from proposing health research in corrections. The authors share lessons learned from a large-scale corrections research project designed to develop computer-based learning modules to train front-line corrections personnel about geriatric and end-of-life care. Key lessons learned include the importance of building a team of experts, planning and punting, coordinating with institutional review boards and examining denied applications to inform future planning. To be effective in a correctional setting, leaders in nursing research and corrections nursing must work together within the contextual nature of prisons and jails to advance evidence-based practices for this vulnerable population. These lessons serve to establish best practices on how to access correctional settings and to enable more research in corrections. **Abstract:** https://bit.ly/3eyKBS0

Strategies to optimize the use of compassionate release from U.S. prisons

AMERICAN JOURNAL OF PUBLIC HEALTH, 2020;110(S1):S25-S26. Many factors have contributed to the aging of the prison population, including reduced judicial discretion (e.g., mandatory minimum sentences, "three strikes" legislation), indeterminate sentencing, and the reintroduction of life without parole. As many incarcerated older adults experience multiple physical and mental health conditions at higher rates than do non-incarcerated persons, prison yards are now peppered with walkers, wheelchairs, and other durable medical equipment. Incarcerated older adults are also vulnerable to predation and often live in environments not designed to meet their physical needs. As a result, older adults generate high costs for overcrowded correctional systems, many of which are ill suited to provide the complex medical care needed for patients of advanced age or approaching the end of life. In response to the aging of the prison population, many jurisdictions have introduced or reinvigorated legal mechanisms to release or parole people with life-limiting illness early to their communities. Nearly all states have some form of early release policies, including medical parole, medical release, and "geriatric" parole... Full text: http://bit.ly/2ScUgNe

Developing computer-based learning on care of aged and dying incarcerated people

JOURNAL OF FORENSIC NURSING, 2020;16(1):36-46. The authors describe the design and development of a media-rich interactive computer-based learning product, which addresses geriatric and end-of-life care issues in corrections. The Enhancing Care for Aged & Dying in Prison contains six modules, created under the careful guidance of the research team and the two advisory boards. Contents, including images and testimonials, were selected purposefully and strategically. Module objectives were developed in alignment with the goals and priorities of each module, and assessments tested user knowledge level pre/post module exposure. Evidence-based training products are critical in preparing not only forensic nurses who work in corrections but also the broader group of correctional personnel in how to better meet the care needs of incarcerated persons. **Abstract:** http://bit.ly/345V0iu

Healthcare needs of older women prisoners: Perspectives of the healthcare workers who care for them

JOURNAL OF WOMEN & AGING, 2020;32(2):183-202. The proportion of older incarcerated women is growing, yet little is known regarding their healthcare needs. This study sought to elucidate the unique healthcare needs of older women prisoners through the perspectives of correctional healthcare providers. Three organizing themes emerged regarding the health of older women prisoners: 1) The meaning of being "older" in the prison setting; 2) Challenges impacting correctional healthcare workers' care delivery; and, 3) Unmet healthcare-related needs. Correctional healthcare workers' insights can provide guidance regarding how to optimize the health of the increasing population of older women prisoners. **Abstract:** http://bit.ly/2uNwbsf

Should patients who are incarcerated on death row receive palliative cancer care?

THE LANCET ONCOLOGY, 2020;21(3):P337-P338. In modern society, it is accepted that individuals have the right to die with dignity. Since 1976, in the U.S., people who are incarcerated have a limited constitutional right to healthcare, consistent with the Eighth Amendment. At present, there are more than 2,600 incarcerated men and women in the U.S. who have been sentenced to death, most of whom have less than a high school diploma or High School Equivalency Certificate, and are disproportionately of minority racial or ethnic backgrounds (42% African American representation on death row vs 13% African American representation in the U.S. census). Abstract: http://bit.ly/2PGBggL

Page | 3

Towards a guiding framework for prison palliative care nursing ethics

ADVANCES IN NURSING SCIENCE, 2019;42(4):341-357. The number of people aging and dying behind bars is growing, bringing greater attention to the need for prison palliative care (PC). While this trend has led to increased scholarship, a focus on understanding the most effective way to deliver prison PC has overshadowed thinking about why the need itself has arisen, as well as deeper ethical thinking about how the nursing profession should respond. Page | 4 This article interweaves four strands of analysis - contextual, relational, social, and political - to produce a framework to guide ethical action in prison PC nursing, relevant to practice, research, policy, and education. Abstract: http://bit.ly/2EDwVVs

Shackled at the end of life: We can do better

AMERICAN JOURNAL OF BIOETHICS, 2019;19(7):61-63. The obligation to provide care at the end of life that preserves human dignity in the correctional setting is not only an ethical one but has legal underpinnings as well. In Estelle v. Gamble the U.S. Supreme Court established that deliberate indifference to serious medical needs of prisoners is a violation of the Eighth Amendment, which prohibits "cruel and unusual punishment." Subsequent case law has established that the incarcerated have a de facto right to a "community standard" of healthcare (Estelle v. Gamble, 1976). Similarly, the United Nations 'Standard Minimal Rules for the Treatment of Prisoners' (Mandela Rules) dictate that "all prisoners shall be treated with the respect due to their inherent dignity and value as human beings" and "enjoy the same standards of healthcare that are available in the community" (McCall-Smith, 2016). First page view (w. link to references): http://bit.ly/2YdU8pJ

Palliative care for inmates in the hospital setting

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2019;36(4):321-325. Previous studies have demonstrated multiple barriers to providing palliative care (PC) for seriously ill inmates. The aim of this study was to assess the frequency of PC consultation and nature of consultation requests for inmates who died while hospitalized at a large tertiary care hospital. A retrospective chart review of all inmate decedents over a 10-year time period was conducted. The reason and timing of consultation was noted in addition to symptoms identified and interventions recommended by the PC team. Characteristics of patients who were transferred to the inpatient PC unit were also recorded. Forty-five percent of inmates were seen by PC prior to their death. Timing of consultation was close to the day of death. Inmates with cancer were significantly more likely to have a PC consultation prior to death. Nearly, 5000 prisoners die each year, mostly in community hospitals. Abstract: http://bit.ly/2JqC0oS

Palliative and end-of-life care in prisons: A mixedmethods rapid review of the literature from 2014-2018

BMJ OPEN, 2019;9(12):e033905. Relationships are important to prisoners at the end of life (EoL), inmate hospice volunteers can build close bonds with the prisoners in their care and the prison environment, and regime conflicts with best practices in palliative and EoL care. Many of the key findings reinforce points made in the Wion and Loeb review,1 such as the value of inmate hospice volunteers and the physical barriers presented by the prison environment. Other findings which were relatively minor in the previous review have become major themes in the literature published since 2014, such as the importance of maintaining family relationships and the potential grief burden of inmate hospice volunteers. Relationships both inside and outside of prison are of importance to prisoners at the EoL. and recommends that those involved in their care should support prisoners to maintain these relationships. Full text: http://bit.ly/2PTCRR2

1. 'End-of-life care behind bars: A systematic review,' American Journal of Nursing, 2016;116(3):24-36. Abstract: http://bit.ly/2ZmwfOe



Share this Backgrounder with a Colleague

Early release rules for prisoners at end of life may be "discriminatory," say doctors

BRITISH MEDICAL JOURNAL - 12 June 2019 - Doctors have called for changes to the rules governing when terminally ill prisoners can be released early on compassionate grounds, amid concern that the current approach is discriminatory. Data obtained from the Ministry of Justice ... indicate that prisoners in England and Wales at the end of life are more likely to be granted early release on compassionate grounds if they have cancer than if they have other conditions, say clinical researchers who examined the data. Under current legislation the secretary of state for justice can grant early release where there is a risk of harm to the prisoner from ongoing imprisonment, potential benefit Page | 5 through release, a low risk of recidivism, and adequate arrangements for safe care in the community. But, crucially, the prisoner's death must be expected "very soon," and HM Prisons & Probation Service considers this to be within three months. Jim Burtonwood, a palliative care specialist ... who led the research, said the current rules meant that timescales often became too tight for a successful application for early release if an acknowledgment of terminal decline was delayed or there was prognostic uncertainty. Full text: http://bit.ly/2WEwEIO

Palliative and hospice care in correctional facilities: Integrating a family nursing approach to address relational barriers

CANCER NURSING - 21 October 2019 - The need for palliative and hospice care for persons with life-limiting conditions who are incarcerated is increasingly common in correctional facilities worldwide. Through a family nursing lens, the authors critically analyze the unique challenges experienced by those requiring palliative care while incarcerated. Key concerns and implications for nursing are illustrated through the discussion of a representative case scenario. By applying a family nursing approach, nurses practicing with correctional populations can ensure persons with lifelimiting illnesses are not denied their right to appropriate end-of-life care by playing a key role in addressing barriers to palliative and hospice care access in corrections. Specific attention to relational issues and holistic care can contribute to enhanced palliative and hospice care, greater dignity in dying, and improved family and peer outcomes, which have benefits for individuals, families, communities, and society. The authors illustrate real issues emerging in correctional contexts and offer evidence of how family nursing relational principles can be applied to promote adequate palliative and hospice care. Abstract: http://bit.ly/2Jz6BiG

A systematic integrative review of programmes addressing the social care needs of older prisoners

HEALTH & JUSTICE - 27 May 2019 - This review details programmes which support older prisoners' social care needs, including hospice and structured programmes, personal care-focused services, and regime and accommodation adaptations. Whilst the papers presented largely positive results regarding prisoner peer supporters and the wider prison, there were mixed results for staff. Additionally, whilst there were positive claims made about the impact on the prisoners attending the programmes, only two papers actually sampled those prisoners. This together with the generally low quality of the papers, and lack of any experimental effectiveness studies, to some extent limits their utility for policy and practice. There is a clear need for more robust effectiveness and cost-effectiveness studies to better support the development of social care for older prisoners at individual, policy and practice levels. Full text: http://bit.ly/2YOZo2U

A brief video intervention to improve medical students' attitudes toward prisoners

JOURNAL OF CONTEMPORARY MEDICAL EDUCATION, 2019;9(2):46-52. Implicit biases against prisoners may negatively impact the quality of care prisoners receive. The inclination to stigmatize prisoners as morally deviant or corrupt, fear of prisoners and other factors can be seen as a justification for lack of equivalent compassion and suboptimal medical care. Healthcare professionals and trainees working in the hospital setting need to be cognizant of their implicit biases toward prisoners and have tools for tackling these perceptions. Introducing medical students to prisoners via a video that depicted them as fellow human beings, without excusing their actions, can lead to attitudinal adjustments more in line with the Hippocratic ideals to which the medical students should be aspiring. Unlike other interventions, a video, such as the one used in this study, can be easily incorporated into medical school training in order to positively impact attitudes toward prisoners. This study is a first step in exploring medical students' attitudes toward prisoners and the effectiveness of video material in shifting attitudes and behaviors toward prisoner care. Next steps include finding ways of optimizing the effectiveness of video interventions and comparing their effects to other interventions, such as prisoner panels. Full text: http://bit.ly/2OSFeDL

