Recognizing Excellence in Care at the End of Life

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Care for patients at the end of life has long troubled American medicine, not only in its failure to provide good palliative care, but also in the tension between technology and ethics as it affects the relationship between providers and patients. Although the palliative care movement has gained momentum and sophistication over recent decades, a better understanding of the end-of-life situation by patients, their closest family and friends, and care providers is needed to give greater structure and integrity to provision of care in this final phase. As the number and percentage of persons in the US who die from chronic and degenerative diseases increase, the skills of all providers — not just physicians — necessary to provide good end-of-life communication and care also must grow. To fuel the expansion of this talent and pool of knowledge, experienced, knowledgeable practitioners must provide leadership and information.

Several overarching leaders deserve to be acknowledged for their dedication to directing attention to the role of palliative care. The Robert Woods Johnson Foundation (RWJF) has supported numerous initiatives to improve care at the end of life. RWJF has specifically pursued three strategies in its effort:

1. Improving the knowledge and capacity of healthcare professionals and others to care for the dying;
2. Improving the institutional environment in healthcare institutions, public policies, and regulatory apparatus to enable better care of the dying;
3. Engaging the public and professionals in efforts to improve end-of-life care.

In June 2000, under a RWJF grant to Tuskegee University’s Center for Bioethics in Research and Health Care, 40 participants, including healthcare providers, academics, researchers, clergy, and professionals from criminal justice and the funeral home industry, came together for a 2-day roundtable discussion and identified end-of-life issues they believed to be most significant to African-American patients, families, and communities involved in end-of-life decision-making and caregiving. Building on this discussion, in February 2004, under another RWJF grant, staff at Howard University College of Medicine in Washington, DC, sponsored a national conference, The Last Mile® of the Way Home, in Atlanta. The 322 participants, including physicians, clergy members, educators, policy-makers, community leaders, caregivers, medical students, nurses, social workers, and consumer advocates, further explored issues identified by the earlier roundtable participants. The project was taken over by Dr. Richard Payne, the project director at the Institute on Care at the End of Life (ICEOL) at Duke University’s Divinity School. A series of papers was published on topics concerning end-of-life care for African Americans so professionals across the country could put into everyday practice key principles developed from these gatherings of experts and thought leaders.

End-of-life care is a central element of the educational mission of the Duke Divinity School, as evidenced by its proactive leadership in convening leaders of key home health, hospice, nursing/long-term care companies from across the country, and scholars and researchers to keep the discussion contemporary, enlightened, and transferable in what Duke refers to as its “Roundtable Initiative.” With each roundtable, participants gain new insight into common challenges as they explore the parallel and competing interests of theory and practice, how to best harness technology as a tool rather than a hindrance to care, and how to integrate individual, corporate, and cultural goods as resources. The group addresses concepts such as patient empowerment and engagement in the context of palliative care directives by this group. Duke also has served as an online resource to facilitate access to helpful materials, such as The Unbroken Circle: A Toolkit for Congregations Around Illness, End of Life and Grief. The toolkit is provided by Project Compassion, a community-based education, advocacy, and support organization in Chapel Hill, NC, for persons dealing with serious illness, death, and grief. Reverend James L. Brooks, Executive Director of Project Compassion, says the toolkit aims to guide clergy and lay leaders in weaving end-of-life care into the fabric of congregational life. This resource also serves as a reservoir from which healthcare providers can draw practical guidance and encouragement; it is available for $34.99 at Amazon.com.

Dr. Muller is the Executive Director, National Association For Continence (NAFC). The NAFC is a national, private, nonprofit organization dedicated to improving the quality of life of people with incontinence. The NAFC’s purpose is to be the leading source for public education and advocacy about the causes, prevention, diagnosis, treatments, and management alternatives for incontinence. This article was not subject to the Ostomy Wound Management peer-review process.
Leadership in this field is not just institutional. The real groundbreaking activity occurs at the individual level, giving us the opportunity to follow in the footsteps of trailblazers. Such is the focus of the Hastings Center Cunniff-Dixon Physician Awards, presented in January 2012 for the third straight year. These awards are given by the Cunniff-Dixon Foundation, whose mission is to enrich the doctor-patient relationship near the end of life, in partnership with The Hastings Center, a bioethics research institute engaged in pioneering work on end-of-life decision-making. Duke’s ICEOL managed the award nomination and selection process. Awards this year went to:

- Janet Bull, MD, at Four Seasons, a nonprofit hospice and palliative care organization serving the Asheville area of western North Carolina;
- Michael Rabow, MD, of University of California at San Francisco’s (UCSF) Helen Diller Comprehensive Cancer Care Center, one of the first outpatient, interdisciplinary palliative care services for cancer patients in the US;
- Justin Baker, MD, of St. Jude Children’s Research Hospital for his valuable research on palliative care for children;
- Jason Morrow, MD, PhD, at the University of Texas – San Antonio Health Science Center for his inspirational passion as an educator of physicians in medical ethics;
- Theresa Soriano, MD, MPH, of Mount Sinai School of Medicine, New York, for her advocacy leadership in championing the delivery of care to the underserved homebound patient.

Read about them all. Follow their lead. Integrate their disciplines into your own work as you confront the daily challenges of delivering outstanding palliative care.

References

Also see the September 2009 Ostomy Wound Management “Continence Coach” for Dr. Muller’s column on compassionate end-of-life care.

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