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# Palliative and end-of-life care in prisons: a content analysis of the literature

Tina Maschi, Suzanne Marmo and Junghee Han

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## Abstract

**Purpose** – *The growing numbers of terminally ill and dying in prison has high economic and moral costs as global correctional systems and the society at large. However, to date little is known about the extent to which palliative and end-of-life care is infused within global prison health care systems. The purpose of this paper is to fill a gap in the literature by reviewing and critically appraising the methods and major findings of the international peer-reviewed literature on palliative and end-of-life care in prison, identify the common elements of promising palliative and end-of-life services in prison, and what factors facilitate or create barrier to implementation.*

**Design/methodology/approach** – *A content analysis was conducted of the existing peer-reviewed literature on palliative and end-of-life care in prison. English-language articles were located through a comprehensive search of peer-reviewed journals, such as Academic Search Premier Literature databases using differing combinations of key word search terms, “prison,” “palliative care,” and “end-of-life care.” A total of 49 studies published between 1991 and 2013 met criteria for sample inclusion. Deductive and inductive analysis techniques were used to generate frequency counts and common themes related to the methods and major findings.*

**Findings** – *The majority (n = 39) of studies were published between 2001-2013 in the USA (n = 40) and the UK (n = 7). Most were about US prison hospice programs (n = 16) or barriers to providing palliative and end of life care in prisons (n = 10). The results of the inductive analysis identified common elements of promising practices, which included the use of peer volunteers, multi-disciplinary teams, staff training, and partnerships with community hospices. Obstacles identified for infusing palliative and end-of-life care in prison included ethical dilemmas based on custody vs care, mistrust between staff and prisoners, safety concerns, concern over prisoners’ potential misuse of pain medication, and institutional, staff, and public apathy toward terminally ill prisoners and their human rights to health in the form of compassionate and palliative care, including the use of compassionate release laws.*

**Research limitations/implications** – *Implications for future research that foster human rights and public awareness of the economic and moral costs of housing the sick and dying in prisons. More research is needed to document human rights violations as well as best practices and evidence-based practices in palliative and end-of-life care in prisons. Future studies should incorporate data from the terminally ill in prison, peer supports, and family members. Future studies also should employ more rigorous research designs to evaluate human rights violations, staff and public attitudes, laws and policies, and best practices. Quantitative studies that use experimental designs, longitudinal data, and multiple informants are needed. Qualitative data would allow for thick descriptions of key stakeholders experiences, especially of the facilitators and barriers for implementing policy reform efforts and palliative care in prisons.*

**Practical implications** – *This review provides a foundation on which to build on about what is known thus far about the human right to health, especially parole policy reform and infusing palliative and end-of-life care for the terminally ill and dying in prisons. This information can be used to develop or improve a new generation research, practice, policy, and advocacy efforts for that target terminally ill and dying in prison and their families and communities.*

**Social implications** – *There are significant social implications to this review. From a human rights perspective, the right to freedom from torture and cruel and unusual punishment is a fundamental human right along with prisoners’ rights for an appropriate level of health care. These rights should be guaranteed regardless of the nature of their crime or whether they are in a prison placement. The information provided in this review can be used to educate and possibly transform individual’s and society’s views toward the terminally ill and dying who are involved in the criminal justice system.*

**Originality/value** – This paper extends the extant literature by using both quantitative and qualitative analysis methods to organize, summarize, and critically analyze the international literature on palliative care and end of life care in prison. This review is designed to increase awareness among the international community of the pain and suffering of the terminally ill in prison and the facilitators and barriers to providing them compassionate care while in custody.

**Keywords** Criminal Justice System, Human rights, Prison, Correctional health care, Elderly prisoners, Health in prison

**Paper type** Literature review

## Background

According to the United Nations and the Universal Declaration of Human Rights (United Nations, 1948), every human being is entitled to be treated with dignity and respect, which includes individuals not being subjected to torture and cruel and unusual punishment. In some countries, such as the USA, the UK and Australia, public policy and the research literature have extended this interpretation to prisoners' rights to receive access to an appropriate level of care for serious medical needs, including the provision of palliative care (Human Rights Watch (HRW), 2012). According to the United Nations Office of Drugs and Crime (United Nations Office on Drugs and Crimes (UNODC), 2009), older prisoners and prisoners with terminal illnesses are considered a special needs populations, subject to special international practice and policy considerations.

The anti-crime wave of the 1980s that began in the USA and spread across the globe, led to stricter and longer sentencing policies (Aday, 2005-2006). There seems to have been a lack of collective foresight during this era of punitive policies for the unintended health consequences and high death toll found among incarcerated persons in the international correctional settings (American Civil Liberties Union (ACLU), 2012). As a result, there have been inadequate preparation to provide preventive medicine and specialized palliative and end-of-life health care in prisons, especially for those individuals serving long-term and life sentences.

Due to age-related health decline, those aging in prison have been shown to be particularly vulnerable in the international prison systems (Aday, 2005-2006; Maschi *et al.*, 2012; Wahidin, 2011). Medical related deaths have been shown to occur among the incarcerated older adults at a younger chronological age when compared to persons in the general non-prison population (Bureau of Justice Statistics, 2010; Boothby and Overduin, 2007; Mumola, 2007; Stone *et al.*, 2012; Wahidin, 2011; Wright and Bronstein, 2007a). Therefore, it is important for correctional systems to incorporate the trajectory of palliative, end-of-life and hospice care for incarcerated people. End of life care includes care needs for individuals diagnosed with life-limiting illnesses up to and including their death. Palliative care and hospice care have emerged as disciplines and systems of care to assist individuals and caregivers with complex care needs in the terminal phase of their illness (Brennan, 2007). Hospice care is commonly used to describe individuals who are no longer pursuing active treatment for their terminal illness, while palliative care tends to assume an upstream, preventive, and holistic approach.

## High financial and moral costs of non-action

For incarcerated persons, especially older and seriously ill persons in prison, medical care has been provided at a great financial cost to society. This is particularly salient in America which has the largest incarceration rate of older persons (Maschi *et al.*, 2012). A 2012 Human Rights Watch report estimates that institutionalizing and providing care for American prisoners over the age of 55, costs state and federal governments an annual sum of \$2.1 billion, which is three times the amount it costs to accommodate a younger prisoner. The American Civil Liberties Union suggests that this cost is actually much higher and estimates that the cost to incarcerate older adults is actually five times more when compared to the younger prison population (ACLU, 2012).

There also are high moral costs to turning a blind eye to the old, and terminally ill and dying in prison. Advocates for human and prisoners' rights have begun to question if chronic and end of life care is being provided in the most compassionate and humane way in the global prison

systems (ACLU, 2012; HRW, 2012; UNODC, 2009). More recently, compassionate policies, such as medical parole and compassionate release laws and programs for mostly non-violent terminally ill prisoners have been implemented in an effort to provide more cost effective dignified care to dying prisoners (Boothby and Overduin, 2007; Bronstein and Wright, 2007; Maschi *et al.*, 2012; Stone *et al.*, 2012).

## **Palliative care human rights and needs**

### ***Palliative care as a human right***

From a human rights perspective, since all individuals are entitled to dignity, respect and fair treatment across the life course, palliative care has been asserted to be a human right. In March 2013, Juan Mendez, the UN Special Rapporteur on Torture, presented his new report focussing on severe abuses in health care settings, which includes prison, that are the equivalent of cruel, inhumane, degrading treatment, and torture. These abuses that countries must prevent include the denial of or lack of access to essential pain treatment, such as oral morphine, especially among marginalized populations (UN, 2011, 2013).

Palliative care rights should also naturally extend to the rights and needs of incarcerated persons. The World Health Organization (2002) broadly defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (p. 1). Human and civil rights advocacy groups also suggest that the lack of palliative care treatment for the sick and dying is a type of torture, suffering, and cruel and unusual punishment (HRW, 2012). Advocates of the palliative care movement have suggested a more comprehensive understanding of suffering that incorporates physical pain, psychological, emotional, social, and spiritual pain (WHO, 2002). A 1995 study found that terminally ill hospitalized individuals reported moderate to severe physical pain during the last months of their lives. In some cases, the availability of pain medication and attention to psychosocial, emotional, and spiritual needs was questionable (SUPPORT, 1995).