Death with dignity for the seemingly undignified: Denial of aid in dying in prison

JOURNAL OF CRIMINAL LAW & CRIMINOLOGY, 2019:109(3). The conversation surrounding quality of life, and by extension end-of-life care, has included whether a competent adult has a right, or should have a right to end their own life on their own terms. The history of aid in dying is wrought with political ideology, notions of morality, and discussions of autonomy. In the wake of an aging population, aid in dying is more relevant now than ever. Aid in dying is often supported by notions of autonomy and dignity in choosing the conditions of if, when, and how to end one's life, however, there is one noticeable segment of the population entirely left out: incarcerated individuals. The incarcerated Page | 6 population is particularly relevant to the aid in dying conversation because, as the justice system continues to balloon and incarcerate more people, prisons are overcrowded, underfunded, and ill-equipped to support terminally ill and aging inmates. This leaves the aging incarcerated population vulnerable. As states [in the U.S.] continue to contemplate and pass legislation that permits aid in dying in particular circumstances, one is left wondering how, if at all, this legislation will affect those incarcerated. Download/view full text at: http://bit.lv/2MUD0nl

Prison – a place for dying? An explorative study on the perspective of professionals

JOURNAL OF CRIMINOLOGY & PENAL REFORM, 2019;102(3):177. The authors review the results of a qualitative pilot study on the meaning of death and dying in prison from the perspective of professionals. In future years, the penal system will increasingly be confronted with the natural death of inmates and those in security detention. Against this background, this analysis of expert interviews shows specific tension between the societal ideal of "good dying" and the restrictive conditions of incarceration. Interviewees discuss the question of how best to support dying inmates within the limitations of the prison system. Abstract (w. list of references): http://bit.ly/37izIGL

N.B. German language article.

Improving care for the overlooked in oncology: Incarcerated patients

THE LANCET, 2019;20(10):1342-1344. Physicians and public health practitioners often view health disparities through the eyes of birthplace, race, sex, economic class, sexuality, religion, or neighbourhood, or a combination of these. In the process, patients who are incarcerated (too often referred to as prisoners rather than patients) are overlooked as a profoundly medically vulnerable population with substantial disparities in healthcare and their health is an understudied public health crisis. Although a third of illness-related deaths in U.S. state prisons are due to cancer, and this mortality rate is double for incarcerated male patients, few recommendations exist to guide oncologists in how to address the unique challenges of providing ethically competent and high quality cancer care for incarcerated patients. Abstract (w. list of references): http://bit.ly/2ngCuly

Developing educational modules to enhance care of aged and dying inmates: Set-up phase

PUBLIC HEALTH NURSING, 2019;36(3):401-410. Public health nurses have an opportunity to support efforts in educating corrections staff to enhance healthcare for older and dying inmates. Such endeavors can promote social justice through inmates receiving evidence-based care that parallels that received by the community at large. "Set-up" is the first of four phases in the Institute for Healthcare Improvement's Framework for Going to Full Scale. The design approach was threefold and included an environmental scan, a modified Delphi survey, and a usability study. An expert advisory board was consulted throughout the Set-up Phase. Participants for the Delphi Survey had expertise in geriatrics and corrections healthcare. The Set-up phase has been instrumental in exposing the available infrastructure for dissemination of an educational product within corrections and may be a first step in addressing public health concerns on issues in aging. Abstract: http://bit.ly/2DteEJV



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness - both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://bit.ly/2RPJy9b

Palliative care and the injustice of mass incarceration: Critical reflections on a harm reduction response to end of life behind bars

WITNESS: THE CANADIAN JOURNAL OF CRITICAL NURSING DISCOURSE, 2019:1(2):4-16. Due to the criminalization of marginalized people, many markers of social disadvantage are overrepresented among prisoners. With an aging population, end of life in prison thus becomes a social justice issue that nurses must contend with, engaging with the dual suffering of dying and of incarceration. However, prison palliative care (PC) is constrained by the punitive mandate of the institution and has been critiqued for normalizing death behind bars and appealing to discourses Page | 7 of individual redemption. The authors argue that prison PC has much to learn from harm reduction. Critical reflections from harm reduction scholars and practitioners hold important insights for prison PC: decoupled from its historical efforts to reshape the social terrain inhabited by people who use drugs, harm reduction can become institutionalized and depoliticized. Efforts to address the harms of substandard PC must therefore be interwoven with the necessarily political work of addressing the injustice of incarceration. Full text: http://bit.ly/2VqLGFI

2018

"We take care of patients, but we don't advocate for them": Advance care planning in prison or jail

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY, 2018;66(12):2382-2388. Participants in this study demonstrated low baseline advance care planning (ACP) knowledge; 85% reported familiarity with ACP, but only 42% provided accurate definitions. Fundamental misconceptions included the belief that providers provided ACP without soliciting inmate input. Multiple ACP barriers were identified, many of which are unique to prison and jail facilities, including provider uncertainty about the legal validity of ACP documents in prison or jail, inmate mistrust of the correctional healthcare system, inmates' isolation from family and friends, and institutional policies that restrict use of ACP. Clinicians' suggestions for overcoming those barriers included ACP training for clinicians, creating psychosocial support opportunities for inmates, revising policies that limit ACP, and systematically integrating ACP into healthcare practice. Abstract: http://bit.ly/2HnEsu0

Preparing to die behind bars: The journey of male inmates with terminal health conditions

JOURNAL OF CORRECTIONAL HEALTH CARE, 2018;24(3):232-242. While research has expanded on end-of-life care in and out of prison settings, to date there has been little research conducted on how inmates experience dying behind bars. Through collecting data during observation of facilitated advance care planning sessions, this qualitative study revealed four main themes: 1) Losing a piece of everything; 2) Not sure what to feel; 3) Where will I die; and, 4) Finding purpose in the midst of purposelessness. These themes characterize the central issues discussed by inmates as they considered death behind bars. As we seek to improve healthcare in prison settings, this study provides insight into how inmates view their dying process. Abstract: http://bit.ly/2JghKUI

What does the implementation of peer care training in a U.K. prison reveal about prisoner engagement in peer caregiving?

JOURNAL OF FORENSIC NURSING, 2018;14(1):18-26. The number of aging and chronically ill prisoners continues to rise within the U.K. prison demography; consequentially, many institutions face health and social care crises of immense proportions. The needs of this group are both complex and costly and in the U.K. this is set to a backdrop of overcrowding, increasing violence, and public spending cuts in line with government austerity targets. The development of prisoner peer caregiving is proposed as an approach to mitigating the effects of aging, disability, and illness. A qualitative study was implemented to design, deliver, and evaluate a peer care training intervention within a U.K. prison. Abstract: http://bit.ly/2EgwPDQ

"No one wants to die alone": Incarcerated patients' knowledge and attitudes about early medical release

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2019;57(4):809-815. Many medically complex incarcerated patients in this study did not demonstrate sufficient knowledge to apply for early medical release suggesting that patient education may help expand access to these policies. Moreover, seriously ill patients with knowledge of early medical release may benefit from enhanced psychosocial support given their disproportionate burdens of anxiety and loneliness. The authors' findings highlight the pressing need for larger studies to assess whether improved patient education and support can expand access to early medical release. Abstract (inc. link to references): http://bit.ly/2VsHiSs

"People don't understand what goes on in here": A consensual qualitative research analysis of inmate-caregiver perspectives on prison-based end-of-life care

PALLIATIVE MEDICINE, 2018;32(5):969-979. There is growing research support for prison-based end-of-life care (EoLC) programs that incorporate inmate peer caregivers as a way to meet the needs of the elderly and dying who are incarcerated. All study participants were male, over the age of 18, and also incarcerated at Briarcliff Correctional Facility, a maximum security, state-level correctional facility in New York State. Five over-arching and distinct domains emerged; this manuscript focuses on the following: 1) Program description; 2) Motivation; and, 3) Connections Page | 8 with others. Findings suggest that inmate-caregivers believe they provide a unique and necessary adaptation to prison-based EoLC resulting in multi-level benefits. Abstract: http://bit.ly/2EhnknN

Differences between incarcerated and non-incarcerated patients who die in community hospitals highlight the need for palliative care services for seriously ill prisoners in correctional facilities and in community hospitals: A cross-sectional study

PALLIATIVE MEDICINE, 2018;32(1):17-22. Overall, 745 incarcerated and 370,086 non-incarcerated individuals died in California hospitals between 2001 and 2013. Incarcerated decedents were more often male, Black, Latino, younger, and had shorter hospitalizations ...and, fewer had an advance care plan. Incarcerated decedents had higher rates of cancer, liver disease, HIV/AIDs, and mental health disorders. Cause of death was disproportionately missing for incarcerated decedents. The average age of incarcerated decedents [i.e., inmates who had died] rose between 2001 and 2013, while it remained stable for others. Palliative care services in correctional facilities should accommodate the needs of relatively young patients and those with mental illness. Abstract: http://bit.ly/2w7Ur97

A toolkit for enhancing end-of-life care: An examination of implementation and impact

THE PRISON JOURNAL, 2018;98(1):104-118. The purpose of this study was to examine the infusion of a Toolkit for Enhancing End-of-Life Care in prisons, as well as the outcome and impact on the quality of prison end-of-life care. A total of 74 front-line staff and administrators were in attendance across two post-Toolkit-infusion evaluation visits. Applying qualitative analysis, co-researcher outcome findings were related to activities, community outreach and relations, multidisciplinary team, quality improvement approach, and participatory action research team effects. Organizational outcomes included barriers and challenges, cost, organizational features, sphere of influence, readiness (for change), and sustainability. Abstract: http://bit.ly/2w4Kcmf

Ageing and dying in the contemporary neoliberal prison system: Exploring the "double burden" for older prisoners

SOCIAL SCIENCE & MEDICINE, 2018;212(9):161-167. Older prisoners face a "double burden" when incarcerated. This double burden means that as well as being deprived of their liberty, older people experience additional suffering by not having their health and wellbeing needs met. For some, this double burden includes a "de facto life sentence," whereby because of their advanced age and the likelihood that they will die in prison, they effectively receive a life sentence for a crime that would not normally carry a life sentence. There has been little popular or academic debate concerning the ethical and justice questions that this double burden raises. Although the authors focus on the U.K. (which by comparison with other European countries has high rates of imprisonment), many of the challenges discussed are emerging in other countries across the world. Full text: http://bit.ly/2Hyk34A

