



Palliative Care – Evolution of a Vision

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Dame Cicely Saunders, MD, OM, DBE, established the first modern hospice, St Christopher's, in 1967 in London. Prior to that time, terminally ill hospitalized patients did not “fit” the mission of hospitals – to cure. Physicians equated terminal illness with failure; thus terminally ill patients were often “placed... at the end of the hall.”¹ Dame Cicely took it upon herself to help these patients, usually suffering from advanced cancer, with the goal of facilitating dignity and comfort as death approached. She founded St. Christopher's Hospice, believing that dying people have the right to an improved quality of life, using pain control and social and emotional support to achieve psychological and spiritual contentment. Dame Cicely's vision for end of life care soon spread to the United States where it became known as “palliative care.”

Dame Cicely's apprentice at St. Christopher's, Florence Wald, MN, brought the new vision for end of life care to the United States, establishing the Connecticut Hospice in 1974. Known thereafter as “the mother of the American hospice movement,” Ms. Wald not only established an inpatient hospice similar to St. Christopher's, but also developed the first home care program for terminally ill patients in the United States.² From these small beginnings the American hospice movement grew rapidly. By the year 2000, hospice organizations in the US were serving an estimated 105,500 patients annually — 18,500 inpatients, and 87,000 home care clients.³

Since its articulation at St. Christopher's four decades ago, the basic, comprehensive approach to palliative care has not changed, but the definition of palliative care has evolved – it has broadened significantly – as have unresolved issues of palliative care.

AN EVOLVING CONCEPT

In the 4th century, hospices were initially places for travelers to rest. Then in the 19th century, churches in England and Ireland began to establish places for dying persons called “hospices.” When St. Christopher's hospice was established, it differed from existing hospices in the United Kingdom primarily because Dame Saunders' vision of end of life care was broader than the established vision. Dame Cicely's hospice was more than a place to gather up dying people; its goal was *to improve the quality of remaining life* (including spiritual and psychological wellbeing) by providing strategic supports, such as effective pain control.

In 1974, seven years after the founding of St. Christopher's hospice, and shortly after the establishment of the first hospice in the United States, The **International Work Group on Death, Dying and Bereavement (IWG)** was founded. IWG is an organization that seeks to advance and nurture the development of the field of palliative care through thanatology, the study of human death. In 1979, IWG officially adopted a definition of palliative care.

A service that provides all the essentials of care needed by those who face a terminal illness; allowing palliative and curative treatment, care for the family, and services at home and in inpatient settings. The combined skills of an interdisciplinary team must bring care to the patient and family in the context of their life and values.⁴

In addition to “the care needed by those who face a terminal illness,” the IWG's vision squarely addresses “care for the family.” Family members of terminally ill patients frequently become caregivers, encountering a gamut of problems—disrupted schedules, fatigue, loss of wages, fear of impending loss, and anxieties related to patient care.⁵ Absent financial assistance and psychological counseling, the caregiver's role can be quite overwhelming.⁶

Furthermore, the IWG promotes a *team approach* to the planning and delivery of services. Individual needs – and wants – of terminally ill patients and caregivers are quite diverse, and change over the course of a terminal illness. Therefore, teams designed to support patients and caregivers must incorporate a diverse—and flexible—set of skills. Medicine, nursing, social work, and spiritual counseling are commonly in the mix.

By 1990, Dame Cicely's concept had spread to many nations. In recognition of this *fait accompli*, the **World Health Organization (WHO)** released its own definition of palliative care.

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment.⁷

The WHO defines the goal of palliative care as “the best possible quality of life for patients and their families,” expanding the reach of palliative care to “earlier in the course of the illness, and thus, to patients with *potentially* terminal illnesses. The WHO definition recognizes that patients undergoing *curative treatments* may benefit significantly from *palliative care*.”

Since 1990, the WHO has been an essential partner in the palliative care movement. In 2002 they revised their official definition of palliative care.

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.⁸

Two important revisions are incorporated in the WHO's new definition. First, "terminal illness" is replaced by "life-threatening illness." Superficially, this modification may appear to be slight, but its implication is nothing short of revolutionary, broadening the reach of palliative care to all people suffering from chronic illnesses. By so doing, the WHO's definition has been brought into line with recent medical advances. Diseases formerly considered to be "death sentences," such as cancer, cardiac disease, and infection with HIV, are now manageable. Second, "relief of suffering by means of early identification" has been added. Thus, palliative care is envisioned as *preemptive*, as well as responsive. In one bold stroke, the WHO affirms that end of life problems have significantly earlier origins, and that treating them early enhances management throughout the course of illness.⁹

Building on the WHO's definitions of palliative care, the **National Consensus Project for Quality Palliative Care (NCP)** developed consensual clinical palliative care guidelines in 2004. The project was launched by 5 organizations committed to end-of-life issues: the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care at the Mount Sinai School of Medicine, the Hospice and Palliative Nurses Association, the Last Acts Partnership, and the National Hospice and Palliative Care Organization. The essence of all previous definitions is incorporated in the NCP's vision of palliative care.

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.¹⁰

This is by far the most comprehensive definition to date. Dame Cicely's original vision of care for the dying is now recognized as nothing less than a *philosophy of care*, operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to the needs, values, beliefs, and cultures of patients and their families.

