# 3 page summary of grant titled: Exploring Palliative Care in Corrections Centre for Forensic Behavioral Science and Justice Studies Faculty Research Grant Program Proposal

# 1. Rationale:

Managing terminally ill offenders within the prison milieu is a time consuming, resource intense, exhausting endeavor, one that is fraught with perplexing practical and moral dilemmas not commonly encountered in traditional health care settings. A recent comparative review of prison palliative care from an American and British perspective concluded "the limited available literature on prison hospices may suggest an attitude of less value being placed on EOL care for incarcerated individuals" (Stone, Papadopoulos,& Kelly, 2012, p.2). No Canadian studies on prison palliative care from a global perspective with emphasis on informing end of life care within the Canadian context.

## 2. Research question(s):

The overall purpose of this scoping review is to explore and synthesize the global evidence and knowledge base currently available to guide research, practice and policy in palliative care in the prison milieu, as a first step in identifying concepts, theories, sources of evidence and gaps in contemporary research. The specific research objectives are to:

- a) systematically search and retrieve all literature relating to the provision of palliative care in the prison/correctional milieu, including reported outcomes;
- b) critically appraise these studies and reports; and
- c) synthesize the findings.

## 3. Methodology:

In a discussion of knowledge synthesis, Grimshaw (2013) purports that reliable, reproducible, and explicit methods must be used to best inform policy, practice and future research. Scoping reviews utilize rigorous transparent approaches thereby allowing researchers to critically examine the extant literature and identify key themes, summarize and disseminate research findings across a body of literature, and clearly identify gaps in the existing research (Arksey & O'Malley, 2005). Specifically, the following steps were addressed: Create Potential Inclusion Criteria: a) all studies and documents pertaining to the care of prisoners at the end of life (all genders, age 18 and older) and the provision of end of life care; b) studies published in English regardless of country of origin; c) published and unpublished studies (such as theses); d) quantitative, qualitative and mixed methods designs, as well as policy and anecdotal documents; and e) all papers dated between 1990 and 2014.

After the team agreed on the final eligibility criteria for the studies and documents to be included, a comprehensive literature search of multiple databases was carried out by an experienced librarian (team member, Vicky Duncan) who ensured the most complete data set was collected. All potentially eligible studies and documents were retrieved to assemble a complete data set, data extracted and a quality appraisal was completed. extract the data and complete a quality appraisal of all studies. The data was analyzed to identify key themes and research foci.

## 4. Findings:

## a. Sample:

- N=128
- Research articles: 32 (includes mixed, syntheses, surveys, qualitative and quantitative)
- Grey literature: 96 documents (includes chapters, anecdotal articles, guidelines, theses)

Country	No. of Articles	Research	Grey Literature
Australia	2	1	1
Canada	5	1	4
France	1	0	1
New Zealand	1	0	1
South Africa	6	0	6
Switzerland	2	1	1
Uganda	1	0	1
United Kingdom	18	5	13
United States	92	24	68
TOTAL	128	32	96



#### PRISMA 2009 Flow Diagram



#### b. Model: The Context of Palliative Care in Corrections

A model was developed that synthesizes the key themes of the findings. The model depicts the levels of individual, relational, institutional and socio-cultural as encompassing the key concerns and considerations that emerged from this scoping review. The individual level describes the many concerns of the inmates in regards to palliative care and end of life in a prison setting. The relational level involved interactions between inmates, staff, health care, and family. The iinstitutional level included constraining policies, costs, physical design, HR issues, and knowledge gaps while the socio-cultural level included an atmosphere of care, human rights vs. punishment, stigma around CR, costs and limited resources.

Extensive guidelines, standards and exemplars for palliative care in corrections were identified, including the GRACE project, United Nations Minimum Rules for Prisoners, the Angola prison as a model, the National Commission on Correctional Health Care and Correctional Service Canada. However, there was little evidence of adoption of these guidelines, and further research is needed in the area, particularly in the Canadian setting.

Many benefits to offering palliative care in prison settings were identified including costeffectiveness, enhanced correction, and human and legal right to care and the transformative experience of the inmate peer caregiver. These benefits highlight the multi-faceted importance of access to palliative care in correctional settings. As such, greater facilitation and support of palliative care provision is imperative to meet the EOL needs of ailing inmates, contribute to the overall goals of corrections, manage health care costs, and promote respect for all persons.

#### 5. Conclusions:

At the level of the individual, prisoners remain voiceless, with a need for information and sensitivity. At the relational level nurses need to get involved in identifying areas for improved care, training inmate volunteers, lobbying for change, and talking to families. At the institutional level the policy regarding inmate caregiving, family visitation, restrictions, prison design, and general policy and procedures needs to be addressed. There is a lack of research (particularly in Canada) on prisoner's health/deaths in prison, despite key statements regarding the need for it. Poor inmate health, aging populations, and special needs of older inmates demand our immediate attention.

#### **6. Implications:**

Few studies have acknowledged the influence of emotional biases of security personnel and prison administration on access to palliative care for the incarcerated. Very little accountability exists to ensure ethical decisions are made, and the literature lacks in providing concrete recommendations for improving palliative care within correctional settings (instead giving general guidelines). Finally, very little literature has given a voice to the offenders themselves or their families, or has suggested how the community can become involved directly or through program support.