End-of-life care in prison

SOCIAL WORK TODAY, 2018;18(6):16. For many of the individuals incarcerated across the U.S., dying is more than a possibility or passing thought. Given their sentences, their age, and, often, their health, dying in prison is inevitable. The circumstances of the death vary based not only on the person but the facility as well. For some, dying in their cell with their cellmate nearby is the best of terrible options. "They die in their 'homes,' where their cellmates are, their friends are," says Marvin Mutch, associate of the Humane Prison Hospice Project and director of advocacy at the Prisoner Reentry Network. Mutch was imprisoned for 41 years after a wrongful conviction in 1975 and was released in 2016. Dying in one's cell, however, is difficult, not only for the prisoner but also for their cellmate, Mutch says. "In San Quentin [State Prison]." where Mutch was, "there were many times when guys died on their cell floor. If you die in your cell, your cellmate goes to segregation until the autopsy is completed. Most of these guys have lived together as lifers for years, [and] now their grief process must start in total isolation." In other circumstances, when the individual goes to the infirmary and end-of-life services are not available, the prisoner is often faced with dying completely alone. Documentary filmmaker Edgar Barens ('Prison Terminal: The Last Days of Private Jack Hall'), whose film 'Angola Prison Hospice: Opening the Door' has been used as a training tool for prisoners, concurs with Mutch. Full text: http://bit.ly/2w8vvOl

"We call it jail craft": The erosion of the protective discourses drawn on by prison officers dealing with ageing and dying prisoners in the neoliberal, carceral system

SOCIOLOGY, 2018;52(6):1152-1168. The U.K. prison population has doubled in the last decade, with the greatest increases among prisoners over the age of 60 years, many of whom are sex offenders imprisoned late in life for "historical" offences. Occurring in a context of "austerity" and the wider neoliberal project, an under-researched consequence of this increase has been the rising numbers of "anticipated" prison deaths; that is, deaths that are foreseeable and that require end-of-life care. The authors focus on "jail craft"; a nostalgic, multi-layered, narrative or discourse, Page | 9 and set of tacit practices which are drawn on by officers to manage the affective and practical challenges of working with the demands of this changed prison environment. Full text: http://bit.ly/2Eeyzxk

Access to palliative care services in prison: Who cares?

WHITIREIA NURSING & HEALTH JOURNAL, 2018;25:53-59. The Aotearoa New Zealand prison system houses a growing number of chronically ill prisoners and, coupled with an ageing prison population, the need for end-of-life care is evident. There are significant barriers restricting the provision of palliative care (PC) for this most vulnerable group, including delays in physical and psychological assessments, restricted access to medications and regulations preventing timely interventions to alleviate suffering. Ethical considerations of "custody versus care" and negative public attitudes contribute further barriers against the provision of equitable care for the dying prisoner. Currently in New Zealand, compassionate release or admission into a purpose-built high-dependency unit are the only options available for the terminally ill prisoner. However, PC is not a "one size fits all" concept, and more work needs to be done in this area. At a Ministry of Health level, the development of a future action plan has commenced, focusing on improving the delivery of PC across the board, thus providing an opportunity for stakeholders to speak out and effect change. Abstract: http://bit.ly/2ZhScxE

2017

Incarcerated patients and equitability: The ethical obligation to treat them differently

JOURNAL OF CLINICAL ETHICS, 2017;28(4):308-313. This article argues: 1) Prisoner-patients are entitled to the same quality of care as all other patients and healthcare providers should be vigilant to ensure the stigma of incarceration does not influence care decisions; 2) Options for treatment should reflect what is most medically appro-priate in the hospital or other healthcare setting, even when not all treatments would be available in the correctional setting; 3) The presence of guards at the bedside requires additional measures be taken to protect the privacy and confidentiality of prisoner-patients; and, 4) When end-of-life decisions must be made for an incapacitated patient, prison physicians are not well placed to act as surrogate decision-makers, which heightens the obligations of the healthcare professionals to ensure an ethically supportable process and outcome. Abstract: http://bit.ly/2WPSoT5

Developing a typology for peer education and peer support delivered by prisoners

JOURNAL OF CORRECTIONAL HEALTH CARE, 2017;23(2):214-229. Peer interventions delivered for prisoners by prisoners offer a means to improve health and reduce risk factors for this population. This paper presents a typology developed as part of a systematic review of peer interventions in prison settings. Peer interventions are grouped into four modes: 1) Peer education; 2) Peer support; 3) Peer mentoring; and, 4) Bridging roles, with the addition of a number of specific interventions identified through the review process. The paper discusses the different modes of peer delivery with reference to a wider health promotion literature on the value of social influence and support. Abstract: http://bit.ly/2WSbHei

End of life in prison: Talking across disciplines and across countries

JOURNAL OF CORRECTIONAL HEALTH CARE, 2017;23(1):11-19. What a good end of life (EoL) means is a particularly relevant question in the context of confinement and prison. Most of the questions and issues raised by EoL for those living in liberty also apply to the correctional setting. However, the institutional particularities and logics of the prison create unique barriers and make it difficult in practice to reconcile concerns in regard to EoL - like care and comfort - with the mandate of corrections - confinement and punishment. the literature on EoL in prison is dominated by U.S. contributions. Full text: http://bit.ly/30raGVF

Integrating correctional and community healthcare: An innovative approach for clinical learning in a baccalaureate nursing program

NURSING FORUM, 2017:52(1):38-49. This article demonstrated how medium/maximum prisons can provide an ideal learning experience for not only technical nursing skills but more importantly for reinforcing key learning goals for community-based care, raising population-based awareness, and promoting cultural awareness and sensitivity. In addition, this college of nursing overcame the challenges of initiating and maintaining clinical placement in a prison facility, collaboratively developed strategies to insure student and faculty safety satisfying legal and administrative Page | 10 concerns for both the college of nursing and the prison, and developed educational post-clinical assignments that solidified clinical course and nursing program objectives. Abstract: http://bit.ly/2WORLcf

The collision of care and punishment: Ageing prisoners' view on compassionate release

PUNISHMENT & SOCIETY, 2017;19(1):5-22. Most prisoners wish to spend their last days outside prison. Early release of seriously ill and ageing prisoners, commonly termed compassionate release, can be granted based on legal regulations, but is rarely successful. The aim of this paper is to present the views of ageing prisoners on compassionate release using qualitative interviews. Participants argued for compassionate release on the grounds of illness and old age, citing respect for human dignity. Their hopes of an early release, however, often contradicted their actual experiences. Abstract (w. list of references): http://bit.ly/2JmCHiY

2016

Older prisoners' experiences of death, dying and grief behind bars

THE HOWARD JOURNAL OF CRIME & JUSTICE, 2016:55(3):312-327. Prison populations are experiencing rapid increases and many more offenders are dying in prison. This article draws on research that was conducted by the authors in the U.S., and in England and Wales. The study interrogates the meanings older prisoners give to the prospect of dving in prison. The themes identified during data analysis included general thoughts about death and dving. accounts of other prisoners' deaths, availability of end-of-life services, contact with social relations, and wishes to die outside of prison. Abstract and access to full text options at: http://bit.ly/2W86RwC

Ageing prisoners: An introduction to geriatric healthcare challenges in correctional facilities

INTERNATIONAL REVIEW OF THE RED CROSS, 2016;98(903):917-939. The rise in the number of older prisoners in many nations has been described as a correctional "ageing crisis" which poses an urgent financial, medical and programmatic challenge for correctional healthcare systems. In 2016, the International Committee of the Red Cross hosted a conference entitled 'Ageing and Imprisonment: Identifying the Needs of Older Prisoners' to discuss the institutional, legal and healthcare needs of incarcerated older adults, and the approaches some correctional facilities have taken to meeting these needs. This article describes some of the challenges facing correctional systems tasked with providing healthcare to older adults, highlights some strategies to improve their medical care, and identifies areas in need of reform. Abstract: http://bit.ly/2YH9h2X

Ethical issues in caring for prison inmates with advanced cancer

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2016;18(1):7-12. This article includes a discussion of the ethical issues ... encountered in provision of care for prisoners that should, but often does not, approximate that of nonprisoner care. The history of the prison hospice movement is described. The case of a prisoner with extensive cancer and multiple symptoms is presented to highlight the ethical, existential, and practical issues encountered especially by the nurses, as well as other team members providing care for prisoners with advanced cancer. Then follows a discussion of the collaborative, compassionate approach to his care that maintained public and personal safety while optimizing symptom management and respect for his goals of care. Abstract: http://bit.ly/30vkQvR

A "good death" for all? Examining issues for palliative care in correctional settings

MORTALITY, 2016;21(2):93-111. Through this critical narrative review of the literature, the authors identify personal, social and political concerns that influence prisoners' ability to access a "good death" and healthcare providers' potential to contribute to such an outcome. In doing so, the authors highlight divergence between PC theory and practice, and the complex issues faced by dying prisoners and their families, prison officials, healthcare providers and other members of PC teams. They conclude, while dying well is potentially achievable within the contentious realm of corrections, further efforts are needed to improve access to PC and ensure the incarcerated are not denied their right to a "good death." Abstract (inc. link to references): http://bit.ly/2YDgA4W

End-of-Life Care in the Prison Environment in the U.S.A.

2019

Characteristics of hospice and palliative care programs in U.S. prisons: An update and 5-year reflection

Page | 11

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE – 6 December 2019 – Individuals with terminal illness are dying behind bars and many state prison administrators have incorporated on-site hospice and palliative care (PC) services. Little is known, however, about these programs since a 2010 study of prison hospice characteristics. The authors provide an updated description and reflection of current hospice and PC programs in state prisons serving incarcerated persons with terminal illness. A cross-sectional survey was sent to representatives of all known prisons offering hospice and PC programs and services. Questions were drawn from an earlier iteration regarding interdisciplinary team (IDT) membership, training length and topics, peer caregivers, visitation policies, bereavement services, perceived stakeholder support, and pain management strategies. Additional questions were added such as estimated operational costs, peer caregiver input in patient care, and the strengths and weaknesses of such programs. Frequency distributions were calculated for all study variables. Responding representatives indicated IDTs remain integral to care, peer caregivers continue to support dying patients, and perceived public support for these programs remains low. Reduced enthusiasm for the programs may negatively influence administrative decision-making and program resources. Further, peer caregiver roles appear to be changing with caregivers charged with fewer of the identified tasks, compared with the 2010 study. Abstract: http://bit.ly/2DOp3Ay

2018

Prison hospice care: Life and death behind bars

AMERICAN JOURNAL OF PSYCHIATRY, 2018;13(3):3. Hospice care is a unique field that enables psychiatrists to use their skill set to improve the quality of life and experience of death for terminally ill patients and their families. Prison hospice is an expanding specialty that should be considered by physicians who are interested in the legal system, hospice care, and care for vulnerable populations. An increase in both the U.S. prison population and average inmate age has burdened the correctional system with caring for chronically and terminally ill incarcerated persons. One response to this problem was the Sentencing Reform Act of 1984, which provided the option of compassionate release for dying inmates. However, this policy has been largely ineffective, with release of few incarcerated persons and with some inmates dying in prison during the long petition process. Full text: http://bit.ly/2Jx5bXF

