

PALLIATIVE CARE CASE OF THE MONTH



Hospice and Palliative Care at 40 David Barnard, PhD, JD

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Case: D.T., a 40-year-old Jewish survivor of the Warsaw Ghetto, was admitted to a hospital surgical floor for symptom management. A few months prior he had received a palliative colostomy for inoperable and obstructed carcinoma of the rectum. Initially, D.T.'s symptoms were poorly managed, and the staff had little time to provide emotional or spiritual support, even though D.T. was experiencing sadness and despair as he awaited the end of what to him felt like an unfulfilled, meaningless life. C.S., a recently graduated medical social worker and former nurse, encountered D.T. when she was assigned to his ward. C.S. visited frequently with D.T. during the weeks before his death. Their conversations became intimate and profound, and helped D.T. achieve a certain quiet peace. Shortly before his death, he made a comment to C.S. that summed up the importance of her visits to him and what he felt most people in his situation would hope to receive from their caregivers: "I only want what is in your mind and in your heart."

Discussion: C.S. and D.T. met each other in 1947, and 20 years after their meeting, in 1967, C.S.—whose full name was Cicely Saunders—opened the first modern hospice, St. Christopher's, in London. She credits her conversations with D.T.—whose full name was David Tasma, and whose story Saunders has told in several accounts of the origins of the modern hospice movement¹—with planting crucial seeds of the hospice concept. "What is in your mind and in your heart," Saunders would say, represents the combination of scientifically based clinical skill with empathic, dependable, human presence that is the hallmark of hospice and palliative care.

In the 40 years since the modern hospice and palliative care movement began, the field has undergone substantial evolution, especially in the United States. The broad outlines of that evolution are depicted in the table at the right, *Palliative Care: 1967-2007.*

In a nutshell, the field of palliative care has evolved from an alternative philosophy of death and dying at the fringes of medical practice to a mainstream discipline that has just this year been recognized as a medical subspecialty; from the domain of charismatic founders and leaders (e.g., Saunders in England, Mount in Canada, Doyle in Scotland, Wald in the United States) to the increasingly routinized protocols and evidence-based treatments to be found in myriad textbooks and websites; from overwhelming reliance on charity and philanthropy to the (relative!) security of the Medicare hospice benefit, NIH research support, and hundreds of millions of dollars from foundations such as Robert Wood Johnson and the Open Society Institute; and from predominantly home-based hospice care of terminally ill cancer patients by nurses, social workers, and chaplains to hospital-based, physician-directed programs providing upstream palliative care for a wide range of chronic, life-limiting illnesses.

Palliative Care: 1967-2007

From	То
• Fringe	Mainstream
• Charismatic founders and leaders	• Evidence-based protocols, textbooks, quality standards
 Home care by nurses, social workers, chaplains 	• Hospital-based physician- directed palliative care services
• Bake sales and golf outings	 Medicare benefit, NIH, foundation support
• On-the-job training for the committed	• Required coursework, certification, recognition as a medical specialty
• Terminal care for cancer	• Upstream palliative care for many chronic, life-limiting illnesses
 Spiritual and existential accompaniment 	 Technical, pharmacological, and psychosocial interventions for symptom management

Arguably, one more change has accompanied these: a shift in the balance between scientific and clinical skill and empathic human presence that was articulated by David Tasma. At 40, palliative care's center of gravity appears to be shifting away from the *spiritual and existential accompaniment of the person*, toward a preoccupation with *technical, pharmacological, and psychosocial interventions to manage the symptoms of the patient*.

A number of factors might explain this shift: real or imagined time constraints; discontinuities in provider-patient relationships; reimbursement schemes that favor efficiency and the use of technology over the exploration of personal issues; subtle or not-so-subtle pressure on palliative care programs to justify their budget requests by taking credit for reduced lengths of stay; the relative ease of measuring or quantifying outcomes with symptom-severity scales and medication logs, compared to the ineffable quality of silent witness and solidarity with suffering or grief; the personal costs of caring for anxious or

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anguished people who are facing the imminent end of their lives.

Depending on one's perspective, the shift away from spiritual and existential support to technical management of symptoms might provoke a range of reactions: a welcome increase in our ability to assuage hitherto intractable suffering, thanks to advances in pharmacology and technology since the early days of hospice; a disappointing loss of focus and weakening of the hospice mission, in keeping with the obsession with technology and the retreat from emotional connection typical of modern life; an artificial dichotomy that understates the enduring role of spiritual and existential care, thanks to the contributions of many members of the multidisciplinary team.

The question of palliative care's faithfulness to its founders' vision has been asked every so often since Cicely Saunders's encounter with David Tasma set her on the path to St. Christopher's Hospice.² As we take aim at our next 40 years, it seems worth asking again.

References

1. Saunders C. Introduction—history and challenge. In C. Saunders and N. Sykes, eds., *The Management of Terminal Malignant Disease*, 3rd ed., London, Edwin Arnold, 1993.

2. Mount, B. Keeping the mission. *The American Journal of Hospice & Palliative Care*, September/October 1992, p. 32-27.

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