### ***A philosophy that transcends borders***

As a philosophy, palliative care has no institutional boundaries or borders that separate treatment for those individuals in prison from those that are in the community. A palliative care approach views the dying process as a normal process in the life course along with developing practices to promote individuals experience with “dying well,” even for those in prison (Byock, 2002). Caring for the whole person is required and the family and patient are viewed as the unit of care (Byock, 1997). By examining the stage of dying in a developmental framework, the dying stage is said to share commonalities to the neonatal or infant stage with respect to needs of comfort, caretaking and need for assistance in negotiating the physical environment (Byock, 1997). As terminally ill individuals proceed along a trajectory toward death, a somewhat predictable experience of functional decline and increased dependency and need for social support from trusting caregivers occurs (Adorno, 2011; Wachtermann *et al.*, 2011). The integration of a palliative care approach into a prison system that incorporates family and caregiving is a challenge in a prison setting focussed largely on custody and punishment. For the incarcerated terminally ill, prison policies have unintended negative consequences. The dying in prison are often separated from family and inmate peer supports where there are strict visitation policies, or they are transferred to outside hospitals or prison infirmaries (Loeb *et al.*, 2011).

### ***Compassion and palliative care in prisons***

The goal of the palliative care philosophy and movement is to provide patient centered care and dying with dignity as a fundamental human right. Based on this philosophy, people in prison are entitled to compassionate end of life care, regardless of the nature of past crimes (HRW, 2012). The goals of compassionate care as posited by the palliative care movement often conflict with the goals of corrections, which are punishment, incapacitation, and custody (Maschi *et al.*, 2012). Newspapers, documentaries, civil and human rights reports, and academic journals have

provided countless examples of palliative care violations, including stories of prisoners suffering isolated, undignified, and often painful deaths without access to pain medication (ACLU, 2012; Craig and Craig, 1999; HRW, 2012). Foley (1998) described incarcerated persons dying handcuffed to their beds in a New Orleans hospital. Finlay (1998) recounted the story of a terminally ill incarcerated person in the UK who remained handcuffed to his bed until just three hours before his death. In a qualitative study of older women in the UK prison system, Wahidin (2003) provides testimony of the denial of prescribed medication to female prisoners as well as symptoms and reports of illness being trivialized. Access to requested medical care was frequently reported to be denied to women in prison due to a perception of women as a “hysterical hypochondriac” (Wahidin, 2011, p. 7). As research from both the UK and the USA has suggested, this lack of access to treatment may cause both delay of diagnosis of a life threatening condition, enhanced suffering and therefore, additional punishment inflicted upon the terminally ill prisoner (Enders *et al.*, 2005; Wahidin, 2011).

The denial of rights to the terminally ill and dying in prison arguably has created one of the fastest growing human made disasters, especially in the USA, which has the highest prison population with 743 incarcerated adults per 100,000 members of the US population (Walmsley, 2011). In a compassionate response to the crisis, the first hospice programs to address the high rates of AIDS-related prison deaths were started in Springfield, Missouri, in 1987. This pioneering program was soon followed by a second in Vacaville, California by Maull, while incarcerated (Maull, 1998).

Four years after these programs were begun, the National Hospice Prison Association was formed to provide educational resources for officials and staff of federal and state prison systems that were interested in developing prison hospices. In 1996, The American Correctional Association mandated that all prisoners should receive health care equivalent to community standards, including services for terminally ill prisoners and compassionate release when deemed appropriate (Craig and Craig, 1999; Maull, 1998). In total, 28 prison hospice programs were in operation by 1997 and by 2009, 75 prison hospice programs were identified as operating in 40 states (Hoffman and Dickinson, 2011; National Institute of Corrections, 1998; Leland, 2009).

### *Purpose and significance of study*

Despite the financial and moral costs raised by the treatment of the terminally ill in prison, there has been a minimal amount of research that examines the infusion of palliative and end of life care in international corrections. The extent to which the research literature has provided sufficient empirical evidence that individualized, patient-centered palliative care is being provided for the terminally ill in prison is not yet fully explored. Stone *et al.* (2012) integrative review of the literature identified 21 studies published in the USA and UK. The purpose of this content analysis is to extend the existing literature by conducting a comprehensive and critical analysis of the international literature on palliative and end-of-life care in prisons. The research questions that guided this review are: what does the international peer-reviewed academic literature report about: the methods and major findings on palliative and end of life care in prisons? and the common elements of promising practices of palliative and end of life care in prisons?

These findings have significant implications for research, practice, policy, and advocacy for people dying in prison by taking stock of the research conducted thus far. In turn, the information garnered from this review can be used to improve future research on this underserved population, identify common elements of promising and evidence-based practices, and identify what factors facilitate or create barriers for the infusion of palliative and end-of-life care in prisons. This information can be used to improve practice, practice, policy, and advocacy for the terminally ill in prison.

## **Methods**

### *Data collection procedures*

To systematically answer the posited research questions, a content analysis was conducted. In order to locate the sample of articles that examine palliative care and/or end of life care in

prisons, the Fordham Library database research, EBSCO Host, PUBMED, SAGE Journals Collection, and Wiley Online Library were used as search engines to identify English-language research studies published as of April 2013. In particular, EBSCOHost was used because it housed 69 research databases of particular relevance to inmates and end-of-life, e.g. *Psych ARTICLES*, *Psyche INFO*, *MEDLINE*, and *SocINDEX*. Keyword search terms were used in a variety of ways to obtain all relevant articles. The following keyword combinations were used: first, palliative care, hospice, end-of-life, pain, pain management, pain care, or compassionate release; and second, prisons, prison reentry, penitentiary, imprisonment, or jail and custody. The research team also manually searched article reference lists to identify any additional articles not found in the archives of the electronic research databases.

### *Sample selection*

Articles were located through a search of online scholarly databases between 1991 and 2013. The years of publication were not limited, but all of the articles in the samples were published after 1990, suggesting that this topic is of relatively new interest to scholars. A total of 69 candidate papers were yielded by the search. Two members of the research team concurred on the inclusion criteria and the selection of articles. Of the 69 results, 20 articles were excluded. The exclusion criteria were that articles must not be: commentaries on other articles; book or video reviews; editorials, columns, or interview articles; not directly evaluative of palliative and end of life care-related issues among prisoners. Also, one article published in French was excluded due to the language barrier, and another article was excluded due to lack of availability (Gautier, 2011; Sithole and Dempers, 2010). A total of 49 scholarly peer reviewed articles that directly addressed end-of-life care among older prisoners formed the final sample. Inclusion criteria were that the article: was published in a peer reviewed scholarly journal; included a reference of cited works; had a title or contents which directly addressed end-of-life issue among prisoners; was available for broad public access via university online research databases.

A data extraction form was developed by the research team to extract the following data into an Excel spreadsheet: publication characteristics (countries and dates of publication), study research methods (which included research designs and sampling strategies), and summaries of major findings across studies (see Tables I-III). A trained research assistant extracted and coded the data. The data were reviewed weekly for an eight-week period with the lead researcher until a 100 percent consensus was reached for all categories of data extracted.

**Table I** Characteristics of the literature on palliative and EOL care for prisoners

<i>Journal articles characteristics</i>	%	<i>n</i>
<i>Article primary-type</i>		
Empirical/research study	45.0	22
Non-empirical/research study		
Descriptive overview (experience-based or data-based)	20.0	10
Discussion paper (with/without case examples)	33.0	16
Briefing paper	2.0	1
<i>Study decade</i>		
1991-2000	20.4	10
2001-2010	65.3	32
2011-present	14.3	7
<i>Country of Studies</i>		
New Zealand/Australia	4.0	2
UK	14.3	7
USA	81.7	40