The health of America's aging prison population

EPIDEMIOLOGIC REVIEWS, 2018;40(1):157-165. In this systematic review, the authors summarize the epidemiologic evidence of the health challenges facing the aging U.S. prison population. Their comprehensive literature search focuses on health outcomes, including diseases, comorbid conditions, mental health, cognition, and mobility. From 12,486 articles identified from the literature search, the authors reviewed 21 studies published between 2007 and 2017. All were observational and cross-sectional, and most were based on regional samples. Sample sizes varied widely, ranging from 25 to 14,499 incarcerated people... In general, compared with their younger counterparts, older incarcerated individuals reported high rates of diabetes mellitus, cardiovascular conditions, and liver disease. Mental health problems were common, especially anxiety, fear of desire for death or suicide, and depression. Activities of daily living were challenging for up to one-fifth of the population. The authors found no empirical data on cognition among older incarcerated individuals. Full text: http://bit.ly/2Eh46yT

Compassionate release for dying prisoners underused: Report

FAMILIES AGAINST MANDATORY MINIMUMS – 27 June 2018 – The non-profit advocacy group has released a comprehensive, state-by-state report on the early-release programs available to prisoners struggling with certain extraordinary circumstances, such as a terminal or age-related illness. The report takes a deep dive into the regulations and requirements of these programs in each state, including the varying categories of release, eligibility criteria, and reporting. The analysis also reveals a troubling number of barriers faced by prisoners and their families when applying for early release. The report is accompanied by a comparison chart, 21 recommendations for policymakers, and 51 individual state memos. **Download/view report at:** http://bit.ly/2WQ32ch

Dying behind bars

JOURNAL OF GERONTOLOGICAL NURSING, 2018:44(1):2-3. Despite the push in nursing research to devote attention to the process of healthy aging, and to better understand the needs faced by the aging population, injustice has occurred for a marginalized group of aging Americans: prisoners. The prison population is aging rapidly. In 2008, more than 74,000 men and 4,000 women older than 55 were in prisons nationwide. In upcoming decades, that number is likely to skyrocket because approximately 162,000 individuals are currently serving life sentences. For the subset of the population destined to age and die in prison, current research on healthy aging is inadequate. Full text: Page | 12 http://bit.ly/2W69EX7

U.S. Department of Corrections compassionate release policies: A content analysis and call to action

OMEGA - JOURNAL OF DYING & DEATH - 6 August 2018 - Large and increasing numbers of inmates with chronic and terminal illnesses are serving time, and dying, in U.S. prisons. The restriction of men and women to die in prisons has many ethical and fiscal concerns, as it deprives incarcerated persons of their autonomy and requires comprehensive and costly healthcare services. To ameliorate these concerns, compassionate release policies, which allow inmates the ability to die in their own communities, have been adopted in federal and state prison systems. However, little is known about the content of compassionate release policies within U.S. states' department of corrections, despite recent calls to release incarcerated persons who meet eligibility criteria into the community. This study provides an overview of compassionate release policies in the U.S., which vary widely across the compassionate release process. Specific policy recommendations are made to assure the timely access and utilization of compassionate release among eligible incarcerated individuals. Abstract: http://bit.ly/2YBBjwE

Extraordinary and compelling: The use of compassionate release laws in the U.S.

PSYCHOLOGY, PUBLIC POLICY & LAW, 2018;24(2):216-234. In 1984, federal compassionate release laws were established, allowing for the release of inmates given "extraordinary and compelling circumstances" not present at sentencing. Many states established similar laws. Despite possible financial and ethical benefits of compassionate release, few inmates have been released under these laws. In Study 1, the authors provided a compendium of relevant laws, including information on jurisdictions with such laws, criteria for release outlined in each law, and exceptions that may preclude release. Results demonstrated that as of 2016, 46 jurisdictions had a compassionate release law in place. The most frequently cited criterion for release was having a chronic illness. In Study 2, to assess the possibility that public sentiment presents obstacles to using these statutes, the authors probed members of the public and prison wardens on perceptions of the laws, including factors (i.e., criminal history and offense type) associated with willingness to recommend release of a chronically ill inmate. Abstract: http://bit.ly/2VLY7wt

2017

Compassionate release policy reform: Physicians as advocates for human dignity

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2017;19(9):854-861. Compassionate release policies are designed in recognition of the fact that an appropriate level of care for patients with severe or debilitating illnesses is difficult, and sometimes impossible, to achieve in the correctional setting. For instance, the community standard for end-of-life care is to offer patients hospice; however, prison hospices are available only at 69 of 1,719 state correctional facilities, and they often require patients to move farther away from family or friends at a time when maintaining social connections is a core component of quality care. Prison hospice programs are costly, straining state allocations for correctional health services, which cannot be billed to Medicare and Medicaid. Cost and logistical limitations make it very difficult to provide standard-of-care hospice care in prisons, threatening the dignity of the seriously ill and offering a strong rationale for compassionate release policies. Full text: http://bit.ly/2JNftSH

N.B. The focus of this issue of the American Medical Association publication is incarceration and correctional healthcare. Journal contents page: http://bit.ly/2wbx3aJ

Psychiatry and the dying prisoner

INTERNATIONAL REVIEW OF PSYCHIATRY, 2017;29(1):45-50. Due to the growing number of ageing prisoners in the American correctional system, penal institutions are increasingly caring for patients with chronic and potentially terminal medical conditions. To address this problem states have attempted sentencing reform initiatives and adopted compassionate release programmes; however, these efforts have failed to significantly reduce the number of elderly or seriously ill inmates. Correctional mental health services are now called upon to aid in the care of prisoners at the end of life. This article presents the common elements of prison hospice programmes and the role psychiatry plays in this multidisciplinary effort. Abstract (inc. link to references): http://bit.ly/2JqQ164

Caring to learn and learning to care: Inmate hospice volunteers and the delivery of prison end-of-life care

JOURNAL OF CORRECTIONAL HEALTH CARE, 2017;23(1):43-55. The increasing numbers of aging and chronically ill prisoners incarcerated in Western nations is well-documented, as is the growing need for prison-based palliative and end-of-life (EoL) care. Less often discussed is specifically how EoL care can and should be provided, by whom, and with what resources. One strategy incorporates prisoner volunteers into EoL services within a peer-care program. This article reports on one such program based on focused ethnographic study including in-depth interviews with inmate hospice volunteers, nursing staff, and corrections officers working in the hospice program. The authors Page | 13 describe how inmate volunteers learn hospice care through formal education and training, supervised practice, guidance from more experienced inmates, and support from correctional staff. They discuss how emergent values of mentorship and stewardship are seen by volunteers and staff as integral to prison hospice sustainability and discuss implications of this volunteer-centric model for response-ability for the EoL care of prisoners. Full text: http://bit.lv/30svPT0

Enhancing care of aged and dying prisoners: Is e-learning a feasible approach?

JOURNAL OF FORENSIC NURSING, 2017;13(4):178-185. Prisons and jails are facing sharply increased demands in caring for aged and dying inmates. The authors' 'Toolkit for Enhancing End-of-life Care in Prisons' effectively addressed end-of-life care (EoLC) care; however, geriatric content was limited, and the product was not formatted for broad dissemination. Prior research adapted best practices in EoLC and aging; but, delivery methods lacked emerging technology-focused learning and interactivity. An environmental scan was conducted with 11 participants from U.S. prisons and jails to ensure proper fit, in terms of content and technology capacity, between an envisioned computer-based training product and correctional settings. Abstract: http://bit.ly/2LTvRDT

2016

Essential elements of an effective prison hospice program

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2016;33(4):390-402. More prisons across the U.S. must address the need for end-of-life care (EoLC). This case study presents one long-running model of care, the Louisiana State Penitentiary Prison Hospice Program. The authors identify five essential elements that have contributed to the long-term operation of this program: 1) Patient-centered care; 2) An inmate volunteer model; 3) Safety and security; 4) Shared values; and, 5) Teamwork. The authors describe key characteristics of each of these elements, discuss how they align with earlier recommendations and research, and show how their integration supports a sustained model of prison EoLC. Abstract: http://bit.ly/2HA71n1

End-of-life care behind bars: A systematic review

AMERICAN JOURNAL OF NURSING, 2016;116(3):24-36. Nineteen articles, all published between 2002 and 2014, met the inclusion criteria. Of these, 53% were published between 2009 and 2014, and 58% reported findings from qualitative research. One article reported on research conducted in the U.K.; the remaining 18 reported on research conducted in the U.S. Capacity (that is, the number of prisoners requiring end-of-life (EoL) care and the ability of the prison to accommodate them) and the site of EoLC delivery varied across studies, as did the criteria for admission to EoL or hospice services. Care was provided by prison healthcare staff, which variously included numerous professional disciplines, corrections officers, and inmate caregivers. The inmate caregivers, in particular, provided a wide array of services and were viewed positively by both EoL patients and healthcare staff. Inmates providing EoL care viewed caregiving as a transformational experience. Full text: http://bit.ly/2HA7tld

What dying looks like in America's prisons

THE ATLANTIC - 16 February 2016 - Mohawk had once been a residential home for the developmentally disabled. It occupied the southernmost corner of the 150-acre Mohawk-Oneida campus and was converted to a mediumsecurity prison in 1988. Today, it houses about 1,400 inmates, 112 of whom are inside the "skilled nursing facility." Walsh Regional Medical Unit, which takes in prisoners from the central and western parts of New York State. What the hospice program at Mohawk did was prevent patients from dying alone. Terminal patients, particularly those dying inside prison, need human contact, companionship, and a chance to talk about their lives, the nurses told me. The program also provided healthy prisoners who had good behavior records the chance to train as volunteers, to give back to their fellow inmates. Full text: http://bit.ly/2WKVmbn

More prisoners die of old age behind bars

KAISER HEALTH NEWS - 15 December 2016 - As the number of older prisoners soars, more inmates are dying in prison of diseases that afflict the elderly. 1 3,483 inmates died in state prisons and 444 in federal prisons in 2014, the highest numbers on record since the bureau started counting in 2001. In addition, 1,053 inmates died in local jails, where suicide is on the rise. The U.S. has the world's largest prison population, with over 2 million people behind bars. While that population has been shrinking in recent years, deaths in custody have climbed steadily. The deaths reflect a dramatic shift in the prison population: The number of federal and state prisoners age 55 or older reached Page | 14 over 151,000 in 2014, a growth of 250% since 1999. Full text: http://bit.ly/2LTILSd

'Mortality in State Prisons, 2001-2014: Statistical Tables,' Bureau of Justice Statistics, U.S. Department of Justice, December 2016. Download/view report at: http://bit.ly/2Ed73Ab

Analysis of U.S. compassionate and geriatric release laws: Applying a human rights framework to global prison health

