A Model to Guide Patient and Family Care: Based on Nationally Accepted Principles and Norms of Practice

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Introduction

Since the discovery of antibiotics in the 1940s, modern medicine has cared a few diseases/conditions, and has markedly prolonged the experience of fiving with a chronic illiness and the dying process (in the last 60 years, average life expectancy for adults in North America has increased by approximately 20 years). Today, most patients and families will experience multiple manifestations and predicaments as a result of the patient's underlying disease process, causing them considerable suffering and changing the quality of their lives.

In an effort to address the issues that were causing suffering during the dying process, the modern hospice and palliative care movement started during the 1960s in the United Kingdom," and the 1970s in both the United States (1972) and Canada (1975). (The term "palliative care" or "soins palliatifs" in French was initially developed by Balfour Mount, Montréal, Canada, as a phrase that would be synonymous

with "hospice care" for use in the Francophone community of Canada where "hospice" was not an acceptable term to describe end-of-life care [due to its longstanding history as a term to describe shelters for the wayward and the disadvantaged]). This grassroots movement developed where there were champions. Approaches to care were usually based on individual opinion. There was considerable variability in the services offered by individual programs and inconsistent access to care.

To bring definition to the practice of hospice and pallistive care, and address the variability, inconsistency, and gaps in care, several provider and accreditation associations initiated the development of national standards of practice relatively early in the movement (see the list in the Methods). In Canada, the development of standards of practice started separately in both British Columbia and Ontario in 1989. In 1993, the Canadian Hospice Palliative Care Association (CHPGA) invited everyone who was developing standards for hospice or palliative care to form a single committee to guide the development of national rather than regional standards of practice. The resulting consensus-building process led to a model to guide patient and family care that is based on nationally accepted definitions of commonly used terms, values, guiding princi-

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