Title of Research Study: Enhancing provision of Palliative Care by Physicians: A demonstration project integrating primary care and interdisciplinary specialist palliative care.

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Main Research Question
How can an expert palliative care team work with family doctors and their patients to best manage patients’ needs at the end of life?

Rational
Primary health care providers, particularly family physicians, are the first line of contact for patients and families. They play a critical role in facilitating access to effective palliative care that contributes to improvement in the quality of dying. Yet, most family physicians in Canada have received little or no training in palliative care and repeatedly identify difficulty in accessing interdisciplinary resources to address the complex issues faced by patients/families at the end-of-life. Because of the multiplicity and complexity of issues involved, ranging from appropriate pharmacotherapy to coping with death and grief, these issues can rarely be addressed by a single practitioner. This has resulted in reports of sub-optimal care at the end-of-life with documented empirical evidence of unrelieved symptoms and intolerable emotional distress in the last days of life and high rates of dying and death in Canadian hospitals. This occurs, despite the fact that the majority of Canadians express a preference to be cared for and to die in their own homes. Effective palliative care that supports care and death at home is not only achievable but also highly desirable and cost-effective. However, it requires the application of palliative care knowledge and skills by primary care physicians combined with a specialist palliative care physician and interdisciplinary team working collaboratively to address complex patient/family needs through integration of services and care approaches. Family physicians have identified the need to have advice from, and shared responsibility for care with palliative care services that are available during evenings and weekends. The need to reform the primary health care system’s delivery of effective palliative care is urgent since the demand for palliative care will increase with an aging population and a rising prevalence of cancer.
**Purpose**
The purpose of this project is to improve and enhance the ability of primary care physicians to deliver effective palliative care, through the development of an integrated community-based palliative care program encompassing 24/7 access to specialist palliative care consultants, interdisciplinary supportive care, practice-based education and Continuous Quality Improvement (CQI) processes, tools and resources.

**Sample Size**
An estimated 100 palliative care patients annually from 3 practices will be eligible for the program with an average monthly caseload of 16 patients and an average length of stay in the program of 120 days. These estimates were made from the current WLPCT statistics. The demonstration model will be deployed to those patients identified as Palliative using specific screening criteria in these three group practices.

**Methodology**
This is a demonstration project of enhanced provision of palliative care that integrates family physicians and an interdisciplinary specialist palliative care team. The evaluation will use a mixed methods study design combining quantitative survey information, administrative data and qualitative perceptions of the participants on their experience of the quality of care. A number of validated instruments will be used for measuring outcomes.

**Study Interventions**
1. *Case-finding in the family practice office to ensure timely patient/family access to the project intervention at the primary care point of contact.*

2. *Define the role of the Palliative Care Resource Nurse both in terms of hours of service delivery to the community and to include the role as community organizer, coordinator and navigator:* The resource nurse will have advanced practice skills in Palliative/End of Life care. The nurse will be the point of contact in a triad with patient and family physician. The nurse will also act as a support for other service providers involved in care (spiritual care advisor, visiting nurses, and other allied health professionals). The explicit goal is to ensure that the family physician and the patient have timely access to services and solutions to expressed needs and expectations, as outlined in the “square of care” in the CHPCA Model to Guide Hospice Palliative Care (3) (pg 27, 99). The resource nurse’s enhanced role on the demonstration project will be a pivotal component of the proposed program.

3. *Provide shift care funding for community nurses to provide urgent respite care in the patient’s place of residence (not in acute care):* Palliative care client statistics for west Niagara over the past 5 years reveal an over reliance on hospital admissions to deal with caregiver burnout and crisis symptom management. Extrapolating patient trends from the WLPCT suggest that in the demonstration model, approximately 2 patients from each study practice per month will require several days of respite care, to avert hospital admission and manage care at home. These services need to be above and beyond the services currently available via CCAC.

4. *Provide a psychosocial/spiritual/ bereavement care expert(s) to the team:* Currently, there is no timely access to specialized psychosocial, or bereavement care and spiritual care is inadequate to meet the need. The existing caseload for patients in the practices included in the demonstration...
model suggests that a 0.5 FTE psycho-spiritual advisor and a 0.1 FTE bereavement expert would be necessary to meet current needs.

5. **Create a shared care clinical and educational model, based in the family physicians office and involving the primary care practice based providers, and the interdisciplinary team:** The family physicians in the demonstration model practices have articulated the need for mentoring/teaching by the Palliative Care physician, in their practices, and involving all members of the physicians’ practice team (nurses, pharmacists, medical students, residents). These clinical/educational multidisciplinary sessions would take place at each practice, twice a month during the demonstration project. Involving the learners in this model of care and educational opportunities was felt to be key. These sessions will involve consultations with patients, chart reviews, teaching, discussions of the literature, and team-based care-planning.

6. **Provide the family physicians with 24/7 access to the resources of the Palliative Care Team:** A physician practice leader will be designated from each of the two group practices, and provided with enhanced training. These two physicians, along with the resource nurse and Palliative care physician will provide 24/7 backup support to the family physicians in the three practices, for support for their palliative patients.

7. **Provide conjoint homecare visits –Family Physician and Palliative Care Team members:** The goal of the conjoint visit is to support the Family Physician in his/her decision-making and skills, and provide another tool for more effective team-based communication. The Family Physician will be encouraged to be the **main** provider of medical care, supported by the Team members.

8. **Customize and develop office-based tools and computer-based resources that allow the primary care team to continue best practice initiatives after the model time period is completed:** Both practices have expressed the desire to develop communication tools, data collection tools and assessment tools that can be used in their practices on an ongoing basis. These tools would be developed, and implemented during the demonstration model, and will continue to be used by the practices after the demonstration finishes.

6. **Primary outcome**
This project will measure:
- Patient and family reduction in symptom severity and distress within 7 days of program entry maintained until death.
- Patient and family perception of how well the quality of end-of-life care addressed needs (satisfaction).
- Timeliness of referral and access to palliative care and interdisciplinary services.
- Family physician knowledge of /comfort with provision of palliative care including advanced care planning.
- Primary care providers and specialist team members’ perception of collaboration, shared care planning/team integration and satisfaction.
- Reduction in emergency department visits and numbers of hospital deaths.
- Preferences for treatment at the end of life and location of death met.