Note: *n* = 49

**Table II** Specific characteristics of peer-reviewed articles on palliative and EOL care for prisoners

Author/s (Year) (in alphabetical order)	Research designs							Sample size
	Country	Setting	Informant	Temporal	Method	Data collection	Sampling	
<i>Empirical studies (n = 22)</i>								
Aday (2005-2006)	USA	Prison	Inmate	Cross-sectional	Mixed	Interview	Non	102
Boothby and Overduin (2007)	USA	University	Student	Cross-sectional	Quant	Self-report	Non	163
Bronstein and Wright (2006)	USA	PHP	Staff	Cross-sectional	Qual	Interview	Non	14
Courtwright <i>et al.</i> (2008)	USA	Hospital	Staff	Cross-sectional	Qual	Observation	Non	1
Davies <i>et al.</i> (2010)	UK	Prison	Data	Cross-sectional	Quant	Not known	P	158
Deaton <i>et al.</i> (2009)	USA	Prison	Inmate	Cross-sectional	Mixed	Self-report	Non	327
Enders <i>et al.</i> (2005)	USA	Prison	Inmate	Cross-sectional	Qual	Focus group	Non	113
Hoffman and Dickinson (2011)	USA	PHP	Staff	Cross-sectional	Quant	Self-report	Non	43
Lin and Mathew (2005)	USA	Prison	Staff Inmate	Cross-sectional	Quant	Interview/self-report	Non	262
Loeb <i>et al.</i> (2011)	USA	Content	Articles	Cross-sectional	Quant	Web search	P	3
Loeb <i>et al.</i> (2013)	USA	PHP	Inmate	Cross-sectional	Quali	Interview	Non	17
Mathew <i>et al.</i> (2005)	USA	Hospital	Data	Cross-sectional	Quant	Not known	P	1,807
O'Connor (2004)	USA	Prison	Inmate	Cross-sectional	Quali	Observation	Non	1
Phillips <i>et al.</i> (2011)	USA	Prison	Inmate	Cross-sectional	Quant	Interview	Non	94
Phillips <i>et al.</i> (2009)	USA	Prison	Inmate	Cross-sectional	Quant	Interview	Non	73
Reviere and Young (2004)	USA	Health Center	Staff	Cross-sectional	Quant	Self-report	Non	65
Stone <i>et al.</i> (2012)	UK	Content	Article	Cross-sectional	Quant	Web search	P	21
Turner <i>et al.</i> (2011)	UK	Prison	Staff	Cross-sectional	Mixed	Interview	Non	27
Wright and Bronstein (2007a)	USA	PHP	Staff	Cross-sectional	Qual	Interview	Non	14
Wright and Bronstein (2007b)	USA	PHP	Staff	Cross-sectional	Qual	Interview	Non	14
Yampolskaya and Winston (2003)	USA	PHP	Staff	Cross-sectional	Mixed	Web search/interview	Non	10
Zimmermann <i>et al.</i> (2002)	USA	Prison	Inmate	Cross-sectional	Quant	Self-report	Non	212
<i>Non-empirical studies (n = 27)</i>								
Bauersmith and Gent (2002)	USA	PHP	–	Descriptive overview	–	–	–	–
Beck (2007)	USA	C.R.	–	Discussion paper	–	–	–	–
Bolger (2005)	UK	Prison	–	Discussion paper	–	–	–	–
Boyle (2002)	USA	PHP	–	Descriptive overview	–	–	–	–
Byock (2002)	USA	Prison	–	Discussion paper	–	–	–	–
Chandler (2003)	USA	Prison	–	Discussion paper	–	–	–	–
Cohn (1999)	USA	Prison	–	Discussion paper	–	–	–	–
Craig and Craig (1999)	USA	PHP	–	Descriptive overview	–	–	–	–
Dawes (2002)	Australia	Prison	–	Discussion paper	–	–	–	–
Dubler (1998)	USA	Prison	–	Discussion paper	–	–	–	–
Evans <i>et al.</i> (2002)	USA	PHP	–	Descriptive overview	–	–	–	–
Finlay (1998)	UK	Hospital	–	Discussion paper	–	–	–	–
Granse (2003)	USA	Prison	–	Discussion paper	–	–	–	–
Linder and Meyers (2007)	USA	Prison	–	Discussion paper	–	–	–	–
Linder and Meyers (2009)	USA	Prison	–	Discussion paper	–	–	–	–
Linder <i>et al.</i> (2002)	USA	PHP	–	Descriptive overview	–	–	–	–
Lum (2003)	NZ	PHP	–	Discussion paper	–	–	–	–
Mauil (1991a)	USA	PHP	–	Discussion paper	–	–	–	–
Mauil (1991b)	USA	PHP	–	Descriptive overview	–	–	–	–
Mauil (1998)	USA	PHP	–	Discussion paper	–	–	–	–
Prison Reform Trust (2008)	UK	Prison	–	Briefing paper	–	–	–	–
Ratcliff and Craig (2004)	USA	PHP	–	Descriptive overview	–	–	–	–
Smith (2000)	USA	PHP	–	Descriptive overview	–	–	–	–
Taylor (2002)	USA	PHP	–	Descriptive overview	–	–	–	–
Tillman (2000)	USA	PHP	–	Descriptive overview	–	–	–	–
Williams <i>et al.</i> (2011)	USA	C.R.	–	Discussion paper	–	–	–	–
Wood (2007)	UK	Prison	–	Discussion paper	–	–	–	–

**Notes:**  $n = 49$ . Setting, the area which samples were recruited (empirical), mainly discussed or recruited case examples area (non-empirical); Hospital, located outside of prison; Health Center, health care facility in prison; PHP, Prison Hospice Program; Non, non-probability; P, probability; C.R., compassionate release

### Data analysis methods

Content analysis strategies as outlined by Krippendorff (2004) and Neuendorf (2002) were used to analyze the data. Content analysis is a systematic procedure that codes and analyzes qualitative data, such as the content of published articles. A combination of deductive and

**Table III** The themes identified across the studies

Inmate experiences of death and dying, caregiving, and palliative and EOL care	
Psychological issues related to inmates' death and dying in prisons	
EOL care decision-making	
Cancer in prisoners (epidemiology)	
Service provision	
Ethical issues	
The need for EOL care for prisoners	
Compassionate release laws, policies, practices	
Prison hospice program	
The challenges of providing compassionate palliative and EOL care and its guidelines	
The disparities of providing palliative and EOL care in prisons across countries	
<i>Empirical studies (n = 22)</i>	
Author/s (year)	Major findings and research focus
Aday (2005-2006)	Older prisoners' death anxiety was slightly higher compared to their community counterparts; age, inmate social supports, and health status were associated with their death fear. Also, some inmates considered death as escape, but others expressed fear of dying in prisons
Boothby and Overduin (2007)	College students held negative attitudes toward prisoners and their compassionate release. Negative attitude toward prisoners were strongly associated with negative attitude toward compassionate release, but the fear of AIDS were not associated with the attitude
Bronstein and Wright (2006)	Most prison hospice programs in the study reported that the team collaboration was high quality. Collaboration with community hospice was critical for program success and collaboration had positive effect on prisoners and prison culture
Courtwright <i>et al.</i> (2008)	This case study illustrated the barriers in providing palliative care services in a hospital for a 34-year-old male inmate with lung cancer. He was refused services for comfort, and the medical team had limited contact with family members due to bureaucracy
Davies <i>et al.</i> (2010)	The study showed that on average, 31 prisoners were diagnosed with cancer in each 5-year period. 83 percent of women were diagnosed with <i>in situ</i> carcinoma of the cervix and 19 percent of men had lung cancer. None of the 25 patients were recorded as dying in prison. Most died in hospitals (48 percent) or in hospices (28 percent)
Deaton <i>et al.</i> (2009)	The study found that for female inmates' aged 50 and over death anxiety, as measured by the Templar Death Anxiety Scale, was higher than for community counterparts. Their perceived health and mental health status were associated with death anxiety. Also, the perception of inappropriate health care services, penal harm, and staff's indifference impacted on their death concerns, and inmates feared the process of dying much more than death itself
Enders <i>et al.</i> (2005)	Female inmates identified informational obstacles related to decisions in medical treatments, advance care planning, and EOL care. The barriers included fear of lack of information and confidence in decisions, unmet expectations such as limited visits and physician practice that focused on only one problem, bad experiences regarding medical care and medical staff, and mistrust in health care staff

(continued)



**Table III**

Hoffman and Dickinson (2011)	As compared to community hospices, prison hospices had more training process for volunteers before contact with patients. Also, general hospice admission standards including agreement to forego curative treatment, a prognosis of 6 months or less to live, and DNR order were not applied to prison hospice care. Most prison hospice programs used the IDT model and relied on inmate volunteers. The sampled program followed both the National Prison Hospice Association and the GRACE project guidelines
Lin and Mathew (2005)	Of inmate cancer patients in the study, 81 percent reported severe worst cancer pain and 49 percent reported severe average pain, but 32 percent reported no pain relief at all and 64 percent were negative in Pain Management Index, indicating inadequate pain treatment. Of the PCPs, 31 percent felt that inmates' cancer pain was under treated and the most cited top two obstacles for effective pain management were concerns about drug misuse/diversion and lack of patient credibility
Loeb <i>et al.</i> (2011)	The study outlined potential barriers for providing humane EOL care for female prisoners; mistrust issues between staff and inmates; inappropriate physical environment, staffing patterns, and security regulations; facing a loved one's death, limits on family visits; and public apathy. However, the authors found that care strategies including partnerships with community and staff education, and the use of frontline workers who fully understand the balance between care and custody, can bring positive changes in prisons
Loeb <i>et al.</i> (2013)	Through semi-structured face-to-face interviews with 17 inmates serving for dying peers, this qualitative descriptive study examined inmates' values, beliefs, and perceptions of EOL care. Key themes emerged from the analyses were getting involved, living the role, and transforming self through assisting peers who are approaching end of life. As well, as inmates served in the important role of caregiver, positive and negative contextual features occurring at the organizational, peer, and personal levels hold potential for influencing inmate caregiving were identified
Mathew <i>et al.</i> (2005)	As Texas prison populations steeply increased, the number of inmates diagnosed with cancer in Texas prisons rose correspondingly. The leading cancers were lung carcinoma, NHL, and oral cavity and pharyngeal carcinomas. Among women, cervical carcinoma was most common among inmates. Lung carcinoma, NHL, and hepatic carcinoma, which were more common among inmates than the SEER cohort, accounted for more cancer deaths among inmates than in the SEER cohort. The median survival was inferior in the inmate cohort (21months), as compared to the SEER cohort (55 months) and the MSEER cohort (54 months)
O'Connor (2004)	By using a client-centered approach drawn from Existential Therapy, the case study of one terminally ill prisoner explored ethical dilemmas that arose during the end-of-life process. There was conflict between health care staff who wanted to increase pain meds for the patient, and the inmate patient who tried to maintain self-control by trying to not accept it. Another ethical dilemma rose for the therapist, balancing roles as a staff of the prison, and as a therapist who has to respect the patient's right to know when the compassionate release was denied. These situations were resolved through the review of meaningful life events in patient's life and consideration of current life goals of the patient
Phillips <i>et al.</i> (2011)	The study examined the effect of subjective parole expectation, functional health status, and psychosocial factors on desire for life-sustaining treatment (CPR, feeding tube, palliative care, and days of desired life) within the context of future health conditions. The effect of parole expectation on the desire for life-sustaining treatment varied by race/ethnicity and treatment. Minority inmates expressed desire for CPR or feeding tubes only if they believed that they would be paroled. Future days of desired life were related to prospective health condition, fear of death, negative impact, and trust in prison health care

