Enhancing primary care capacity to deliver quality, population based Palliative Care: The Niagara West, Shared Care Model

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We are here on earth to do good to others. What the others are here for, I don’t know.

W. H. Auden
Why Community Care?

- Most Canadians with advanced progressive illness prefer to receive end-of-life Care at home.
- Most prefer to die there IF adequate supports is available to minimize suffering and burden on family caregivers.
- Patients suffer with transitions and long for continuity of care (Heyland et al).
Clinical issues
- Emotionally challenging but high degree of commitment
- Blurred distinction between private and professional life
- Social and geographic isolation
- Interprofessional team “gold standard” non existent
- Generalists trying to maintain knowledge and skills
- Inadequate role preparation since undergraduate education
- Specialists as asset vs undermine local skills?
- Lack of resources and support
- No 24/7 access to support or care
- Medications after hours
Canadian Background

- **Family physicians:**
  - view palliative care as an inherent and important part of their role (Lehman & Daneault, 2006; Marshall, Howell, et al, 2007)
  - potential to provide effective palliative home care given adequate knowledge, skills, confidence and timely access to specialist advice (Fainsinger, et al, 2001; Higgins on, 1999).
  - family doctors and specialists often fail to develop the collaborative working relationships that would protect patient-doctor relationship and strengthen the role of the family physician (Kasperski, et al, 2006).

- Shared care between specialists and primary care physicians in mental health, maternity care, and chronic diseases have shown improvement in timely access and improved health outcomes (Rocker, 2006).
Proposed solutions

- Willingness to provide care influenced by knowledge base
- Receptive to educational interventions
- Psychosocial aspects of care perceived as most challenging thus education on this
- Stress management
- Networking important to survive
- Interdisciplinary face to face interactive small group programs offered outside home community (LEAP)
4 Key components

- Universality
- Care coordination
- Ready access to a broad range of basic and advanced EOL services
- Assurance of EOL care regardless of care setting
  - Wilson et al
Why a Shared Care model?

- Primary caregivers are seldom able to address the multiple domains of care that occur at end of life.
- Primary caregivers repeatedly express the desire to be able to provide such care if given adequate support.
- Interprofessional, collaborative practice now known to be key to sustainability, efficiency and effectiveness of our healthcare system.
- Primary Health Care Reform.
What do we mean by Shared Care?

- Primary care providers in a team partnership of care with expert clinicians who *together share the care* of the patient in an *integrated and seamless way*
  - Primary care *gatekeepers*
  - Primary care *capacity is enhanced* and the pattern of practice is *sustainable* for the primary care providers (provider satisfaction)
  - Expert clinicians are *collaborative consultants*
  - Care is negotiated patient by patient
  - To the patient, care is *seamless* (patient satisfaction)
Components of Shared care models
Primary care...secondary care interface

- Defined population
- Patient identification
- Standardized assessment and process of care (mutually agreed upon)
- Education from specialist to primary care
- 24/7 access to specialist support
- Primary care does the “ABCs…”
- Specialists assess, reassess and do the “DEFGs…”
- Crosses care settings
- System navigation
Shared Care model in Palliative Care

- Are not new.....but they aren't widespread either...
- UK Gold Standards framework (across the UK)
- Pan Canadian Gold Standards
- Individual programs and services currently exist
- Shared care is a concept and based on a spectrum (Peirera et al)
- Overarching tenets and components, with locally driven customization
The Niagara West Palliative Care team (NWPCT) jointly funded program of West Lincoln Memorial Hospital, in Grimsby Ontario, and the Community Care Access Centre (CCAC) of the Hamilton Niagara Haldimand Burlington Local Health Integration Network (HNHB LHIN). Serve the three western municipalities of Niagara region in Ontario. Total population of approximately 80,000. 3 towns and large rural areas.
HNHN Local Health Integration Network
MODEL HISTORY

- 1996-Primary care physicians identified a need for increased access to Palliative care services and sought the help of a palliative care physician.
- 1996-97- A coming together of local resources, developing into a part time “team”.
- Initial funding was provided by West Lincoln Memorial Hospital.
- Referrals grew, data became available regarding hospital vs home care and cost savings to the hospital.
- 2003-2006- Primary Health care Transition Fund grant from the Ontario Ministry of Health enhanced the team to a full compliment of doctor, nurse, counsellor, administrative assistant, and collaboration with CCAC case management.
- Data from grant identified patient, family, caregiver (family MD and bedside nurses) satisfaction with care and efficient use of financial resources.
- Increased home deaths and home as primary place of care.
Enhancing Family Physician Capacity to Deliver Quality Palliative Home care: 
*The Niagara West End of Life, Shared-Care Model*

**Project Investigators:**
Principals: Dr. Denise Marshall and Dr. Doris Howell
Co-Principals: Dr. A. Taniguchi, Dr. J. Kaczorowski, Dr. K. Brazil, Dr. M. Howard.

**Funding:** MOHLTC, Primary Health Care Transition Fund Project
Purpose and Specific Aims

- **Purpose:** To improve quality of EOL care through implementation of a shared care model that integrated family physician care with specialist interdisciplinary palliative care.

- **Specific Aims:**
  - To build capacity of family physicians to provide quality palliative care 24/7 through academic detailing, role modeling and shared care.
  - Improve access to quality palliative care early in the EOL trajectory through best practice screening in GP offices.
  - Evaluate impact of model on patient/family outcomes; primary care provider outcomes; and health system outcomes.
Patient and Provider Outcomes

- **Provider**
  - Sustainable care
  - Increased capacity and confidence
  - “who to call for what”
  - Help in times of need

- **Patient and Family**
  - Satisfaction with care
  - Decrease symptom burden
  - Caregiver support

- **Health Care system**
  - Cost effective
  - Decreased hospital utilization
The consult team supports primary care.

