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Spiritual Care at the End of Life: The Influence of Dame Cicely Saunders

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The modern hospice movement is generally recognized to have begun in 1967 with the establishment of St. Christopher's Hospice in London by Dame Cicely Saunders.[1] The principles of care developed then continue to influence hospice and palliative care today, including the incorporation of spiritual care as an essential part of end-of-life care.

Cicely Saunders' health care background was multi-disciplinary: she worked as a nurse at St. Thomas' Hospital in 1941, got her degree from Oxford to qualify as a medical social worker in 1947, and finally undertook medical studies in 1951-57.[2] Her experiences as a nurse caring for terminally ill cancer patients at St. Luke's Hospital and then as a doctor at St. Joseph's Hospice, led her to realize that patients at the end of life had specific care needs.[3] She founded St. Christopher's Hospice as an institution dedicated to meeting those needs.

Saunders had seen too many terminally ill patients suffer through intractable pain in their final days. This suffering affected not only the patient, but family members and staff as well. Saunders believed that a core aim of hospice care was to ensure that patients be free of physical pain whenever possible.[4] This meant undertaking research to discover effective drugs and drug combinations, being unafraid to treat pain aggressively, and providing medication to patients before they were in the grip of unbearable pain. According to Saunders, "Adequate relief must be given from the beginning of the patient's downhill course for he should become accustomed to expect freedom from discomfort rather than its constant presence."[5]

Saunders also recognized that patients at the end of life were not dealing only with physical pain; many of them also had emotional, social, and spiritual issues that caused great fear and distress. She termed this multi-faceted suffering, "total pain."[6] She believed that once physical pain and the fear of it were controlled, patients would then be free to address their anxiety and depression about their situations; their concerns about friends and loved ones who would be left behind; their search for meaning, purpose and connection. As Saunders wrote, "It soon became clear that each death was as individual as the life that preceded it and that the whole experience of that life was reflected in the patient's dying."[7] The purpose of hospice care, then, was to care for patients in their dying and to help them find peace from suffering.

Palliative Care and Spiritual Care

For Saunders, spiritual care was an essential part of hospice care. She believed that unresolved spiritual issues could intensify, even cause, physical pain.[8] Patients might be wracked by guilt or regret and be in need of forgiveness; they might find themselves questioning whether their lives had meaning or purpose; they might feel abandoned by a transcendent presence that had once been a source of comfort. While physical pain might

respond to drugs, Saunders believed that spiritual care was far more complex.

She recognized that, as difficult as it might be, spiritual distress was not something to be masked but had to be worked through by the patient,[9] and not always within a religious framework.[10] It was a task that required patients to face their anguish and regrets, to review their life narratives, "to reach out towards something greater than themselves, a truth to which they can be committed."[11] It was a task that was individual to each patient and to be done in the patient's own time and way.

Saunders believed that in this task the patient needed the support and help of the entire health care team.[12] In other words, all caregivers and not just chaplains had to be prepared to help patients in their struggles to find meaning, reconciliation, and connection; they had to understand that patients might raise questions or concerns for which staff had no answers, or for which no answers were required; they had to realize that "the important thing is being there, perhaps silently, to share the pain of spiritual growth in the awareness that one can do nothing, with the patient gaining support simply by being understood."[13]

Finally, as much as she valued the professional expertise of health care staff, Saunders believed that, in spiritual care, staff members' greatest gift to patients was the gift of themselves. As she wrote: "If we can come not in our professional capacity but in our common, vulnerable humanity there may be no need of words on our part, only of concerned listening."[14] This listening, this presence, this affirmation of the patient's value and dignity might help the patient to achieve peace at the end of life. At the same time, Saunders noted that "Those who work in palliative care may have to realise that they, too, are being challenged to face this [spiritual] dimension for themselves."[15]

Discussion

Although Dame Cicely Saunders was a deeply religious person and the founding of St. Christopher's Hospice was the culmination of her vocation to care for terminally ill patients,[16] spiritual care remains a fundamental component of palliative care even in secular settings.[17] There are several reasons for this.

First is the current trend to treat patients holistically, that is, to realize that patients are more than physical beings, that they have histories and exist in a network of relationships and that wellbeing is multi-faceted.[18] Practitioners recognize that spiritual distress, such as a sense of meaninglessness or feelings of unresolved guilt, can intensify, even be experienced as, physical pain.[19] If one of the goals of end-of-life care is to help patients be free of pain, then spiritual care must be a part of it.