*(continued)*

**Table III**

Phillips <i>et al.</i> (2009)	This study examined the association among age at end of the sentence, race, physical/emotional health, and death anxiety with EOL care preferences including CPR, feeding tube, and palliative care. Inmates who were non-Whites, minorities, or reporting high death anxiety were more likely to have a greater desire for a feeding tube, whereas inmates who were Caucasian were more likely to have a greater desire for palliative care
Reviere and Young (2004)	Of 65 state and federal prisons for women, most of them provided basic health and mental health services on-site. Also, over one-half reported offering hospice services, and those were more likely to be offered on-site (28 percent) than off-site (23 percent). The sampled prisons having 10 percent or more female inmates aged 50 and over were more likely to have hospice services than those with < 10 percent over 50. 92 percent of the prisons reported offering bereavement counseling, all on-site. However, those that house more (and which expect to house more) elderly female inmates did not significantly differ in their approaches to access or to offer health care from their counterparts
Stone <i>et al.</i> (2012)	This integrative review of literature highlighted important issues in palliative care in prisons including pain relief, trust issues among staff and prisoners, the implementation of palliative care services within the prison setting, and the roles of inmate volunteers. Also, the study emphasized the disparity between the US model of care which emphasizes the in-prison hospice, and the UK model of care which emphasizes palliative care in-reach for dying prisoners (and has only one prison hospice in operation)
Turner <i>et al.</i> (2011)	Findings showed some challenges of providing end-of-life care in prisons. The challenges included maintaining security, limits to assessing an inmate patient among outside hospice workers, staff's lack of knowledge and skills in prisons, potential for misuse of pain meds, and limited choice of place of death
Wright and Bronstein (2007a)	All programs shared a similar program goal, employed an inter-disciplinary team approach, and relied on inmate volunteers to provide emotional support to patients. Program staff's backgrounds varied across the sampled programs and in general, all respondents stated that their programs had been successfully integrated within the confines of a prison and medical unit within that institution. Also, the prison hospice programs had positive effects on patients, staff, inmate volunteers, and prison culture. Based on these findings, careful planning, training of staff and inmate volunteers, administrative support, the buy-in of correctional services personnel, and diversity of care team members were suggested as critical to integrate hospice care into a prison setting
Wright and Bronstein (2007b)	Existence of prison hospice programs had a transformative influence on the individual prisoners who volunteer for the program as well as on the overall institutional climate. The most cited impact on prisoner volunteers was to enhance the capacity to feel compassion for others. The largest impact for the entire prison community was to encourage a view that staff and prisons can be caring and behave humanely. Staff also could see inmates as human beings to be treated with dignity, and greater cooperation between staff and inmates was observed
Yampolskaya and Winston (2003)	The study found that all existing prison hospice programs shared common elements: establishing hospice care inside prison, multi-disciplinary team, inmate volunteer involvement, comfort care, and eligibility criteria for admission. These components were associated with outcomes of successful palliative care in prison including cost-effectiveness, psychological rehabilitation for inmate volunteers, and the dying prisoners' experience of comfort care

*(continued)*

**Table III**

Zimmermann <i>et al.</i> (2002)	In addition to interviews with various staff related to the prison system, the study conducted an inmate survey to find out the needs and individual resources, and to assess the prisoners' attitude on and knowledge of hospice care. More than one half of the female samples had been homeless for some time, and 73 percent of inmates reported that they had at least a satisfactory experience with prison health care. Also, prison inmates showed lack of knowledge of hospice care and 84 percent of the inmate participants preferred to receive hospice care from outside workers rather than prison staff trained to provide hospice care. 91 percent of the female inmates reported they would become a hospice peer volunteer, and 84 percent wanted support from an inmate peer volunteer should the need arise
<i>Non-empirical studies (n = 27)</i>	
Bauersmith and Gent (2002)	The study described Broward County's jail hospice program initiated in 1985. It was distinguished from other prison hospice programs in that compassionate release and expedited case disposition were available. Initial attitudinal resistance for prisoners had changed over time, but many challenges remained (e.g. supplies, visitation procedures, and dietary needs of hospice patients)
Beck (2007)	This paper described the medical parole program, focusing on New York state, and identified the deficiencies of it, including overly restrictive eligibility criteria and a review process which overburdens prison doctors with lengthy paperwork, and suggested recommendations to fix those flaws
Bolger (2005)	Due to demographic trends, the ongoing failure to use medical parole, and the recorded psychosocial status of dying inmates, this paper recommends that palliative care for prisoners should be developed and expanded within a prison in the UK
Boyle (2002)	The study described the Maryland Division of Correction hospice program. It was started with the help from a community hospice; one site was in operation and another site was due to open as of 2002. The program only served male inmates, and required a prognosis of six months or less to live, a DNR order, and patient consent. Some obstacles of the program such as visitation procedures and special dietary needs were noted
Byock (2002)	The study argued that we should provide adequate EOL care for prisoners because everyone is at risk to be placed in similar situation of dying alone. At the end of life, inmates should be seen as disfranchised groups (like people with dementia) due to the similarities in the groups
Chandler (2003)	The author illustrated medical neglect among women in California prisons and argued that the neglect is due to the pursuit of prison profits and increased social punitive response to social problems. The search for prison profit pushed female inmates to labor, eliminated ways of maintaining health and wellness, and reduced access to care. Also, in a culture of punishment, adequate pain management was sometimes not provided for dying inmates
Cohn (1999)	This study argued the need for providing EOL care for prisoners, based on philosophical ethics. Society should value prisoners as human beings with dignity, fulfill social contracts with them, recognize the need for just policies to address the issue, and consider societal pros and cons from a utilitarian perspective
Craig and Craig (1999)	The study reviewed the challenges facing the current prison hospice program and its components and development. It suggested some alternatives, including continual nurturing for staff by local hospice professionals and cooperation with outside hospices near prisons
Dawes (2002)	The author introduced three different prison hospice models developed in the USA, and argued that they all should be employed for prisoners in Australia
Dubler (1998)	This paper argued that humane end-of-life care should be provided in the facility as ethical mandate, and also that compassionate release programs should be used to meet the needs of dying inmates. They needed increased medical attention, accommodation of visiting hours for family and clergy, special dietary items, and relaxation of restrictive routines

(continued)