Referrals for patients come from primary care doctors and bedside nurses in the community or hospital.

The team provides hands on consultative care wherever the patient currently is.

Care plans are implemented as a group and the family doctor remains most responsible MDs.

Bedside nurses are supported in their care plan by the nurse clinician.

“Who does what” is negotiated behind the scenes patient by patient and varies depending on the family doctor, the patient and their needs.

Practice based education and just in time teaching is an integral part of the service.
Integrated Care Model

PALLIATIVE CONSULT TEAM
Palliative Care MD, Nurse Clinician/Navigator, Psychospiritual and Bereavement Counselors
24/7 on call consultations to primary care MD and nurses
Designated CCAC Manager

ASSESSMENT and ACCESS
Standardized tools
Including ESAS, PPS, CAM and Distress Thermometer
Early Case finding in MD office

COORDINATION
Follows Patient Across Care Sectors
Seamless Negotiated patient by patient

EDUCATION
Family MD; Academic Detailing: “just in time” teaching; case based learning; Designated practice lead
Community nurse- advice and role
Primary Care Outcomes

- Family physician uptake - 100%
- Physician practice leads emerged from each FHT
- MD leads continuing with role
- Education became practice-lead
- Improvements made in non-pain symptoms, and patient communication and confidence in providing care
- High acceptability of the PC Nurse clinician as Coordinator
- Increases perception of ability to manage and feel capable to take on care (nurse and MD)
Provider Outcomes-Physician and nurse focus groups

- **Most valued components:**
  - Access to the team and oncall support

- **Impact on role and practice**
  - Confidence in decision making
  - Better anticipation of patient needs

- **Care coordination**
  - Comprehensiveness, quality of communication, nurse/md trust and respect

- **Impact on Care Quality**
  - Enabling home death, averting crisis, reduced fears of suffering
NATURE OF INNOVATION

- Integration with primary care
- Population based approach to seamless care
- Case finding to facilitate early access
- Practice based education to primary care
- Sharing clinical care - not take over care
- Palliative care nurse clinician as coordinator/navigator
- 24/7 access for primary care to access consult care as “second line”
- Primary care driven and maintained
- Communication is key to relationship
Costs Vary by Patient Need and Less than Hospital Day

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What is capacity? Capacity development?

- **Capacity** is the capability of individuals, groups, organizations or communities, to perform or produce something of value, related to their desired development or performance.

- **Capacity development** is the evolutionary process of change and adaptation that occurs from inside as individuals, groups, organizations or communities act to accomplish their goals.

(Chaskin 2001; European Centre for Development Policy Management 2003; Kaplan 1999)
Principles of Capacity Development

- Development is essentially about building on existing capacities within people, and their relationships.
- Development is an embedded process; it cannot be imposed or predicted.
- The focus is on change, and not performance.
- Change is incremental in phases, however development is dynamic & non-linear
- The change process takes time
- Development process engages other people & social systems
- Different levels and forms of capacity are interconnected in a systematic way (individuals, teams, organizations and communities)

(Kaplan 1999; Lavergne & Saxby, 2001)
Developing palliative care in Communities:
A four phase model
Mary Lou Kelley
Lakehead University 2007
family doctors report enhanced confidence to take on palliative care especially in the home setting

community nurses and doctors report enhanced sustainability of their work life and decreased stress of care

skills of both groups increased

“steady state” is achieved with a small consult team, of part time consult MD, full time nurse, part time counselors since care is shared

as primary care skills increase, team can shift to involvement with newer MDs and increase volumes without increasing team resources
FEASIBILITY AND ADOPTABILITY

- cheap, efficient and low tech
- can be adapted to any identified population to be served
- incorporates the ML Kelley community development model which outlines steps of development and sustainability
- community driven and sustained
ENABLERS

- High level of engagement from primary care
- Stable funding from hospital and local CCAC
- Logical collaborations between hospital sector and home sector
- "catalyst" (Palliative care MD) emerged early and lead for several years
- Consult team academically affiliated
- Local MDs academically oriented
- Robust clinical relationships and highly evolved interactions on an hourly, daily, weekly basis form the essence of the innovation
BARRIERS

- resistance to change took several years
- cultural shifts are required and this takes time
- needs champions and readiness in the primary care community
- purpose and process outcomes are vital but antithetical to government driven performance outcomes
- purpose/process outcomes evident early; performance outcomes require time for the cultural shift
EVALUATION

- patient and family satisfaction high
- providers ie family doctors and bedside nurse satisfaction very high
- distress scores decrease despite decrease in PPS
- costs for consult team less than cost of hospital days saved
- increased congruency between expressed preference for place of care and place of death, and actuals

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Growing Shared Care teams

- Expected Outcomes
  - Impact on Alternative Level of Care (ALC),
  - Emergency Room (ER)
- Growing Physician Capacity via Engagement
  - Education in all the ways that work
  - Mentorship, locally customized peer consultation
  - “putting the expert out of work”
- Building Community Capacity – the Kelley Model
- Patient and caregiver outcomes
  - Greater achievement of requested place of death
  - Fewer patient transitions in care
What matters most in end of life care: perceptions of seriously ill patients and their family members. Heyland et al. CMAJ Feb 2006 174(5)


Developing rural community capacity for palliative care; a conceptual model. Kelley et al J of PallCare August 2007 23;3

Building primary care capacity in palliative care; proceedings of an interprofessional workshop. Brazil et al J of Pall Care Summer 2007 23;2

Every system is perfectly designed to get the results it gets.

P Bataldin