JOURNAL OF HUMAN RIGHTS & SOCIAL WORK, 2016;1(4):165-174. A content analysis of 47 identified federal and state laws was conducted using inductive and deductive analysis strategies. Of the possible 52 federal and state corrections systems (50 states. Washington DC, and Federal Corrections), 47 laws for incarcerated people, or their families, to petition for early release based on advanced age or health were found. Six major categories of these laws were identified: 1) Physical/mental health; 2) Age; 3) Pathway to release decision; 4) Post-release support; 5) Nature of the crime (personal and criminal justice history); and, 6) Stage of review. Eighteen of the laws noted that the medical hospital or hospice, or family home with healthcare professionals, must be vetted prior to release to ensure both safety and proper healthcare. In addition, 11 of the laws mentioned that the incarcerated person must have financial resources to cover healthcare, such as Medicaid, in place prior to early release. Full text: http://bit.ly/2Ekpl2O

National survey of prison healthcare: Selected findings

NATIONAL HEALTH STATISTICS REPORTS, No. 96 (p.6) - 28 July 2016 - Hospice care followed a pattern similar to that of long-term or nursing home care, with 35 participating states providing hospice care exclusively on-site. Of these. 12 had either a specific hospice program or reserved beds for hospice care in at least one facility, and 6 of the 12 states jointly provided hospice care and long-term care in shared units or beds. The other 23 states providing hospice care on-site did not provide any qualifying information. Respondents from 9 states reported hospice care was provided both on-site and off-site, though most stated that off-site care was rarely used. Two of the 9 states sent all or most female prisoners off-site for long-term or hospice care to ensure the safety of female prisoners who would otherwise be cared for in areas with mostly male prisoners. Full text: http://bit.ly/2Vu9leR

End-of-Life Care in the Prison Environment in the U.S.A. (State-by-State)

California

REUTERS - 19 June 2018 - 'Inside the prison hospice where no inmate dies alone.' One of Fernando Murillo's greatest fears is dying in prison. The 38-year-old former gang member, serving a sentence of 41 years to life for second-degree murder when he was 16, says it is that fear which helps him empathize with the terminally ill inmates he looks after at a California prison hospice. Murillo's work in the 17-bed hospice unit at the medium-security California Medical Facility in Vacaville, about 55 miles (88.51 km) northeast of San Francisco, includes helping dying prisoners take a shower or go to the bathroom. But there is another, more important element to the job, he says. "I listen to people's regrets, their stories, their happiness, their joy. I listen to their confessions," Murillo says. "I befriend somebody when they're perfectly healthy, walking around, I'll take care of them when they're unable to talk and eventually hold their hands when they're taking their last breaths." https://reut.rs/2LUZuVg

THE NEW YORK TIMES - 16 May 2018 - 'Where both patients and caregivers are prisoners.' The hospice at the California Medical Facility is one of the nation's first and the only licensed hospice unit inside a California prison. Built in 1993 in response to the AIDS crisis and inmate-led demands for more humane care, the hospice was originally populated with young men dying of complications of the disease. Today, the 17-bed unit is filled with a different demographic: graying men with everything from end-stage cancer to Alzheimer's shuffle around with walkers, sit in wheelchairs watching television or lie curled up under heavy blankets. Prisoners older than 55 serving time in federal and state prisons make up the fastest-growing age group behind bars, increasing more than 500% since the 1990s, from 26,300 aging inmates in 1993 to 164,800 at the end of 2016. https://nyti.ms/2Jrs3rg

Connecticut

NATIONAL PUBLIC RADIO (Hartford) - 8 May 2017 - 'From primary care to hospice: Treating aging inmates and ex-offenders.' Connecticut's prison population is getting older, upping the demand for healthcare, including hospice programs that serve inmates and ex-offenders. [In this episode of 'Where We Live'], we find out what it means to die with dignity behind bars. We hear about a hospice program for prisoners at Osborn Correctional Institution in Somers, Connecticut, and the younger inmates who care for the dying. We look to Louisiana to find out how that state cares for its aging population. And we hear about a nursing home in Rocky Hill, Connecticut, that is getting attention Page | 15 beyond state lines. http://bit.ly/2VLOq15

THE HARTFORD COURANT - 26 April 2017 - "Model" nursing home for paroled inmates to get federal funds." 60 West is the first correctional facility in the country to win approval from the Centers for Medicare & Medicaid Services for federal nursing home funding - a designation that has national significance ... because it's a new option for cash-strapped states looking for ways to care for growing populations of older and sicker inmates. Ailing inmates who qualify for nursing home-level care and who the state deems are not public safety risks are referred to 60 West. Medicaid covers half the cost of their care, which will save the state about \$5 million annually. http://bit.ly/2EhZRD5

Georgia

THE ATLANTA JOURNAL-CONSTITUTION - 19 December 2016 - 'Nursing home for prison inmates to get federal funds.' A former prison doctor has opened a nursing home that will take up to 280 elderly and infirm inmates who otherwise might not have a place to go when they're paroled. "Even for a person who has no health issues, finding appropriate housing when on parole can be very, very complicated," said Sara Totonchi, executive director of the Southern Center for Human Rights. "When you add in health issues or mobility issues or other challenges it can be nearly impossible to find." The Bostick Nursing Center in Milledgeville, on the site of a demolished prison, is the first in Georgia that was conceived specifically for parolees. It will begin accepting parolee-residents early next year. There were already three nursing homes in South Georgia that accepted parolees, but catered to the general public... http://bit.lv/2EhZRD5

Guantánamo Bay Naval Base (Cuba)

THE NEW YORK TIMES - 27 April 2019 - 'Guantánamo Bay as nursing home: Military envisions hospice care as terrorism suspects age.' Nobody has a dementia diagnosis yet, but the first hip and knee replacements are on the horizon. So are wheelchair ramps, sleep apnea breathing masks, grab bars on cell walls and, perhaps, dialysis. Hospice care is on the agenda. More than 17 years after choosing the American military base in Cuba as "the least worst place" to incarcerate prisoners from the battlefield in Afghanistan, after years of impassioned debates over the rights of the detainees and whether the prison could close, the Pentagon is now planning for terrorism suspects still held in the facility to grow old and die at Guan-tánamo Bay. With the Obama administration's effort to close the prison having been blocked by Congress and the Trump administration committed to keeping it open, and with military trials inching ahead at a glacial pace, commanders were told last year to draw up plans to keep the detention center going for another 25 years, through 2043. At that point, the oldest prisoner, if he lives that long, would be 96. https://nyti.ms/2W8T2KT

Illinois

THE SOUTHERN ILLINOISAN (Carbondale) - 26 May 2019 - "We carry a light": Inmates at Shawnee Correctional Center care for the prison's dying.' Karen Smoot ... has worked for the Illinois Department of Corrections since 2016, and said hospice or end-of-life care (EoLC) is different for prisoners. They are not in their homes, in their own beds, and oftentimes are not surrounded by loved ones. But still, Smoot sees it as her job to comfort them. "We're tasked with taking care of him and providing for him the appropriate and humane EoLC." she said. Another thing that separates hospice care at Shawnee is the team of caretakers Smoot has assembled. The seven men that stood next to Ernest Cornes and have cared for his most intimate needs in the weeks he's been in the infirmary were not nurses. They are inmates. Smoot said a 2017 directive came from the state that prisons in the Illinois Department of Corrections needed to implement some form of EoLC, and she decided to go a bit further. She created the Shawnee Hospice/Adult Comfort Care Program, which trains select inmates in the type of therapeutic, non-medical care given to people who are nearing death. Smoot said that many who come to prison and through her program are not used to thinking beyond themselves - for some, that was a means of survival before they were incarcerated. The hospice program is a way, she said, for them to learn how to think about others. http://bit.ly/2VSGLt0

Louisiana

THE JOHN A. HARTFORD FOUNDATION - 3 August 2018 - 'As America's incarcerated age, the need for hospice rises.' At the Louisiana State Penitentiary prison known as Angola, over 80% of the 6,500 inmates are serving life sentences and can expect to die behind bars. Of those who eventually receive terminal medical diagnoses, many voluntarily choose to enter Angola's innovative hospice program in lieu of pursuing medical care. Hospice care programs like the one at Angola have opened across the country in prison facilities desperate for ways to meet the needs of their increasingly aging incarcerated populations. As this demographic trend continues, some proponents of Page | 16 humane end-of-life care in prisons are advocating for even more wardens to implement hospice programs, while others work to increase the number of "compassionate releases" granted to inmates. http://bit.ly/2JPkp9M

PSYCHOLOGY TODAY - 8 March 2017 - 'Prisoners working with the dying.' Angola State Prison in Louisiana is home to approximately 5,000 men. Their crimes range from murder, rape, armed robbery to drug offenses. It is described as the largest and most notorious prison in the country. It has the highest percentage of prisoners in the U.S. serving life sentences and it is estimated that 85% of these prisoners will die there. In the past, dying at the prison meant that you were left alone in a room, without medication, just waiting for death to come. After death, the body was put in a cardboard box for burial. In 1998, Warden Burl Cain changed the face of death in the prison by introducing hospice. The entire death and burial experience was transformed. Full text: http://bit.ly/2LV1UmO

Maine

THE BANGOR DAILY NEWS - 8 February 2020 - 'An inmate serving 50 years for attempted murder is an unlikely caretaker for dying prisoners.' Prison might be the worst place you can think of to die. Isolated from the outside world, perishing behind concrete walls and metal locking doors because death caught up with you while you were serving a sentence. That is the reality for inmates housed in Maine State Prison's infirmary because they are suffering from a terminal illness and are not expected to live longer than six months. But a group of inmates has made it their mission to make sure no prisoner dies alone. The prison began offering hospice services when its new facility opened in 2001 through a partnership with the Maine Hospice Council. In 2008, the council began training inmates to provide end-of-life care to their fellow inmates. Over the past decade, this group of incarcerated hospice volunteers has worked hand-in-hand with prison medical staff to provide comfort care to terminal inmates. http://bit.ly/39nBHUD

Missouri

THE MISSOURIAN (Columbia) - 24 June 2017 - 'Solutions remain elusive as elderly prisoners grow in number.' In Missouri, the number of people age 50 and older who are in prison is increasing at 11 times the rate of the prison population overall. Prisoner advocates, prosecutors and state agencies have differing ideas of how to address the increase and its impact on the prison system. No comprehensive state-wide policy exists. In short, there is no consensus on how long it makes sense to keep geriatric prisoners behind bars. The oldest currently incarcerated person in Missouri is 92-years-old... Missouri's 50-and-older prison population has nearly doubled since 2005, compared to a less-than-10% increase in the total prison population during the same time. http://bit.ly/2LSFoem

KBIA RADIO (Columbia) - 10 January 2018 - 'Missouri offenders help their peers come to terms with death.' Offenders in some Missouri prisons are breaking down walls – emotional walls. They're demolishing the barriers they've spent years building while inside a prison cell. But it's only at the end of their sentence, the end of their life, that those walls finally crumble. And they crumble with a fellow inmate by their side. It's all part of the Missouri Department of Corrections (MODC) Hospice Program ... where offenders are trained to provide end-of-life care for their peers. Deloise Williams, assistant division director of medical services at MODOC, said Missouri prisons have anywhere between eight to 10 hospice patients each month. http://bit.ly/2M6CPWi

