

# Journal of Rural and Community Development

## Palliative and End-of-Life Services in Rural and Remote Geographies

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## **Introduction**

# **Palliative and End-of-Life Services in Rural and Remote Geographies**

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This special issue of the *Journal of Rural Community Development* provides a focused presentation on current research and knowledge translation initiatives in the area of Palliative and End-of-Life Care in rural Canada. The literature reviewed in the background for each of the papers collectively contributes to our understanding of the gaps in provision of palliative care resources and services to individuals, families and communities in rural settings. Additionally, the range of methodologies used by the researchers highlights the complexities that inform the development of knowledge to address palliative and end-of-life care needs given the diversity of Canadian rural geographies and provincial/territorial health care systems.

The articles in this journal capture palliative and end-of-life research across the rural continuum: from local to national levels and from care providers to care recipients. This special issue represents the first time that such a collection of knowledge gained from this wide range of perspectives which links the rural context to palliative and end-of-life care needs has been made available. The first paper in this special issue, by Dykeman and Williams, *Mobilizing Outcomes from a 5-year Research Program addressing 'Timely Access and Seamless Transitions in Rural Palliative/End-of-Life (P/EOL) care in Canada': A Knowledge Translation Strategy*, provides an overview of a national-level, rural-based Canadian study. The extent of the work performed by this interdisciplinary cadre of researchers has been commendable. The multi-site studies have enhanced our awareness and stimulated change in an area of health care that has received limited academic, policy or health services attention. The paper by Dykeman and Williams is followed by DeMiglio and colleagues *Evolution of Palliative Care in Ontario: The Impact of Geography, Funding and Advocacy*. Readers will gain an understanding of the narrow history of palliative and end-of-life services in our country. These two articles solidify the need for continued researcher and stakeholder collaboration, knowledge translation efforts and patient interventions to expand rural services and resources.

The third article, “*Community capacity building in palliative care: An illustrative case study in rural Northwestern Ontario*,” by Kelley et al., describes the development of palliative care services in two rural communities. This study, built through the initiatives led by the community, presents a model for palliative care service creation and for program development. One of the key findings was the momentum for change that coincided with the program growth and the importance given to the model as supplying a much needed foundation for organization, policy and future planning.

In the next article by McIntosh et al., a description of the evaluation of a tool for the development of a care team for rural palliative care services is provided. In this article, *Evaluating Use of a Toolkit to Enhance the Capacity of Rural Communities to Provide End-of-Life Care*, the authors provide results from their study identifying the benefits and challenges for rural professionals in creating a team approach to end-of-life care and assessment of rural resources. This evaluation study suggested a need for the refinement of tools for rural communities that can be modifiable while also addressing the distinct nature and uniqueness of rural communities.

In contrast to the toolkit developed for rural care teams, *Development of a “Changes Toolkit” for Rural Older Palliative Patients and Their Family Caregivers*, by Duggleby et al., documents the process used to develop an important resource for rural palliative care patients and their caregivers. The authors, guided by the theoretical framework, “Navigating Unknown Waters”, evaluated the use of the toolkit as an intervention to assist with the transition to palliative care in a rural setting. An important finding from this study was the participant’s positive regard for the usefulness of the toolkit to guide patients, families and caregivers during transition to palliative care and as a communication tool to facilitate dialogue.

There is one article in this special issue that contributes to knowledge development in patient-provider communication for rural palliative care. Focused on understanding interactions between rural palliative care patients and their professional caregivers, Penz et al. in *Palliative Care Professionals’ Perceptions of Effective Interpersonal Communication in the Context of Caring for Older Adults in Rural Settings*, move the discussion of rural palliative services towards a meaningful presentation of the elements that contribute to positive patient-provider relationships in the context of rural caregiving. The voices of the participants in this study illustrate the perceived mutual benefits, for rural patients and caregivers, when care was facilitated with a vested interest in the quality and timing of communication about prognosis and illness trajectory.

In the paper, “*This is just where I live*”: A Situational Analysis of Rural Caregiving, McIntosh and colleagues report the findings from the perspective of female caregivers living in a geographically rural community. The initial aim of the study was to explore the effect of rural location on female caregivers, with the researchers learning that rural geography did not lead to the conceptualization of the analysis. The resulting analysis, illustrated through excerpts from their interviews with participants, provides a new conceptualization of female gendered caregiving as a “dislocated self.”

The last paper in this issue focuses on the profession of nursing and perceptions on providing care in geographically rural environments. In *Barriers and Facilitators to Providing Palliative Care in Rural Communities*, Kaasalainen et al. highlight

the voices of rural nurses and their efforts to provide quality palliative and end-of-life care. This paper contributes an essential acknowledgement for access to palliative care training for nurses and the “sense of community and cohesiveness” that are weaved into the intricate fabric of life in small communities and benefit the patient, family and caregivers.

In reading this issue there is a common theme – palliative end-of-life care services need to be available and structured to take into account the individuality and personality of the patient, family, caregiver, the community and the local team of caregiving resources. There is no “one size fits all” approach to rural palliative services; however, the benefit from a broad exploration of end-of-life caregiving and resources is the development of templates that can be modified to “fit the essence of a rural community.”

We would like to thank all of the authors who contributed to this special issue and the Journal of Rural Community Development for the opportunity to be involved in the creation of this seminal collection of Canadian research in the area of rural palliative and end-of-life care. The ongoing development of the important research, interventions and knowledge translation efforts will assist patients and caregivers in their transitions through the “unknown waters” in the trajectory of rural palliative care services.