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The Team Approach to Hospice Palliative Care: Integration of Formal and Informal Care at End of Life

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The Team Approach to Hospice Palliative Care: Integration of Formal and Informal Care at End of Life

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Key Implications for Decision Makers

The purpose of this research was to develop an integrated team approach for hospice/palliative care in the community. Implementing an integrated model of care that brings together both the formal and informal caregivers will result in improved care for hospice palliative care clients and their families.

- The four key features to an integrated hospice/palliative care system are improving communication, having a central co-ordinator, building community awareness of hospice services, and increasing the number of services offered.
- For a model of care to be truly integrated, there needs to be a unity of purpose that focuses on the needs of the patients and their families and builds on effective partnerships between formal (for example, doctors and nurses) and informal (for example, volunteer agencies, family members) care providers.
- Services should be provided in a regional network.
- There are six key activities to implementing an integrated system:
 - create community networks that use multiple points of access, customize care, and ensure minimum standards;
 - establish a provincewide information system;
 - develop a dedicated body to mobilize/co-ordinate a community response at the local level;
 - create and use innovative collaborative models to develop healthcare professional teams;
 - promote links between nurse practitioners, palliative care physicians, trained volunteers, informal caregivers, and other personnel; and
 - examine new management models.
- The research provides a detailed 15-point plan that shows how to implement an integrated model of care. It covers the following areas:
 - provincial policy framework;
 - governance entity;
 - network development;
 - situational analysis;
 - ideal systems planning;
 - integration of partners;
 - communication strategy;
 - working relationships;
 - co-ordinated care;
 - access and entry points;
 - awareness;
 - education and training;
 - funding;
 - evaluation; and
 - culture and philosophy.

Executive Summary

Introduction

The purpose of the research was to develop an integrated team approach for hospice/palliative care in the community. The research was, and is, particularly timely given the changing nature of community-based care brought about by recent fiscal, demographic, and political imperatives, and the increasing awareness that Canadians prefer to die at home.

Background and Context

More than 220,000 Canadians die each year, 75 percent of whom die in hospitals and long-term care facilities (Senate Subcommittee, 2000). The Senate subcommittee notes that, on average, each death potentially affects the well-being of five other people. People receive different treatment and support across the country. Seniors are less likely to want to die at home than younger people, and there is “considerably less access to palliative care” in rural areas compared to urban centers (Senate Subcommittee, 2000). A recent national survey conducted by Angus Reid, however, indicates that 51 percent of respondents would very likely use hospice care services if they had a terminally ill family member (Angus Reid, 1997).

While medical care is traditionally associated with acute-care settings, this is now changing. There are considerable benefits to integrating care among an inter-disciplinary team (Wright, 2001) and broadening hospital-based palliative programs into the community to more effectively address pain management and the psychological, social, and spiritual needs of both those dying in their homes and their family members (Early et al, 2000; Lycan and Glass, 2001, Ratner et al, 2001; Steinhauer et al, 2000; Thompson, 2000). This also requires improved co-ordination among formal providers (Lynn, 2000), and indeed the informal network of support in the community (Parent and Anderson, 2001).

While formal homecare services from community care access centres in Ontario have become more restrictive, there has been substantial growth in the contribution of informal volunteers through the 88 hospices of the Hospice Association of Ontario. These hospice agencies provide care and support in more than 400 communities. In the year 2000, for example, they co-ordinated more than 12,000 volunteers, operating almost entirely with private funding outside the publicly funded system.

Given the continuing constraints on the *formal* system and the substantial and rising commitment of *informal* volunteers, it is desirable to examine ways that the different modes can work together (and with families) to ensure people receive consistent access to a consistent array of services and supports for hospice/palliative care across the province. The findings from this research can greatly assist government, community care access centres, and hospice volunteer agencies develop an approach to improving the care and support for individuals who are dying at home and their families.

Approach

The extensive consultation process involved a wide range of stakeholders including hospices, community care access centres, family caregivers, hospice volunteers, other key informants, and members of the palliative pain and symptom management network. The methods included mailed surveys, focus groups, e-surveys, e-delphi, interviews, case studies, and integrating workshop participation.

Findings

Synthesis of the eight data collection phases revealed several necessary features required for a truly integrated model of hospice palliative care. Fundamentally, there needs to be a unity of purpose — one that focuses on patients/clients and their families that is developed and built upon effective collaborative partnerships among formal and informal providers. This team approach emphasizes a regional network of services and point of care teams that have a culture of respect and inclusiveness.

The eight core features of an integrated system are:

- unity of purpose;
- collaborative partnerships and relationships;
- access to comprehensive hospice palliative care services;
- communication structures;
- co-ordinated care;
- a governing body;
- training and education; and
- a formal evaluation plan.

How to Put the Findings to Real Use

The culmination of the study is a detailed 15-point implementation plan that will assist current providers and caregivers to implement an integrated model of care. The plan covers the following areas:

1. building a provincial policy framework for palliative care;
2. identifying a governance entity;
3. establishing a local or regional network;
4. defining the state of current systems/processes in local area;
5. identifying future ideal systems and processes;
6. establishing tools to facilitate integration of regional network partners;
7. generating an effective communications strategy;
8. developing effective working relationships;
9. ensuring co-ordinated care;
10. facilitating access and establishing functional entry points;
11. increasing awareness of hospice and palliative care services as a specialty;
12. improving education and training strategies;
13. integrating funding and resources;
14. building strong evaluation strategies; and
15. establishing a culture and philosophy related to palliative care.

Conclusion

This research initiative did not finish with the completion of the study. The dissemination of the findings is well-timed to coincide with the newly agreed upon charter for hospice palliative care and the formation of local area health networks in Ontario. Most specifically, the 15-point implementation plan will prove beneficial to decision makers at the macro, meso, and micro levels. We believe that hospice palliative care clients and their families will receive improved care through an improved understanding and implementation of an integrated model of care.