Nevada

THIS IS RENO - 25 August 2018 - 'Nevada's first prison hospice opens.' The Northern Nevada Correctional Center opened the first of its kind dorm-style hospice unit in the Nevada prison system to serve inmates with severe lifeending illnesses. Today, there are approximately 100 prisons across the country that acknowledge the unique longterm physical, psychological, and spiritual needs of aging inmates. Hospice programs are a part of the solution to tackle the heavy financial burden and growing medical needs of what is reported to be the fastest growing incarcerated population: those age 55 and older. Approximately 10% of inmates serve life sentences and another 11% are sentenced to serve 20 years or more. Longer and stricter sentencing lengths to help enforce public safety is one contributing factor. However, the reality is that a majority of the aging population are first-time, violent offenders who will be facing longer sentences. Inmates age two to three times faster while in prison, and an aging body with limited access to preventative healthcare creates its own set of challenges. http://bit.ly/2LV2Es6

Ohio

THE BLADE (Toledo) – 17 April 2016 – 'Hospice program gives prisoners a chance to die, and live, with dignity.' Roughly 120 people a year die in Ohio prisons. Dozens or even hundreds more are medically incapacitated, including paraplegics, quadriplegics, and those suffering from Alzheimer's disease and dementia. They pose no risk to society, but cost the state millions of dollars a year in medical expenses that Medicare, Medicaid, or private insurance would cover if they were released. Still, nearly all of them will remain in prison. Ohio has no timely and expedient way to release dying and medically incapacitated inmates. http://bit.ly/2EfL7ok

Page | 17

Pennsylvania

THE INQUIRER (Philadelphia) – 27 September 2017 – 'More people than ever are dying in prison. Their caregivers? Other inmates.' "The death squad." Or, "the executioners." That's what many inmates used to call the inmate-volunteers who work the Graterford state prison hospice unit, a bleak row of isolation rooms – each one-part hospital room, one-part jail cell —where inmates with terminal illnesses are placed to die. Then, they saw how the inmates cared for dying men in shifts, undertaking the intimate tasks of feeding, cleaning and comforting them. For many, it is a calling. Over time, attitudes changed, said James, a 51-year-old inmate who volunteers to do this work. "There's a lot of progress in this place. There is more humanity here now." It's needed, given that far more people are dying in prison than ever before. In Pennsylvania, 483 state inmates have died since January 2015. That's about 180 deaths in prison each year. From 2005 to 2014, the average was 150 deaths per year. http://bit.ly/2Efl_dwc

Virginia

THE DAILY PROGRESS (Charlottesville) – 7 July 2019 – 'First compassionate care program in state offers inmates chance to care.' In April, Melanie Mason, a social worker for the Hospice of the Piedmont, received a call from the Fluvanna prison, notifying her that a new inmate had previously received hospice care at a different facility and had requested hospice care at Fluvanna. The Hospice of the Piedmont provides end-of-life care and services to people within a geographic region, services that are often reimbursed by Medicare, Medicaid and insurance plans. Mason's coverage area includes Fluvanna County, so she began coordinating care efforts. The prison didn't have trained medical staff who were available to sit by the woman's bed 24/7, so Mason, hospice nurse Ruth Hurley and prison nurse manager Mikayla Osborne suggested asking other inmates to volunteer. "This was a patient who didn't have a strong family background and unfortunately had to do this process [of dying] by herself," Osborne said... "When Melanie brought up giving compassionate care to the patient, it was an epiphany, and we rolled with it." With Aldridge's approval, they asked the prison's honor wing – a set of women who have a history of good behavior – if they wanted to participate, and inmates started "coming out of the woodwork," Mason said. http://bit.ly/2JGvNTJ

Washington State

THE DAILY HERALD (Snohomish) – 17 December 2019 – 'Breakdown in Monroe prison left man to die of cancer.' Seven months after a nurse found a lump in his chest, an inmate at the Monroe prison wrote a note to the only people who could help him. "I do not have long to live according to an outside specialist who is the fourth leading cancer doctor in the world," the man wrote in fall 2018. "He told me I need to start chemo aggressively right away or would not live nine months. This was 2 months ago. What is taking so long?" The man died in June 2019. For more than a year, he'd received no real treatment for his cancer, according to findings released ... by the state Office of the Corrections Ombudsman. The man was due for release six months after the date of his eventual death, with time off for good behavior. His passing has led to reforms in how medical issues are handled and documented at the Monroe Correctional Complex. http://bit.ly/2tol2AF

Wisconsin

THE MILWAUKEE JOURNAL SENTINEL – 18 April 2018 – 'Release programs for sick and elderly prisoners could save millions. But states rarely use them.' Around the country, early release provisions for elderly and infirm prisoners are billed as a way to address problems such as prison overcrowding, skyrocketing budgets and civil rights lawsuits alleging inadequate medical care. But throughout the U.S., they are used so infrequently that they aren't having much impact. Of the 47 states with processes to free such prisoners early or court rulings requiring them to do so, just three ... released more than a dozen people in 2015, according to a *Journal Sentinel* survey. The reasons for the low numbers, according to experts, are usually found in the statutes that created the programs, known as compassionate release, geriatric release and medical parole, among other things. https://bit.ly/2HGcx7w

End-of-life care in the Prison Environment in Australia

Caring for the terminally ill in prison

PURSUIT (University of Melbourne) - 14 July 2020 - With an increasing and, age- Added Since 06,15,2020 Update ing population, there are now more people who are likely to face their end of life

(EoL) in prison. Of those prisoners who die in Victoria, approximately 38% will spend their final weeks or months of life in a secure, guarded public hospital ward. The authors' research uncovered the opportunities perceived by health Page | 18 professionals to improve the models of care for prisoners dying with progressive and life-limiting illnesses. They explored the perspectives of public hospital-employed doctors, nurses and allied health staff from a range of disciplines about their experiences of providing care for dying prisoners in the public hospital setting. Health professionals described the unique constraints and obstacles faced by people in prison across a range of areas of care, and for themselves, as they strove to provide optimal EoL care for prisoners. Health professionals identified the opportunities for improved clarity of protocols around some of the processes for dying prisoners - such as allowances to remove shackles when providing care, as well as considerations for healthcare professionals in advocating for compassionate release. https://bit.ly/3eqeVh9

'Complexities and constraints in end-of-life care for hospitalised prisoner patients,' Journal of Pain & Symptom Management, published online 24 May 2020. Abstract (w. link to references): https://bit.ly/2ZBnOk3

Complexities and constraints in end-of-life care for hospitalised prisoner patients

JOURNAL OF PAIN & SYMPTOM MANAGEMENT - 24 May 2020 - Managing the care of an increasing and ageing prisoner population, including providing palliative and end-of-life (EoL) care, is a challenge worldwide. There is little known about the views of health professionals who provide palliative care (PC) to hospitalised prisoner patients. A qualitative study was undertaken involving semi-structured focus groups and interviews with 54 medical, nursing and allied health staff engaged in the care of hospitalised prisoner patients. Purposive sampling from a metropolitan teaching hospital responsible for providing secondary and tertiary healthcare for prisoners in Victoria, Australia, for 40-years was utilised to identify and seek perspectives of staff from a variety of clinical disciplines. Participants in this study described significant constraints in how they provide PC to hospitalised prisoners. Key themes emerged describing constraints on: prisoner health decisions; provision and place of care; patient advocacy; and, how care is delivered in the last days of life. Participants highlighted a deep philosophical tension between prison constraints and the foundational principles of PC. Clarity of correctional services processes, protocols, and aspects of security and related training for health professionals is needed to ensure improved care for prisoners with progressive and lifelimiting illness. Abstract (w. link to references): https://bit.ly/2ZBnOk3

Systematic review of aged care interventions for older prisoners

AUSTRALASIAN JOURNAL OF AGEING, 2018;37(1):34-42. This review found no significant effects of aged care interventions in prisons. However, qualitative findings showed aged care interventions to have a beneficial impact on older prisoners when the intervention targeted the specific health and well-being needs of this population, while simultaneously addressing barriers to participation and facilitating engagement among older prisoners. Recommendations arising from this review include targeting aged care interventions in prisons to the unique physical health, mental health, social care and spiritual needs of older prisoners. The review also showed that prison-based interventions should specifically aim to address the isolation and anxiety of older prisoners to ensure engagement with a program. The review findings also centre recommendations on addressing certain barriers to aged care in the prison environment. Importantly, relationships between older prisoners and prison staff need to be cultivated to establish trust and mutual goal setting. Full text: http://bit.ly/2W3DHyH

Exploring barriers to and enablers of adequate healthcare for indigenous Australian prisoners with cancer: A scoping review drawing on evidence from Australia, Canada and the U.S.

HEALTH & JUSTICE, 2016;4(1). Prisoners are a group with complex needs and high levels of social disadvantage and exclusion. Indigenous Australians are overrepresented in the prison system and experience higher rates of cancer mortality. This review found a very small evidence base and no studies from Australia. Therefore a strong conclusion to be drawn from the limited data is that further rigorous, empirical research is needed to better elucidate how the barriers to adequate cancer care for prisoners may be identified and overcome, in Australia and internationally. In particular, the experiences of Indigenous prisoners with cancer are largely invisible in the research literature. The main themes identified here offer potential starting points for future research and policy development to better align access and service use with best practice for cancer care in Australia. Full text: http://bit.ly/2EgFDtf

Report shows shortcomings in aged prison care

SBS WORLD NEWS RADIO (Sydney, New South Wales) – 2 November 2016 – A new report has found Australian prisons are failing to meet the needs of elderly prisoners. And a Salvation Army study – 'Old behind bars: What is being done for the incarcerated?' – has found elderly prisoners make up the fastest-growing prison population. At what age is a prisoner classified as aged? The latest research suggests it is just 50-years-old, or, for the Indigenous prison population, even younger, at just 45. http://bit.ly/2HF2wr9

Page | 19

End-of-life Care in the Prison Environment in Canada

End-of-life care for federally incarcerated individuals in Canada

MCGILL JOURNAL OF LAW & HEALTH, 2020;14(1):1-50. The authors review the current legislation, policies, and practices related to end- of-life care (EoLC) for federally incarcerated individuals as set out in statutes, guidelines, and government reports and documents that were either publicly available or obtained through Access to Information requests from the Parole Board of Canada and Correctional Service of Canada (CSC). Based on this review, they describe the *status quo*, identify gaps, and offer reflections and raise concerns regarding EoLC for federally incarcerated individuals. The authors conclude that there are significant information gaps about the number of people seeking EoLC and about how CSC is managing the provision of such care. The sparse information available is nonetheless sufficient to support the conclusion that there are good reasons to be concerned about EoLC is regulated, monitored, recorded, and provided. Significant reforms are needed. Full text (click on pdf icon): https://bit.ly/3cQVH4t

As the prison population ages, parolees with age-related illnesses struggle to find support

THE TORONTO STAR – 3 February 2020 – Cliff Strong just spent two weeks in the hospital with his latest bout of pneumonia. He has a litany of illnesses now, at 78, including the Parkinson's disease that requires him to use an electric wheelchair to get around. Strong is also on day parole for second-degree murder, living at a halfway house in Peterborough that is specifically designed to provide supportive and palliative care to former inmates on parole. It's the kind of place you wouldn't hear about until you – or someone you care about – needed it. Resources for elderly parolees is one part of a new guidebook released by the Provincial Human Services & Justice Coordinating Committee that provides a crash course in navigating the criminal justice system for people with age-related illnesses and their caregivers. "There really isn't a lot of information out there for family members or caregivers of people that are caught up in the justice system, or are getting out. What supports or resources are available in the community on their release?" said Jeff Morgan, a case manager at Haley House, the halfway house where Strong has lived for the past four years. There is a growing number of inmates over the age of 50 in the prison system – now 25% of the population, according to a 2019 report from the Office of the Correctional Investigator. http://bit.ly/2ttKplc

- 1. 'Older Adults and the Justice System: A navigational guidebook for caregivers and service providers,' the Provincial Human Services & Justice Coordinating Committee, February 2020. **Download/view at:** http://bit.ly/3927nim
- 'Aging and Dying in Prison: An Investigation into the Experiences of Older Individuals in Federal Custody,' Correctional Investigator of Canada & Canadian Human Rights Commission, 28 February 2019. Download/view at: http://bit.ly/2GP4aZr

Assisted dying for prison populations...