**Table III**

Evans <i>et al.</i> (2002)	The study described the Angola Prison Hospice program developed in partnership with a community hospice which provided consultation and training. The program provided specialized care services for terminally ill inmates without additional prison costs and was characterized by use of inmate volunteers and staff, specific admission criteria, a team approach, and bereavement services
Finlay (1998)	This paper discussed issues about care of terminally ill inmates. By illustrating one case report of a dying inmate who was shackled to his bed until shortly before his death, the authors argued that the Cardiff guideline, which was developed to clarify security procedures for prisoners attending outside hospitals when the case was covered by mass media, would be helpful for meeting family needs as well as escorting and managing ill inmates
Granse (2003)	By using information based on formal and informal data and by presenting case examples of dying inmates in prisons, the author showed prison hospice programs limitations, including: safety precaution problems, trust issues between inmates and staff, the physical environment, and negative attitudes of free society. It also suggested social workers' roles in the program, and compassionate release as an ideal alternative to meet dying prisoners' needs as human beings
Linder and Meyers (2007)	This paper showed why changing demographics of prison populations necessitates hospice in this setting and many obstacles that physicians face while providing palliative care for ill inmates. Also, it described various issues related to prison hospice programs such as palliative care standards in prison, inmate-physician and inmate-family relationships, confidentiality, DNR orders and advance directive care planning, medical parole, and the use of inmate volunteers in the programs. In conclusion, the authors suggested practical ways for community physicians to work with released ill inmates
Linder and Meyers (2009)	The author described current existing demographic changes in prisoners, some common elements in prison hospice programs, and social workers' perspective on caring for dying inmates within prison. The author highlighted the importance of social workers within the prison hospice system
Linder <i>et al.</i> (2002)	This paper described a specific prison hospice program (CMF) started in 1996 due to increases in both the number of inmates with HIV and "graying" prisoners. The characteristics of the program included inmate volunteers, staff training, community partnerships, family involvement, and bereavement services
Lum (2003)	The author summarized the US prison hospice model and argued that it should be adapted to New Zealand prisons with considerations for New Zealand prisoners' situations
Maul (1991a)	This paper discussed socio-cultural and psychosocial characteristics of terminally ill incarcerated patients, which were very similar to Kubler Ross's five stages of emotional direction. It presented five case examples (all males with HIV or cancer diagnosis) and illustrated each stage: denial, anger, bargaining, hope, depression, and acceptance, in this unique environmental situation
Maul (1991b)	This paper described the development of an innovative prison hospice program characterized by an inmate-staffed hospice volunteer program. It was started following one prisoner's concern about the sharp increase in the number of prisoners dying alone. With support from staff sponsorship, there was a six month pilot prison hospice program in 1987. A group of potential inmate volunteers were screened and trained, and after the pilot program was done, an evaluation was conducted. The response rates of staff were low, but majority of respondents were supportive and approved the program. All volunteers and patients were highly appreciative and enthusiastic toward the program. Based on the results, the hospice program became an ongoing medical program for federal prisons in 1988

*(continued)*

**Table III**

Maul (1998)	This paper discussed the critical issues affecting delivery of prison hospice, including DNR orders and curative palliative care decisions, pain management, AIDS care, inter-disciplinary care teams, staff and volunteer training and supervision, and the need for compassionate release and community placement programs
Prison Reform Trust (2008)	This briefing paper illustrated the lack of palliative care in prison in the UK. Also, key findings were although health care in prison has been improved following local primary care trusts taking over health care units, preventative and screening health care remained poor; many older inmates have not met their social care needs in prisons; some older inmates got a benefit from formal or informal peer support; sentence progression affected morale of older prisoners serving long sentences; poor regimes and lack of engagement with older inmates led to their isolation; and lack of planning for resettlement in community caused anxiety for the future
Ratcliff and Craig (2004)	This study overviewed the GRACE project and its results, including offering guidance materials to prisons, developing recommended standards for EOL care in corrections, and publishing several journal articles through the project
Smith (2000)	Through the security officer's eyes, the importance of inmate volunteers' roles in prison hospice programs was described. As per the author, the hospice program offered the chance to work together within prison to achieve the success of the program, and inmate volunteers were the heart of the program because inmate patients could be free from fear of dying lonely with comfort and love of the volunteers
Taylor (2002)	Based on personal visits to successful prison hospice programs in the USA, the author described some important parts of the programs such as inmate volunteers and bereavement services, and how they worked in the programs
Tillman (2000)	This paper described the Louisiana State Penitentiary (LSP) hospice program: the program's main features, development process, culture of prison life, and challenges for implementing hospice programs in prison. Also, recommendations were provided for undertaking a hospice initiative in a correctional setting
Williams <i>et al.</i> (2011)	The authors found flaws of eligibility criteria (medical eligibility varied by jurisdiction) and review process for compassionate release, which may hinder the expansion of the program, in spite of its legalization in most states. Authors suggested establishing standardized national guidelines and categorization of medical eligibility into three groups, not only based on prognosis but also disease trajectory and functional and cognitive status
Wood (2007)	The author stated the barriers of providing palliative to prisoners in the UK, and argued that prisoners should have the same rights to palliative care as those given in the free world. Also, the use of inmate volunteers was recommended

**Note:** *n* = 49

inductive approaches can be used (Bernard and Ryan, 2010). For example, the current study used deductive analysis, which consisted of pre-existing categories for journal article characteristics and research methods to extract data (e.g. the study's country of origin, study setting, research design, data collection, and primary informant). Counts of textual variables were then calculated to identify frequencies and percentages using the descriptive statistics function of SPSS 18.0. For example, types of articles were classified as empirical studies (i.e. research studies vs non-research studies).

The narrative data on major findings of the sample studies were analyzed inductively using Tutty *et al.*'s (1996) four-step qualitative data analysis strategies. Step 1 involved identifying "meaning units" (or *in-vivo* codes) from the data. For instance, the assignment of "meaning units" included assigning codes to reflect the major findings across studies. In step 2, second level coding and first level "meaning units" were sorted and placed in their emergent categories (e.g. "inmate experiences of death and dying and palliative" and "end of life care and service provision").

Meaning unit codes were organized by clustering similar codes into categories and separating dissimilar codes into separate categories. The data were analyzed for relationships, themes, and patterns. In step 3, the categories were examined for meaning and interpretation. In step 4, a conceptually clustered matrix was constructed to illustrate the patterns and themes found in the data (see Table III; Miles and Huberman, 1994).

## Major findings

### *Descriptive results*

Table I provides an overview of the characteristics of scholarly peer-reviewed literature on palliative and end of life care among prisoners. This includes the article primary (whether the article is an empirical/research study), the year of publication, and the country where the study was conducted. The sample consisted of 49 articles published in scholarly journals between 1991 and 2013, with a majority ( $n = 39$ ) conducted after the year 2000. Except for two articles, published in New Zealand and Australia, all of the sampled articles were conducted in the UK and/or in the USA ( $n = 47$ ). The majority of studies ( $n = 40$ ) were conducted in the USA. This result was congruent with findings in the study by Stone *et al.* (2012). Our analysis found evidence that the majority of samples ( $n = 27$ ) were non-empirical conceptual articles. Empirical research articles comprised a smaller part of the sample ( $n = 22$ ). Additionally, there is a lack of theoretically driven empirical research studies on the aging and serious and terminally ill in prison (Phillips *et al.*, 2011).

Table II shows the characteristics of sampled articles that examined palliative and EOL care in prison settings. This includes the methodology of empirical studies (e.g. study settings, research designs, sampling strategies, major informants, data collection procedures, samplings, and sample sizes) of all sampled studies. Also, Table II provides a chance to compare differences in the characteristics between empirical studies and non-empirical studies.

### *Characteristics and research methodology across empirical studies*

As shown in Table II, all sampled empirical studies were published after the year 2002, and this pool reveals only recently, empirical evidence been used to evaluate palliative and end of life care for prisoners. Except for three articles published in the UK, all the empirical studies were conducted in the USA ( $n = 19$ ). Overall, the study settings varied in that the primary study settings extended across universities, content analyses, and health care facilities in prisons, hospitals, and prison hospice programs. The majority of the empirical studies were conducted in prisons ( $n = 10$ ) followed by prison hospice programs ( $n = 6$ ) and hospitals outside of prisons ( $n = 2$ ). No studies were found that collected data from community hospices or long-term care facilities that were in partnership with a prison to provide palliative and end of life care for prisoners.

As for the use of informants, most data were collected from inmates or staff. Eight articles used staff (i.e. prison hospice coordinators, health care professionals, and directors of prisons) and

eight studies used inmates as informants. Five studies used other informant sources, such as articles, secondary data, and university students. Only one study included more than one type of informant. It is useful to note that none of the researches used family members as informants, although the role of family members are important element in the palliative and end of life care literature. Only one of the empirical studies used inmate peer volunteers as primary informants (Loeb *et al.*, 2013).

As for research design, there appears to be some consistent limitations across studies. All of the empirical studies ( $n = 22$ ) used a cross-sectional research design, which can hamper the ability to establish causality. Also, most of the studies ( $n = 18$ ) used non-probability sampling and a majority of the studies ( $n = 16$ ) employed small sample sizes of  $< 150$  participants, which may limit generalizability to larger populations. In all, 11 studies used quantitative research methods such as surveys, content analyses, and secondary analyses. Seven studies employed qualitative research methods and four studies utilized mixed research methods. Data collection strategies differed across studies. Interviews were used most often to collect data ( $n = 8$ ), followed by self-reporting ( $n = 5$ ). Internet searches, focus groups, observations of case studies, and mixed methods data collection strategies were also used.