PALLIATIVE CARE VS. HOSPICE CARE

In 1967, Dame Cicely Saunders redefined hospice care by incorporating an expansive, patient-centered approach to the care of terminally ill patients, focusing on dignity and comfort. In essence, St. Christopher's Hospice *defined* palliative care with clear vision, specific goals, distinct methods, and of course, a successful, functioning model. Since that time, hospice care has become a distinct *subset* of palliative care, as the latter concept has expanded. Palliative care is now broadly valued, not only for terminal illness, but also throughout the trajectory of all serious illness. Hospice care incorporates all of what palliative care (now) is, but continues to focus on the special needs of patients and caregivers *as end of life approaches*.

ISSUES OF PALLIATIVE CARE TODAY

The foremost issues of palliative care today are *accessibility* and *utilization*. In Rhode Island, as elsewhere in the United States, palliative care is largely inaccessible and greatly underutilized.¹¹ Cancer patients, for example, are often unaware of palliative care options, and those who are not considered to be terminally ill do not have access to a palliative care team; minority groups may be distinctly disadvantaged in this regard.¹² The Rhode Island Comprehensive Cancer Control Plan, developed by the Partnership to reduce Cancer in Rhode Island and released in 2007, aims to increase access to palliative care by the year 2012.

As well, issues have always swirled around the use of *palliative sedation*—the use of sedatives to relieve extreme suffering by inducing unconsciousness (deep sleep) while the disease takes its course, eventually leading to death.¹³ Advocates of palliative sedation believe it should be used to avoid unnecessary suffering, even if sedation hastens death (by suppressing respiratory function).¹⁴ Opponents argue that palliative sedation is a euphemism for euthanasia.¹⁵ This issue is certainly not new. It is discussed more openly now, however. Let us hope that this new willingness to confront the issue will benefit the patient, as Dame Cicely, who strongly opposed euthanasia,¹⁶ would have insisted. In this regard, perhaps it is fitting to quote the following from Dame Cicely's obituary:

Many years ago, in response to a question at a symposium about the prospect of death, Saunders declared that she would hope for a sudden demise but would prefer to die—as she has—with a cancer that gave due notice and allowed the time to reflect on life and to put one's practical and spiritual affairs in order.¹⁷

Dame Cicely died peacefully as a patient of St. Christopher's Hospice in 2005.

REFERENCES

1. Krisman-Scott MA. *The Room at the End of the Hall: Care of the Dying*, 1944-1976. Unpublished doctoral dissertation in Nursing, University of Pennsylvania, 2001.
2. Hevesi D. Florence Wald opened first U.S. hospice. *New York Times*, 16 November 2008.

3. National Center for Health Statistics. *National Home and Hospice Care Data*. (Data from the National Home and Hospice Care Survey, 2000) Current Hospice care Patients, Tables 1-13. Bethesda, Maryland: National Center for Health Statistics, February, 2004. <http://www.cdc.gov/nchs/data/nhhcsd/curhospicecare00.pdf>
4. International Work Group on Death and Dying. Assumptions and Principles Underlying Standards for Terminal Care. Appendix I. *Amer J Nurs* 1979; 79: 296-7.
5. Lynn J. Serving patients who may die soon and their families. *JAMA* 2001;285:925-32.
6. Roy DJ. Need I believe? *J Palliative Care* 1997; 13:3-4.
7. World Health Organization: *Cancer Pain Relief and Palliative Care*. Technical Report Series 804. Geneva, Switzerland: WHO, 1990; p.11.
8. World Health Organization. *National Cancer Control Programs: Policies and Managerial Guidelines*, 2nd ed. Geneva, Switzerland: World Health Organization, 2002.
9. Sepulveda C, Marlin A, et al. Palliative care. *J Pain Symptom Manag* 2002; 24: 91-6.
10. National Consensus Project for Quality Palliative Care. *Clinical practice guidelines for quality palliative care*. Pittsburgh: National Consensus Project for Quality Palliative Care, 2004.
11. The Partnership to Reduce Cancer in Rhode Island. *Rhode Island Comprehensive Cancer Control Plan 2007*. Providence, RI: Rhode Island Department of Health, p. 36.
12. The Partnership to Reduce Cancer in Rhode Island. *Rhode Island Comprehensive Cancer Control Plan 2007*. Providence, RI: Rhode Island Department of Health, p. 36.
13. Brender E, Burke A, Glass RM. Palliative sedation. *JAMA* 2005; 294: 1850.
14. Carr MF, Mohr GJ. Palliative Sedation as part of a continuum of palliative care. *J Palliative Med* 2008; 11: 76-80.
15. Rousseau PC. Palliative sedation and the fear of legal ramifications. *J Palliative Med* 2006; 9: 246-8.
16. Richmond C. Dame Cicely Saunders. (Obituary) *British Med J* 2005; 331 (7509). <http://www.bmj.com/cgi/content/full/331/7509/DC1>
17. Dame Cicely Saunders: Visionary founder of the modern hospice movement who set the highest standards in care for the dying. Obituary. *The Times of London* July 15, 2005. <http://www.timesonline.co.uk/tol/comment/obituaries/article544059.ece>

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