MEDICAL LAW INTERNATIONAL – 20 August 2019 – Canadian federal legislation setting out the framework for medical assistance in dying (MAiD) in Canada came into effect in June 2016. Because of section 86(1) of the Corrections & Conditional Release Act, as soon as MAiD became available in the community, it also needed to be made available to federal prisoners. There are some good reasons to be concerned about MAiD in the Canadian corrections system based on logistical, legal, and moral considerations. Fortunately, Canada is not the first country to decriminalize assisted dying and so Canadian policies and practices can be compared to others and take some lessons from their experiences. Thus, by reviewing the legal status of assisted dying in prisons internationally, the regulation of assisted dying, demand for assisted dying from prisoners, and the process for prisoners accessing assisted dying, this article offers a comparative overview of assisted dying for prisoners around the world in an effort to inform Canadian and other jurisdictions' law, policy, and practice. Abstract: http://bit.ly/2ZENp8m

Aging and Dying in Prison: An Investigation into the Experiences of Older Individuals in Federal Custody

CORRECTIONAL INVESTIGATOR OF CANADA & COMMISSIONER OF THE CANADIAN HUMAN RIGHTS COM-MISSION - 28 February 2019 - Some older, long-serving federally sentenced offenders are being warehoused behind bars well past their parole eligibility dates. There is no legal or policy recognition that older individuals represent a vulnerable population in prison or that they have unique characteristics, needs and rights which must be respected and met. As a result, their health, safety, dignity and human rights are not adequately protected. Federal penitentiaries were never intended or physically designed to accommodate an aging inmate population. The physical infra- Page | 20 structure of institutions does not adequately meet the needs of older individuals in federal custody. Correctional healthcare costs are rising as the number of aging individuals in federal custody with chronic disease increases. Offenders with terminal illness and those requiring palliative care are living out their single greatest and expressed fear - dying in prison. Prison is no place for a person who requires end-of-life care. Federal corrections lack adequate, compassionate and responsive release options for older individuals in federal custody who do not pose an undue risk to public safety. **Download/view at:** http://bit.ly/2TmgIND

Federal correctional investigator: Needs of aging prisoners not being met

THE OTTAWA CITIZEN - 22 June 2018 - Some halfway houses should be converted to hospices and nursing homes to accommodate growing numbers of federal inmates developing dementia and dying in prison, says federal correctional investigator Ivan Zinger. The Office of the Correctional Investigator, along with the Canadian Human Rights Commission, are jointly investigating what they say is "systemic discrimination" against aging, elderly offenders (50 and older). After years of calling for a policy on older offenders, Zinger said the joint investigation was launched partly in response to the case of an inmate with dementia who, after being in a halfway house for nine years without incident, was sent back to prison, where he died. Zinger said older offenders who are dying or have serious, complex medical issues and no longer pose a threat should be placed in the community. Providing palliative care in the community would be a lot cheaper than the \$115,000 annual cost of maintaining a federal prisoner, he noted. http://bit.ly/30rVi2x

Even behind bars, aging prisoners deserve proper healthcare

THE GLOBE & MAIL - 2 October 2017 - According to the Office of The Correctional Investigator, which serves as an ombudsman for inmates, nearly 25% of people (3,500 prisoners) incarcerated in federal penitentiaries are 50 or older, a number that has doubled in the past decade. More than one-third of them are serving long sentences – usually a minimum of 25 years - and rarely get parole. Most of them die of cancer, heart disease or liver failure, accounting for 366 of 542 prison deaths in the 10-year period between 2007 and 2017. There is a compassionate parole provision for terminally ill inmates, Section 121 of the Corrections & Conditional Release Act, but very few are granted - about four or five a year, according to the ombudsman's office, with most prisoners dying before the parole board reaches a decision. Why should we care if an inmate old enough to be somebody's grandparent dies in a cell without adequate medical treatment, access to appropriate palliative care or medical assistance in dying? I think there are three reasons: compassion, equality and autonomy. In a [recent] panel discussion, Crystal Dieleman of Dalhousie's School of Occupational Therapy pointed out that although prisoners are deprived of liberty while they are incarcerated, the rest of their human rights remain intact. Forget vengeance, they are entitled to the same access to healthcare as the rest of us, especially because our universal system is based on medical need, not social status. https://tgam.ca/2VJSnne

End-of-life Care in the Prison Environment in China

Behind bars, hospital care is blind to crime

CHINA | Shanghai Daily - 24 November 2019 - Doctors working at a unique hospital in Shanghai can rarely hope that a patient who is successfully treated will walk out into the sunshine. Their domain is Shanghai Prison General Hospital, the only one of its kind in the city prison system. Besides ordinary departments, the 450-bed hospital has specialized sections for prisoners suffering from AIDS, tuberculosis, drug addiction and mental diseases. Many young doctors who work in the hospital initially regard the patients as beasts shut in cages, but that impression fades as time passes and they treat what is certainly an unusual population of people suffering from poor health. Inmates with treatable maladies remain in the prison hospital. http://bit.ly/34iw9bU

End-of-life Care in the Prison Environment in France

The collision of inmate and patient: End-of-life issues in French prisons

JOURNAL OF CORRECTIONAL HEALTH CARE, 2017;23(1):66-75. This article highlights the realities regarding inmates at the end of life (EoL), putting into perspective the viewpoints of the sick prisoners with those of the health and correctional professionals accompanying them. The challenge is to identify potential barriers to palliative care (PC) for inmates in order to consider possible improvements. The study results reveal that inmates at the EoL were Page | 21 not fully considered as patients and did not benefit from a comprehensive PC approach. For most dying inmates, and according to many health professionals, compassionate release on medical grounds remains the best approach to deal with EoL issues. Abstract (inc. list of references): http://bit.ly/2WjjXY1

Prevalence and characteristics of prisoners requiring end-of-life care: A prospective national survey

PALLIATIVE MEDICINE, 2018;32(1):6-16. Overall, France has been reluctant to promote palliative care (PC) units in the prison sector, probably because terminally ill prisoners are supposed to be released, given that the law provides for this option. Prison palliative and hospice care units have been created in the U.S. and the U.K., and many promising practices have already been proposed, such as the use of peer volunteers, multi-disciplinary teams, special health units inside the prison, staff training, and partnerships with community hospices. Nevertheless, figures are not easily available to plan for resources. This study contributes to providing important data regarding end-of-life care (EoLC) in prisons in France and could serve as an example for other countries, although the methodology would need to be adapted to the context and legislation in other countries. Knowledge of the profile of prisoners (medical, social, and jurisdictional) and the estimated prevalence of ill prisoners requiring PC could help define healthcare needs for dying prisoners in agreement with humanitarian values and the Right to Health & Medical Care promulgated by the European Commission of Human Rights and the United Nations Bill of Human Rights. Abstract (w. list of references): http://bit.lv/2WcATPC

End-of-life care in the Prison Environment in Poland

Solidarity and compassion: Prisoners as hospice volunteers in Poland

ANNALS OF PALLIATIVE MEDICINE, 2018;7(Suppl 2):109-117. Over many years the project of hospice volunteering of prisoners in Poland has helped to break down stereotyping and the perceptions of prisoners, starting with the Gdansk experience, where they gradually became full members of a care team... Over 600 prisoners have passed through the hospice in Gdansk in over 10 years of cooperation. Convicts, who are mostly doing time on charges of burglary, non-payment of alimony and petty crime, see working in the hospice as a chance to change their attitudes. They see a different world, in which compassion and understanding for other people are most important. Some volunteer prisoners, after their release from a correctional facility, have been employed by the hospice in Gdansk. It is believed that such places as a hospice, where we undergo extreme experiences, can provide more radical answers to questions regarding our own attitudes. The initial data has showed that those who work in hospices receive better results in re-education and have the chance to receive a reduction of their sentence. Thanks to the correctional programs prisoners are currently working in over 40 hospices and more than 70 nursing homes. Full text: http://bit.lv/2Q9Wq64

The operations of the prison service towards the social inclusion of convicts: The cooperation with palliative care institutions

SOCIAL STUDIES: THEORY & PRACTICE, 2018;4(1):31-43. The author is a practitioner who has been working in the prison service [in Poland] for over 20 years. Among his professional experiences, a special place is occupied by those connected with the issue of hospice voluntary service of persons deprived of their liberty. He presents a bold idea carried out in Polish prisons, consisting of preparing and directing prisoners to help the terminally ill pass away in a dignified manner. The implementation of this program is very difficult and involves great responsibility. However, many years of experience-hospice staff, employees of prisons, members of patients' families and firstly, patientsconfirm that this is a very good direction for activating convicts who have an opportunity to experience their humanity on a daily basis. Hospice, contact with other people, contact with patients-all this transforms their thinking, behavior, allows it to verify the hierarchy of personal values. An added value is also the opportunity reintegrate people who are not related to penitentiary isolation into the community.

N.B. Polish language article. Scroll down journal contents page and click on article title to access full text at: http://bit.ly/2QfIVC4.