Except for sample size, little information concerning social demographic characteristics of the samples were provided. Out of the 22 studies, 12 identified the gender of samples. Seven studies were gender specific (male only or female only), and in only seven of the studies, over two-third ( $n = 5$ ) included men only. Only 11 studies provided the age of samples, and only four included samples aged 55 and older. In addition, of the 22 empirical studies, almost 70 percent ( $n = 15$ ) provided no information on the race and ethnicity of the samples. Of the seven studies provided information on the race and ethnicity of the samples, there were no significant differences in proportion of participants between white and African-American groups sampled. Non-African-American minorities, including Latino and other ethnicities, were minimally represented ( $< 30$  percent) across the empirical studies.

#### *Differences in characteristics between empirical studies and non-empirical studies*

Among 49 sampled peer-reviewed articles, 22 were empirical studies published after 2002. The majority of non-empirical studies ( $n = 17$ ) were published in or prior to 2002, strongly suggesting that trends in studies on end of life care for prisoners appears to have changed from raising awareness to a current focus of evaluation and description of end of life care programs for prisoners.

#### *Qualitative analysis of results*

The research team conducted an inductive analysis of the major findings extracted from the sample of studies. As shown in Table III, the outcomes of those studies focusses on explaining: first, incarcerated people's experiences of death and dying, caregiving and palliative and end of life care: psychological issues related to the incarcerated person's death and dying; end of life care decision-making; cancer in prisoners (epidemiology); second, service provision; ethical issues; the need of EOL care for incarcerated persons; compassionate release policies and laws; prison hospice programs; the barriers and facilitators for providing compassionate palliative and end of life care; and the disparities for providing palliative and end of life care in prisons internationally.

*Psychological issues related to inmates' death and dying.* Of the 49 studies, only three discussed or explored psychological issues concerning inmates' contemplation of their own death and dying (Aday, 2005-2006; Deaton *et al.*, 2009; Maull, 1991a). Maull (1991a) described how terminally ill inmates follow a very similar emotional path to the Kubler Ross five stages of grief model. Aday (2005-2006) and Deaton *et al.* (2009) also found levels of death anxiety among sampled inmates to be higher than their community counterparts. The limited number of available studies on these issues appears to be justification for an underrepresentation of the incarcerated person's and their families voice in the research literature. The research in this sample showed that prisoners show a higher prevalence of mental disorders than their community counterparts as well as a fear of the process of dying more than dying itself (Deaton *et al.*, 2009; Needham-Bennett *et al.*, 1996). Additional research is needed to explore the psychological health

of inmates during end-of-life processes and propose successful interventions to address the emotional suffering associated with their illnesses.

*Ethical issues.* In a study by O'Connor (2004), ethical issues related to end of life care in prisons were identified. Using a client-centered approach drawn from existential therapy, a case study of one terminally ill prisoner explored ethical dilemmas that arose during the prisoner's dying process. The study revealed how issues were resolved appropriately with adherence to Department of Corrections' protocols and consideration for the patient's mental health. The author suggests, as the number of terminally ill inmates increases, ethical issues such as those described in this case study, will be unique and complex. No other studies identified within the sample shed light on individual ethical issues, suggesting a need for increased attention to development of practice models more in line with palliative care's philosophy of individualized patient centered care.

#### *End of life care decision making*

Only three of the studies sampled examined incarcerated individual's care preferences and end of life decision-making processes (Enders *et al.*, 2005; Phillips *et al.*, 2009, 2011). In a study by Enders *et al.* (2005), female inmates identified informational barriers related to medical treatment care decisions due to the low level of literacy among prisoners while also identifying lack of autonomy and individualized decision-making ability for medical care and treatment for incarcerated individuals. Phillips *et al.* (2009, 2011), examined factors associated with inmates' care preferences such as life-sustaining treatments such as CPR, feeding tubes, and palliative care. Although very few studies have explored such issues, it may be of worthy consideration to expand research focus to specific care preferences of inmates, and how to best provide for effective decision making for end of life care within involuntary confinement.

#### *Cancer in prisoners (epidemiology)*

Three of the studies dealing with cancer diagnoses and cancer pain among prisoners were found within sampled studies (Davies *et al.*, 2010; Lin and Mathew, 2005; Mathew *et al.*, 2005). A study by Mathew *et al.* (2005), explored the rise in both the Texas prison population and the increase in the number of cancer diagnoses. Cervical carcinoma among women and lung cancer among men were highest in prevalence. This study also found that inmates had more cancer deaths than SEER (Surveillance Epidemiology and End Results) cohorts, and the median survival was lower in the inmate cohorts than the SEER cohorts and MSEEER cohorts. The study by Davies *et al.* (2010) supported these findings. Additionally, the majority of deaths from cancer died in hospitals or in hospices, not in the prison environment. Lin and Mathew (2005) examined prisoners and cancer pain, revealing that 81 percent of inmates with cancer reported untreated and severe pain.

#### *The need for end-of-life care for inmates*

Among sampled studies, seven argued or assessed the need for end of life care for inmates (Bolger, 2005; Byock, 2002; Cohn, 1999; Dubler, 1998; Prison Reform UK Trust, 2008; Reviere and Young, 2004; Zimmermann *et al.*, 2002). Byock (2002) argued for provision of adequate end of life care for prisoners and described this population as a highly marginalized group. Cohn (1999) and Dubler (1998) also seemed to take a human rights perspective by arguing that failing to provide end of life care for prisoners based on social bias is inhumane and unethical.

Prison Reform UK Trust (2008) identified the need for end of life care by describing a lack of care in UK prisons. Bolger's (2005) study argued that palliative care for inmates should be offered and expanded in the UK as inmates are also part of the larger community. Zimmermann *et al.* (2002) found a majority of sampled inmates lacked any knowledge of hospice care, and when given information about it, they expressed interest in participating in and receiving hospice care. As per the study by Reviere and Young (2004), it has been established that older prisoners' access to prison health care systems and services, including hospice care, were the same as that of their younger counterparts, although their healthcare needs were different from those of younger inmates. As shown above, several studies showed the need for providing end of life care for prisoners. However, there appeared to be a gap in the research literature on how to provide



an individualized patient centered comprehensive needs assessment such as may be more consistent with palliative care philosophy.

### *Compassionate release law, policies, and practices*

Compassionate release may be a more cost-efficient alternative for reducing the expense of caring for dying prison inmates. It has been described as a preferred end of life care choice for terminally ill inmates (Granse, 2003). In the USA, all but five states have mechanism to petition for early release, but medical parole is not easily granted. The obstacles include an unfavorable political climate, societal bias, the conservative nature of bureaucratic systems, and concerns for public safety (Granse, 2003; Williams *et al.*, 2011).

As a result of diverse public opinion and complex sentencing laws, medical release remains relatively rare, and often, inmates die before their petition can be granted (Williams *et al.*, 2011). According to Zimmermann *et al.* (2002), more than one half of sampled inmates reported lack of stable housing as impacting their ability to apply for compassionate release. Limited social support and the special circumstance of inmates (e.g. the lack of an establish community residence or the lack of family members capable of caring for an ill inmate patient after their release) also serve as a barrier for dying inmates and compassionate release.

Of the 49 articles, compassionate release was specifically described within only three studies (Beck, 2007; Boothby and Overduin, 2007; Williams *et al.*, 2011). Two non-empirical studies discussed flaws in the eligibility criteria and the review process of compassionate release programs, and recommended ways the programs might be altered to serve deserving inmates fairly (Beck, 2007; Williams *et al.*, 2011). The study by Boothby and Overduin (2007), the only empirical study dealing with compassionate release identified in this sample, examined college students' attitudes toward compassionate release. Further research will be needed with more relevant stakeholders to better understand the potential cost benefit and need for comprehensive discharge planning for terminally ill prisoners who may be eligible for compassionate release.

### *Prison hospice program*

In the absence of a compassionate release option, prison-based hospice care strives to meet the needs of terminally ill inmates by providing care and symptom control with a multidisciplinary and holistic approach to care for patients. Reviere and Young (2004), examined the accessibility of health and mental health care for prisoners and discovered that hospice services in the USA were more likely to be offered on-site (28 percent) than off-site (23 percent). Studies in the sample that primarily examined or discussed prison hospice programs were all from the USA and reflected two main themes:

1. an examination of critical components of existing prison hospice programs and potential barriers to successful implementation (Bauersmith and Gent, 2002; Boyle, 2002; Craig and Craig, 1999; Evans *et al.*, 2002; Hoffman and Dickinson, 2011; Linder *et al.*, 2002; Maull, 1998; Taylor, 2002; Tillman, 2000; Wright and Bronstein, 2007a; Yampolskaya and Winston, 2003); and
2. the impact of prison hospice programs on the prison environment as an organization (Bronstein and Wright, 2006; Loeb *et al.*, 2013; Maull, 1991b; Smith, 2000; Wright and Bronstein, 2007b).