Second is the recognition that, while we may not necessarily be religious, human beings are spiritual by nature.[20] Having said this, it should be noted that many authors discussing spiritual care in health care generally and palliative care specifically, admit to the difficulty of defining "spirituality."[21] However, many make the attempt. One author, for instance, describes spirituality "as the web of relationships that gives coherence to our lives."[22] In these connections we find our identity, meaning, and security. Another describes spirituality as involving "the need for meaning and the quality of transcendence – the sense that one's spirituality is something beyond one's physical self … a sense of connection that will endure beyond the life of the individual."[23] In the same vein, another writer believes that spirituality is about "the quest for meaning and purpose in life … and a sense of relatedness to a transcendent dimension."[24] Similarly, a hospital chaplain writes that spirituality has "something to do with transcendence: how the suffering individual grapples with issues

of identity, meaning, and purpose."[25]To say, then, that human beings are spiritual by nature is to say, at the very least, that we search for meaning about our circumstances and the purpose of our existence, and we seek connection – with others, within ourselves, and with the transcendent.

Finally, there is the recognition that spiritual concerns come forward as people near the end of life[26] and may become a source of distress and pain.[27] Even for patients who are not dealing with unresolved guilt or angst, there is still a need "to see that their lives have had meaning or purpose, to reconcile relationships, and to love or be loved."[28] There is a need for spiritual care.

What this care requires will vary. Some patients will ask for the presence of clergy and religious ritual. Others may seek connection to the transcendent by being with loved ones or in nature.[29] Patients may struggle with existential questions about the meaning of life, suffering and death, of whether their lives have made a difference or if they will live on in some way. Whatever the need, spiritual care must begin with the patient and the patient's understanding of spirituality and the patient's needs within that context.[30] And, following Saunders' model, spiritual care is not relegated to the chaplain but is the responsibility of the entire health care team.[31] Here the role of the practitioner is not to be an expert but a "companion",[32] one who journeys with the patient, who listens to and supports the patient and, in this, affirms that the patient's search for meaning, purpose and connection is a valuable part of the human journey to wholeness and peace at the end of life.

This approach is in keeping with the "Declaration on Euthanasia" which states:

> As for those who work in the medical profession, they ought to neglect no means of making all their skill available to the sick and dying; but they should also remember how much more necessary it is to provide them with the comfort of boundless kindness and heartfelt charity. Such service to people is also service to Christ the Lord, who said, 'As you did it to one of the least of these my brethren, you did it to me" (Mt. 25:40)."[33]

Conclusion

In developing this model of hospice care, particularly its attention to treating pain in a comprehensive way, Saunders was providing a viable alternative to euthanasia.[34] Her concept of total pain was an acknowledgement that patients at the end of life were dealing with multifaceted suffering. In order to help them to a peaceful death, she believed in freeing patients from physical pain so that they could address other forms of suffering, including spiritual pain. It was important to Saunders not only that patients be confident that pain could be controlled but that the public have this confidence as well. She saw "the relief of pain as a most vital component in confronting the issue of euthanasia."[35]

But it was not enough to treat physical pain; spiritual care was also an essential component of hospice care. Subtle and deeply personal, as Saunders wrote, "the way [spiritual] care is given can reach the most hidden places. Feelings of fear and guilt may seem inconsolable, but many of us have sensed that an inner journey has taken place and that a person nearing the end of life has found peace."[36] This was and remains the goal of hospice care. ■

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[1] "Dame Cicely Saunders: Her Life and Work," www.stchristophers.org.uk/page.cfm/link= 898 (accessed Sept. 2010); Keith G. Meader, "Spiritual Care at the End of Life: What Is It and Who Does It?

North Carolina Medical Journal 65(2004), p. 226 www.ncmedicaljournal.com/jul-aug-04/a5070407.pdf (accessed October 2010); Milton J. Lewis, *Medicine and Care of the Dying: A Modern History* (Oxford: Oxford University Press, 2007), p. 11.

[2] "Dame Cicely Saunders: Her Life and Work"; Cicely Saunders, "A personal therapeutic journey. (Into the Valley of the Shadow of Death)" *British Medical Journal* 313 (Dec. 1996) http://find.galegroup.com/gtx/infomark.do?&contentSet=IAC-Documents&type=retrieve&tabID=T002&prodId=HRCA docId=A19036486&source=gale&srcprod=HRCA&userGroupName=ko_pl_cobourg&version=1.0 (accessed September 2010).

[3] Cicely Saunders, "A personal therapeutic journey."

[4] Lewis, p. 131.

[5] Dame Cicely Saunders and Mary Baines, *Living with Dying: The management of terminal disease* (Oxford: Oxford University Press, 1983), p. 21. See also: Shirley du Boulay, *Cicely Saunders: Founder of the Modern Hospice Movement* (London: Hodder and Stoughton, 1984), p. 175.

[6] Saunders and Baine, p. 13; du Boulay, pp. 174-5.