End-of-life care in the Prison Environment in Russia

Russian Justice Ministry proposes to set palliative care procedure for convicts

RUSSIAN LEGAL INFORMATION AGENCY (Moscow) - 13 August 2019 - The Justice Ministry of Russia has developed a draft order to organize the delivery of palliative healthcare services for detainees and inmates, a ministry statement reads. The penitentiary system medical organizations would provide palliative care (PC) to convicts and detained defendants when indicated. If the restrictive measure is changed, in particular for health reasons, but a per- Page | 22 son needs the continuation of treatment or PC, penitentiary doctors would give him or her a tertiary referral... http://bit.ly/2TrYmZn

End-of-life care in the Prison Environment in Switzerland

Dying in dignity behind bars

SWISSINFO (Bern) - 23 August 2019 - Swiss prisons were designed for 20-to-30-year-old offenders who are released after serving their sentences. However, the number of older inmates is steadily increasing. In 2017, there were 828 prisoners over the age of 50. Yet most prison facilities lack the necessary infrastructure to meet their needs. For some people, prison is not just a place to live, but also a place to die. "No one should have to die in prison against their will," says anthropologist Ueli Hostettler. The question of death is one that brings us all together in a way. Hostettler is a researcher at Bern University's Institute of Criminal Law & Criminology, and led the project 'End of life in prison: Legal context, institutions and actors." The study found Swiss prisons, designed for offenders between 20 and 30 years old, are not ready to meet the different needs of the growing group of over-50s. http://bit.ly/2TWuTXG

1. Prison Research Group, Institute for Penal Law & Criminology, University of Bern: http://bit.ly/33SPznX

End-of-life Care in the Prison Environment in the U.K.

Ageing prisoners

INSIDETIME - 8 November 2019 - As of December 2017, more than 13,500 people aged 50 plus were incarcerated, making up 16% of the entire prison population. That number has trebled in the past 20 years. By 2020, it's expected to rise to 15,000. The reason for this ageing population is a combination of tougher sentences and the rise in convictions of historic sex offences. The latter means that many are inside for the first time, and struggling with the physical disadvantages that accompany old age. What's considered "old age" in prison varies significantly from wider society. because any period of incarceration adds around ten years to the physical age of a prisoner. Prisons Inspector Peter Clarke warned the number of men over 50 being held in jails would rise to more than 14,000 by 2022, representing 17% of the prison population. "The Prison Service has so far said that it's not going to develop an overall strategy to deal with this issue," he said. "When prisoners get older, less capable physically or infirm, they don't provide an escape risk, they still have to be held in custody very often and it's not to say they wouldn't present a risk to the public if they were completely at liberty. But the question is do they need to be held still in levels of security which are not needed for their physical capabilities and which inevitably are very expensive as well?" The obstacles facing this generation of prisoners include: mobility, incontinence, menopause, isolation, dementia, bullying, poverty and difficulty adapting upon release. http://bit.ly/2JXRKOX

Ageing prison population "sees officers working as carers"

BBC NEWS (London) - 21 October 2019 - The ageing jail population has left prison officers providing care for a growing number of older inmates "dying in front of them," officers have said. The warning from the Prison Officers' Association (POA) has come as new figures revealed the oldest prisoner in England & Wales was 104 years old. The data showed there were 13.617 inmates aged above 50 out of a prison population of 82.710 in June 2019. The Prison Service said it was working to meet the needs of elderly prisoners. More and more inmates were frail, incontinent or had dementia, the POA said. https://bbc.in/2gBkg20

The ethics and practicalities of dealing with prisoners who are growing old and dying in custody

THE CONVERSATION - 4 October 2019 - In England & Wales, the number of prisoners aged over 60 is rising faster than any other age group, and government projections are that this trend will continue into the foreseeable future. HM Prison & Probation Service faces an increasing challenge to provide appropriate and safe custody for older prisoners. Research has shown high levels of frailty and vulnerability in the older prisoner population, including multiple complex health and social care needs, and challenges associated with having to take multiple medicines regularly. Many prisons are simply not suitable for old, frail people, and the equipment and resources needed to care for them Page | 23 are often not available. Prison staff with responsibility for older prisoners need adequate training and support, particularly when dealing with deaths in custody. Ageing and dying in prison poses important questions about ethics and justice. The United Nations General Assembly has endorsed a set of standard minimum rules for the treatment of prisoners, which includes rules governing healthcare. Rule 24 states: "Prisoners should enjoy the same standards of healthcare that are available in the community, and should have access to necessary healthcare services free of charge without discrimination on the grounds of their legal status." http://bit.ly/2OnGZZ3

How dying prisoners are treated at HMP Dartmoor

PLYMOUTH LIVE - 16 September 2019 - The healthcare team who provide dignified and compassionate end-of-life (EoL) care for prisoners at Her Majesty's Prisons Dartmoor have spoken about how they look after dying prisoners. Care UK's Health in Justice team recently won the top award in the EoL category in this year's Health Service Journal Patient Safety Awards. The awards are among the most prestigious in healthcare and recognise the hard work and dedication of teams across the country to patients' care and safety. Natasha Head, head of healthcare at the prison, said: "I was amazed when the judges called our name. It is an award that has been made possible by lots of committed and compassionate people. Specialist nurses come into the prison to review the care for prisoners nearing the end of their lives. These prisoners would usually have to be escorted to a hospital outside the prison or be transferred away from the prison, which would not only cost taxpayers thousands of pounds but would also reduce access to the right care - and add another layer of stress to their loved ones. Our own complex care lead nurse works with colleagues throughout the prison to make the necessary arrangements for a dying prisoner. For instance, a prisoner may need care at night, when most are locked up, or their diet may need to be changed as their health deteriorates. The new role means that there is a single point of contact for all such issues." http://bit.ly/2m2dslc

'Organisation in collaboration sets up a project to deliver compassionate care to patients in prison settings, delivering personalised care and enabling patients to spend their last days with dignity,' Health Service Journal, 2019. http://bit.lv/2kRu99d

Care homes with bars

INSIDE TIME - 28 July 2017 - The Prisons & Probation Ombudsman has just published a thematic review about older prisoners. As the number of older people in our prisons increases, both proportionately and in absolute terms, the number of deaths we see in prisons will inevitably follow suit. In the last decade, the number of naturally-caused deaths of prisoners over 50 has more than doubled. The substantial increase of older people dying in prison has meant that the Prison Service increasingly has to grapple with risks and procedures they were not previously forced to consider, when prisons in England & Wales were more likely to hold fit young men. The Care Act clarified that Local Authorities are responsible for assessing the care needs of older prisoners and providing support. This legislation, along with the national and international expectations that require prisoners to be able to access a level of care equal to that in the community, are significant and positive developments for health and social care in prisons. However, faced with an increase in the population of older prisoners and without a properly resourced and coordinated strategy for this group, prisons still face a number of challenges associated with ageing populations. http://bit.ly/2Efi04A

'Learning from Prisons & Probation Ombudsman Investigations,' Prisons & Probation Ombudsman, June 2017. Download/view report at: http://bit.ly/2Jte30q

"Old people's homes with walls" required for elderly prisoners, says watchdog

THE DAILY TELEGRAPH - 18 July 2017 - The Government should build "care homes with walls" to house a growing number of elderly prisoners, the chief prisons inspector has said. Speaking at the launch of his annual report, 1 Peter Clarke said that he had raised the idea with ministers in response to a rise in the number of older prisoners who struggle to cope with standard prison facilities. The number of over-70s in prison is predicted to increase from 1,400 in June of last year to 1,900 over the next three years. http://bit.ly/2Jte58y

Prisons taking role of care homes and hospices as older population soars

THE GUARDIAN (London) - 20 June 2017 - Prisons are now the largest providers of residential care for frail and elderly men in England & Wales and are increasingly turning into hospices, providing end-of-life care for older prisoners and even managing their deaths. The first report on older prisoners by the prisons and probation ombudsman¹ ... reveals that the number of prisoners over 60 has tripled in 15 years. There will be 14,000 prisoners aged over 50 by 2020, amounting to 17% of the total prison population, up from 13% in 2014. The situation is so serious ... the time has come to introduce purpose-built "old prisoner" jails; essentially, residential care homes surrounded by a wall. The Page | 24 prisons and probation ombudsman's report holds the government to account for abandoning prisons to cope alone with the seismic change in their population. Prison officers are inadequately training in the care of the elderly and often infirm inmates... http://bit.ly/2YwrKyM

'Thematic Review: Older Prisoners,' Prisons & Probation Ombudsman, 2017. Download/view report at: http://bit.ly/2YyMzK3

Prison healthcare "falling short" under National Health Service, as report warns of plummeting staff morale

THE HERALD (Glasgow, Scotland) - 24 November 2016 - Scotland's top nurse has warned that there is "little evidence" that health gap between prisoners and the general population has narrowed since the National Health Service (NHS) took over responsibility for inmates five years ago. Theresa Fyffe described the findings of the first major review into the transfer of prisoner care from the Scottish Prison Service to the NHS as "uncomfortable reading," adding that the ambitions behind the shake-up "have not been achieved." In a wide-ranging report ... the Royal College of Nursing Scotland highlights "significant concerns" over plummeting morale among prison nurses and failings in mental health and the management of long-term conditions such as dementia and cancer, which are becoming increasingly common with one in 10 prisoners now aged over 50. The number of prisoners aged over-50 have increased 50% in five years due to a trend towards longer sentences, people living longer and convictions for historic sex offences. Nearly half of these inmates have a long-term condition, such as cancer or dementia, but the report found that prison care is "falling short." http://bit.ly/2LTtlxd

1. 'Five Years On: Royal College of Nursing Scotland Review of the Transfer of Prison Health Care from the Scotlish Prison Service tom National Health Service Scotland,' Royal College of Nursing Scotland, November 2016. Download/view report at: http://bit.ly/2w8AuyZ

Improving palliative care for prisoners: The "both sides of the fence" study

PRISON SERVICE JOURNAL, 2016;224:42-47. The study is taking place in Her Majesty's Prison Wymott, a Category C prison with a high number of older prisoners, and is funded by the charity Marie Curie. The overall aim is to develop a model of palliative and end-of-life (P&EoL) care for prisoners that can be shared with other prisons to improve practice. The study uses action research methodology, in which the research participants (in this case, prison staff and prisoners) and the research team work together to make changes to practice. The research is designed in two main phases, with a short third phase for consolidating the findings and sharing them with other prisons. Analysis of data is ongoing and the final results will be published at the end of the study. However, it is already clear that the number of prisoners requiring P&EoL care is likely to continue to increase in the foreseeable future. Download/view at: http://bit.lv/2WSLdJQ

Current and emerging practice of end-of-life care in British prisons: Findings from an online survey of prison nurses

BMJ SUPPORTIVE & PALLIATIVE CARE, 2016;6(1):101-104. There are concerns about prisoners and detainees not having equal access to end-of-life care (EoLC) while in prison. There is a lack of existing literature about the standards of EoLC in U.K. prisons. The reported barriers included some prison regimes, lack of appropriate care and visiting facilities, lack of privacy and inadequate visiting hours. Respondents also reported examples of good practice, including having access to specialist palliative care and specialist equipment, and being able to receive visits from family and friends. Abstract: http://bit.ly/2HpMlz2

Barry R. Ashpole, Ontario, CANADA

e-mail: barryashpole@bell.net