Involvement of inmate volunteers (9/10) and an interdisciplinary team approach (9/10) were the most frequently cited components to implementing prison hospice programs. As noted in the literature, the interdisciplinary approach has been noted in the palliative care literature to be an essential component for end of life care. The interdisciplinary team has been distinguished in the palliative care research literature as different from a multidisciplinary team in that it is the interactions between the different specialties in care planning, along with the patient care unit that comprises essential components to the team model (Byock, 1997; Loeb *et al.*, 2013). These findings were consistent with a study by Hoffman and Dickinson (2011), which described commonly shared characteristics of existing prison hospice programs. A more recent study by Loeb *et al.* (2013) has provided an opportunity to examine the volunteer prisoner's voice as a

member of the interdisciplinary team. Staff training (7/10) and partnerships with community hospices (6/10) were also frequently cited as important elements in prison hospice programs. Completion of DNR and/or advance directives were also one of the elements most often cited (7/10). As per the study of Hoffman and Dickinson (2011), only one-third of prison hospice programs required a patient's DNR order for admission.

Additionally, the literature indicated barriers to expanding programs. The most frequently cited barriers were restrictive visitation procedures (8/10), followed by safety concerns (7/10). Meeting the special needs of patients (availability of foods, bereavement services, and pain control) were identified as barriers to providing effective hospice care. In all, 29 percent of prison hospices allowed patient inmates daily or almost daily visitors (Hoffman and Dickinson, 2011). According to Reviere and Young (2004), 92 percent of the sampled prisons reported offering bereavement counseling on-site.

Five of the sampled studies explored the influence of prison hospice programs on inmate patients, inmate volunteers, and the prison as an organization (Bronstein and Wright, 2006; Loeb *et al.*, 2013; Maull, 1991b; Smith, 2000; Wright and Bronstein, 2007b). These studies showed hospice as having a positive impact on individual prisoners, volunteers and staff, as well as positively impacting the institutional environment of the prison.

The most cited positive impact of the program was noted among prison peer volunteers, who often reported experiencing personal transformations, such as increased self-esteem and feelings of compassion for others. Those studies revealed that the entire prison environment could be positively changed by the group observation of dying prisoners being provided care with dignity. Correctional staff members were able to change their views of prisoners as "non-humans" to being human beings deserving care as opposed to punishment. Moreover, staff and prisoners were able to establish more trust-worthy connections through collaboration in the prison hospice program.

#### ***Barriers to treatment***

Although there were many diverse barriers discussed in successful implementation of prison hospice programs, the following issues were most frequently cited in the research study sample: mistrust between staff and inmates, potential misuse of pain medications, safety concerns, and negative public attitudes toward compassionate end of life care for the prison population (Chandler, 2003; Courtwright *et al.*, 2008; Granse, 2003; Linder and Meyers, 2007, 2009; Loeb *et al.*, 2011; Turner *et al.*, 2011; Wood, 2007). Courtwright *et al.* (2008) argued that bureaucracy and prison restrictions caused barriers to providing effective palliative care to prisoners, and Chandler (2003) critiqued an increase in for-profit prisons along with a punishment-centered culture as causing reduced access to palliative and end of life health care.

To overcome barriers to accessing effective end of life care for terminally ill prisoners, Granse (2003) and Linder and Meyers (2009) emphasized the distinctive role of social workers within the prison system. Loeb *et al.* (2011) argued that partnership with the community, effective staff training, and the use of frontline workers who fully understood the balance between care and custody could be helpful in overcoming the challenges. Turner *et al.* (2011) suggested enhancing the collaboration between community hospice staff and prison staff as possibly an effective means of bringing positive changes in the delivery of care. Finlay (1998) provided guidelines developed to clarify security procedures for prisoners needing to access outside medical care. In an article by Ratcliff and Craig (2004), the authors offered information about the GRACE project, which developed standards of prison hospices and provided guidance materials for prisons.

#### ***Disparities in treatment in international corrections***

Three of the studies assessed the current state of palliative care in prisons and differences in care between nations other than the USA (Dawes, 2002; Lum, 2003; Stone *et al.*, 2012). Dawes (2002) and Lum (2003) introduced the prison hospice model developed in the USA and argued that it should be adapted into prison settings in Australia and New Zealand. Also, the study by Stone *et al.* (2012) emphasized the disparities between the US model of care, which emphasizes

the use of in-prison hospice care, and the UK model that stresses palliative care in-reach for dying prisoners and cites only one prison hospice in operation.

## Discussion

This study sought to build upon the literature by systemically and critically examining methods and major findings of the peer-reviewed literature on palliative and end of life care for prisoners. Even though we recognize that the importance of this research topic has received greater recognition recently, the research conducted in this area remains in its infancy. As noted in the findings section, the majority of articles were conceptual and theoretical, and the number of empirical studies was relatively small with very little rigorous methods for evaluating program effectiveness. In terms of methodology, all sampled empirical articles were cross-sectional and most of them employed non-probability samplings and small sample sizes. Concerning the use of informants, most data were based on inmates or staff, but none of the studies used family members; suggesting this may be a forgotten population when working with dying prisoners.

In general, these findings bring to light prisoner and human rights as an area of policy debate. For example, in 2011, severe overcrowding and inadequate medical care contributed to a Supreme Court decision in favor of prisoners' rights. In this ruling, the court found that providing little to no health care for severely ill prisoners had violated prisoners' constitutional rights. This poor provision of care has contributed to accelerated illness, suffering, and death (Stone *et al.*, 2012). Similarly, in the *US Supreme Court decision of Brown v. Plata 131 US 1910* (2011) Justice Kennedy stated: "For years the medical and mental health care provided by California's prisons has fallen short of minimum constitutional requirements and has failed to meet prisoners' basic health needs. Needless suffering and death have been the well-documented result" (p. 3).

Beginning in the 1970s, compassionate release and medical parole laws, especially in the USA, also were passed into law (Maschi *et al.*, 2012). In theory, these laws are a possible cost-efficient option for the care of dying inmates when the additional level of security is not needed. However, these laws are rarely ever used despite the research finding have shown more public support compassionate release of the terminally ill persons incarcerated for nonviolent offenses compared to those with violent offenses. A 2012 survey conducted by the PEW research center found that the majority of US citizens supported policy changes that would shift non-violent offenders from prison to more effective, less expensive alternatives (The PEW Research Center, 2012).

### *Toward compassion and palliative care rights in prison*

The UK has long been considered a leader in the end of life care since Dame Cicely Saunders emerged as a leader in the hospice movement in the 1960s. Recent research into cross-national comparison of end of life care services determined end of life care provision in the UK and Australia to be ranked first and second on the Quality of Death ranking index while the USA ranking ninth among 40 nations (Economist Intelligence Unit (EIU), 2010). It has been suggested that contributing factors to these higher rankings in the UK and Australia can be attributed to increased public acceptance and awareness of end of life care along with universal access to end of life healthcare (EIU, 2010). These factors, combined with negative public attitudes toward death and a primary focus on curative treatment in the USA, are suggested to contribute to the USA lower ranking (EIU, 2010). However, as noted in this content analysis on end of life care in the prison system, the overwhelming majority of research on palliative and hospice care in the prison system has been conducted in the USA. It has yet to be determined to what extent these palliative care promising and best practices can be infused within international correctional systems.

### *Practice implications*

The United Nations has provided recommendations to its member states for creating specialized compassionate care responses to special needs populations, such as older prisoners and the terminally ill. These provisions include recommendations for courts to review and revise, if needed, sentencing policies. This would include minimal use of long-term

sentences (unless community safety is a concern) and the development of alternatives to incarceration and diversion programs for older, seriously or terminally ill offenders (UNODC, 2009). For prison management, the following UN recommendations include: developing special strategies for older prisoners; obtaining the input of a multidisciplinary team of prison specialists who work in conjunction with community service providers; providing geriatric-specific staff training and encouraging staff to participate in community organizations to best ensure a continuum of care; assisting older prisoners in accessing legal counsel and services to reduce discrimination based on age or disability status; conducting initial and ongoing comprehensive assessments to identify the varied and changing needs of older prisoners; providing appropriate accommodations, including special units within prisons; ensuring health care needs such as medical, nutritional, and psychological health, social engagement with interdisciplinary staff, and special programs to address mental health and psychosocial concerns; and placing older prisoners close to their home to maintain family and community contacts, including the use of family visit programs (UNODC, 2009).