[7] Saunders, "A personal therapeutic journey."

[8] David Clark, "Total Pain: The Work of Cicely Saunders and the Hospice Movement" *APS Bulletin* 10 (2000) www.ampainsoc.org/pub/bulletin.jul00/hist1.htm (accessed Sept. 2010); du Boulay, p. 175.

[9] Saunders and Baine, p.53; Karen Pronk, "Role of the doctor in relieving spiritual distress at the end of life" *American Journal of Hospice and Palliative Care Medicine* 22 (2005), p. 421.

[10] Saunders, "A personal therapeutic journey"; Saunders and Baine, p. 62.

[11] Saunders and Baine, p. 63.

[12] Ibid., p. 64.

[13] Pronk, p. 421.

[14] Saunders, "A personal therapeutic journey."

[15] Ibid.

[16] du Boulay, p. 155; Lewis, p. 11.

[17] In its "Definition of Palliative Care", the World Health Organization recognizes that spiritual care is a component of palliative care. Spiritual care is provided by a home telehealth organization offering end-of-life care. See: World Health Organization, "WHO Definition of Palliative Care" http://www.who.in/cancer/palliative/definition/en/print.html (accessed October 2010); Jim Maudlin, Jeannie Keene, and Rita Kobb, "A Road Map for the Last Journey: Home Telehealth for Holistic End-of-Life Care" *American Journal of Hospice and Palliative Medicine* 23 (2006), pp. 400-401 http://journals2.scholarportal.info.cat1.lib.trentu.ca:8080/tmp/14691493172321437339.pdf (accessed September 2010). See also: Martha R. Jacobs, "What are we doing here? Chaplains in contemporary health care" *The Hastings Center Report* 38 (2008) http://find.galegroup.com/gtx/infomark.do?&contentSet=IAC-Documents&type=retrieve&tabID=T002&prodId= SPJ.SP00&docId=A195317856&source=gale&srcprod=SP00&userGroupName=ko_pl_cobourg&version=1.0 (accessed September 2010); Bruce Jennings, et. al., "Access to Hospice Care: Expanding Boundaries, Overcoming Barriers," in Jennifer A. Parks and Victoria S. Wike, eds., *Bioethics in a Changing World* (Upper Saddle River: Prentice Hall, 2010), pp. 714, 716.

[18] Canadian Nurses Association, "Position Statement: Spirituality, Health and Nursing Practice" http://www.cna-aiic.ca/CNA/documents/pdf/publications/PS111_Spirituality_2010_e.pdf (accessed Sept 2010). See also: Pronk, 424.

[19] Pronk, pp. 420.

[20] Pronk, pp. 420, 424; Carol Penrod Hermann, "Spiritual Needs of Dying Patients: A Qualitative Study" *Oncology Nursing Forum* 28 (2001), p. 68.

[21] See: Lewis, p. 233; Jane A. Simington, "Ethics for an Evolving Spirituality" in Janet L. Storch, Patricia Rodney and Rosalie Stazowski, eds., *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice* (Toronto: Pearson, 2004), p. 474; Hermann, pp. 67, 71; Bruce D. Rumbold, "Caring for the spirit: lessons from working with the dying" *The Medical Journal of Australia* 179 (2003), p. S12 http://www.mja.com.au/public/issues/179_06_150903/rum10297_fm-2.pdf (accessed September 2010); Maudlin, Keene and Kobb, p. 401; Pronk, pp. 420-1; Meader, p. 226, among others.

[22] Rumbold, p. S12.

[23] Pronk, p. 420.

[24] Hermann, p. 67.

[25] Jacobs, p. 401.

[26] Hermann, p. 67; Pronk, p. 424; Maudlin, Keene and Kobb, pp. 400-1.

[27] Pronk, p. 420; Rumbold, p. S11; Maggie Callanan, *Final Journeys: A Practical Guide for Bringing Care and Comfort at the End of Life* (New York: Bantam Books, 2008), p. 183.

[28] Milton, Keene and Kobb, pp. 400-1.

[29] Hermann, pp. 68, 70, 71; Pronk, p. 420.

[30] Rumbold, p. S12; Pronk, p. 420.

[31] Rumbold, p. S12; Meader, p. 227; Hermann, p. 71.

[32] Rumbold, p. S12.

[33] Sacred Congregation for the Doctrine of the Faith, "Declaration on Euthanasia" in Kevin Wm. Wildes, Francesc Abel, and John C. Harvey, eds., *Birth, Suffering and Death: Catholic Perspectives at the Edges of Life* (Dordecht: Kluwer Academic Publishers, 1992), p. 223.

[34] Lewis, p. 130; Clark.

[35] Clark.

[36] Saunders, "A personal therapeutic journey."