Other relevant recommendations specific to terminally ill prisoners included the establishment of palliative and end-of-life care practices and policies with ongoing: services of qualified interdisciplinary professionals; medical and psychosocial/spiritual assessment and care plans; 24/7 staff availability; counseling services by qualified counselors or social workers; and spiritual care provided by a qualified chaplain of the interdisciplinary team (UNODC, 2009). In general, governments, local correctional institutions and advocates can use these UN guidelines as a benchmark to the extent to which current policies and practices meet the special needs of older adults in prison and enhance their right to well-being.

The United Nations Standard Minimum Rules for Prisoners, which assure the equality of treatment and service accessibility, is designed to apply to all prisoners without discrimination (UNODC, 2009). As described above, prisoners should have equal access to care, including palliative end of life care. Governments and other authorities should take necessary actions, including implementing effective policies and appropriate administrative procedures, encouraging reinforcement of partnerships with the community, improving staff training, promoting inter-disciplinary team interventions and research, and conducting research to better understand public attitudes toward special needs for prisoners.

### *Policy implications*

These findings also have important policy implications, especially given available United Nations and Human Rights Guidelines that specify the rights and needs of compassionate healthcare for the aging, serious and terminally ill in prisons (Maschi *et al.*, 2013). At the grassroots and national levels, advocates and governments should assess the extent to which human rights declarations, covenants, and conventions are being realized. As this review suggests, despite laws and policies that guarantee prisoners' rights to healthcare and compassionate release for the serious and terminally ill in prison, there are still attitudinal and systemic barriers to their implementation. The global movement toward multi-stakeholder evidenced informed and evidence-based policymaking, which would incorporate the voices of the incarcerated and their families, in the decision-making process make help to overcome these barriers to realizing palliative care approaches in prisons. The call for a United Nations working group to address serious and terminally ill in prison is certainly warranted.

New developments in national palliative care standards also are useful to prison settings. For example, the National Consensus Project for Quality Palliative Care identified eight domains to address multiple domains of well-being for the effective provision of a holistic approach to hospice and palliative care. These domains include: structure and processes, physical, psychological and psychiatric, social, spiritual, religious and existential, cultural, care of patients at the end of life, and ethical and legal (NCP, 2013). Specifically identified within these domains are care needs specific to the need for social, spiritual and cultural aspects of care, along with attention to the family and the importance of bereavement support. Given that the prison population consists of a diverse population, the incorporation of a multi-dimensional approach that addresses health and well-being are important avenues to pursue, especially for the ethnically diverse terminally ill in prisons and their families.

### *Limitations of the current review*

Due to methodological limitations, the results and conclusions of this content analysis on palliative and end-of-life care in prisons should be interpreted cautiously. First, although a comprehensive search of 69 research databases available in the USA was used by the research team, the search was more than likely not exhaustive. There may be additional empirical articles available that were conducted in other countries that would shed further light on the state of palliative and end-of-life care in prison. Second, although multiple coders were used to select the sample of articles, classify the studies, and analyze the findings, there is no absolute guarantee that other research teams may obtain different results. Third, the content analysis categories and themes were developed inductively by the research team. It is quite possible another research team might have devised different content analysis categories and frequency counts based on their analyses. Yet, despite these limitations, this comprehensive assessment of the methods and major findings of the research on palliative and end-of-life care in prisons, offers insight into the next steps for research and evaluation to improve conditions for the old and serious and terminally ill persons in prison and their families and communities.

### *Future directions for theory and research and evaluation*

The results of this content analysis results also suggests future directions for theory development and refinement and research and evaluation. Our results showed that theory has been used in empirical studies that address the older and seriously ill and dying in prison. Several researchers and scholars offer insight on future directions for theory development that centers around core themes raised in this review related to human development, systems of care, and power structures. Given the unique social context of prison, Scheidt and Norris-Baker (2012) suggested the usefulness of ecological theory to guide research with the serious and terminally ill in confined setting. Wahidin (2004) suggests using need for a “Foucauldian lens” (p. 44) to assess how the prison power structure influence access to incarcerated persons health care needs and experiences of confinement, surveillance and punishment, particularly for women aging in prison. Phillips *et al.* (2011) used Prospect Theory to explain incarcerated persons medical decision-making process as it relates to their functional ability and the prison context (Kahneman and Tversky, 1979). The theory posits that people will select the option with the highest subjective value over the highest objective gain. In partial support of the theory, the authors found that terminally ill prisoners’ who considered the prospect of being paroled as opposed to their level of functional capacity were more likely to want active treatment and to want to remain alive longer.

Maschi *et al.* (2012) propose an interdisciplinary holistic theory, the Social Context Model (SCM) of Human Development and Well-Being for assessment and intervention. The SCM model integrates multiple perspectives, such as human rights, the life course perspective and social justice/oppression and ecological systems theories. This perspective allows for the three dimensional lens that assesses from birth to death cumulative interpersonal and social/structural inequalities that often occur to social disadvantaged groups. The culmination of these lifetime cumulative disadvantages (e.g. age, race/ethnicity, social class, and disability and legal status) may account the all too often reported undignified treatment of the older and seriously ill populations in international prisons. Based on this analysis a human rights-based that integrates human development, social environments, and power structures is warranted. This approach is promising toward addressing the multilevel longitudinal factors that fuel the proliferation of the aging, seriously ill, and other marginalized populations in prisons and understand and eradicate the barriers toward providing more compassionate and palliative care practices in prisons.

Future research studies should target the multisystemic barriers and facilitators to providing palliative care in prisons. Research can serve as an important tool to document human rights violations, especially in regards to the treatment of the aging and serious and terminally ill in prison and their families. A largely overlooked area of research is the stigma and biases that fuel the general public and criminal justice staff’s attitudes toward the intersection of aging, death and dying, and crime and punishment. More research is needed on the development and implementation of evidence-informed and evidence-based policymaking in regards to United Nations guidelines and local, national, and international laws and policies that impact the

treatment of the seriously ill and dying in prison, such as palliative care and compassionate release laws and their cost effectiveness. Documentation and evaluation of criminal justice reform advocacy efforts and public awareness campaigns, especially sentencing and parole release reforms, also are needed that address the development and implementation of guidelines, laws, and policies that affect individuals with disabilities and serious and terminal illness in the international prison systems.

At a practice level, evaluation studies need to be conducted that document the infusion of palliative care and hospice models in corrections, hospice programs, strategies for successful care transitions from prison to the community, family and peer support models, and patient centered care. Of particular concern is how service providers integrate care vs custody concerns in the prison environment (Wright and Bronstein, 2007a). As Hoffman and Dickinson (2011) suggest that the hospice care model has been adapted to serve “the unique circumstances of the prison environment” (p. 251). However, as shown in this content analysis, attempts to measure successful implementation used only prison staff, prison volunteers and hospice staff. Since palliative care is an interdisciplinary approach that involves the patient and family as the unit of care, future studies should incorporate the patient, family, and interdisciplinary team perspectives to evaluate the extent to which multidimensional well-being, grief and loss and bereavement rights and needs are being met.

A wide variety of research methods also can be used. Cross-sectional descriptive studies that document the treatment of terminally ill prisoners and their families can be used for local advocacy efforts as well as cross-national comparisons. The incorporation of innovative research methods that include providing longitudinal mixed methods designs to incorporate culturally responsive measures of patient-centered care can document process and outcomes of the infusion of palliative care and prisons to better inform evidence informed and evidence-based policy making. Alternative research methods, such as participatory action research methods, can be used as an empowerment tool, especially with the incarcerated and formerly incarcerated in designing and implementing programming. Strategies, such as photo voice, can be used to gain the images and experiences of the terminally ill and dying in prisons and their families, and build public awareness surrounding these issues. Since corrections, in theory, is designed for rehabilitation and restoration, studies should examine the experiences of human and spiritual development, especially the role of compassion, mercy, and forgiveness and personal transformation among volunteer caregivers may better describe the of effect reestablishing purpose and meaning to successful community reintegration.

## Conclusion

Palliative care in prisons is an often over looked right to health, especially among people in prison. Human rights advocates, journalists, and scholars have documented cruel and unusual practices, such as chaining the dying to their bedposts and the denial of pain medication to incarcerated persons with substance use histories. The questions raised by the treatment of the serious and terminally ill in prison suggests that we need to open our eyes to the pain and suffering of the sick and dying in international prisons and offer mercy with or without forgiveness. An infusion of a palliative care paradigm in correctional care necessitates that correctional staff and the society at large must move beyond thinking that fosters the punishment paradigm to a more compassionate palliative approach that all humans deserve.

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