

Commonalities and Differences in Palliative Care in Two Countries

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Gary Stein with participants of Lancaster University's International Research Summer School at the International Observatory on End of Life Care.

Participating in a Fulbright project in the U.K. during the summer of 2010 offered an excellent opportunity for learning firsthand the commonalities and differences in palliative care in our two countries. I had the privilege to join the guest faculty of Lancaster University's International Research Summer School at the International Observatory on End of Life Care. Additionally, to observe how hospice care is delivered, I met with directors and program staff at the internationally-renowned St. Christopher's Hospice in London, as well as at community hospices near Manchester. My dialogue with hospice leaders offered observations into a highly-developed network for the care of chronic and terminal illness.



Gary Stein with Dr. Iris Cohen Fineberg, Director of the Research Summer School, at Lancaster University's International Observatory on End of Life Care; and Dr. Paolo Mazzotta, Research Summer School participant.

At the International Observatory, I conducted seminars for health care practitioners – nurses, social workers, and physicians – from the U.K., Kenya, Slovenia, Canada, Nepal, and the U.S. The topics reflected my research interests: ethical obligations regarding informed consent for providing care and conducting human subjects research; the needs of people with disabilities to access quality and compassionate care for life-limiting illnesses; and conducting research with vulnerable minority communities, in this talk as developed for the lesbian and gay community in the New York area.



Fulbright Specialist Gary Stein with Dame Barbara Monroe, Chief Executive, St. Christopher's Hospice, London.

Staff at U.K. hospices share with their U.S. colleagues the commitment and enthusiasm in providing high quality, effective, and compassionate care. However, there are unique and important differences. Hospice patients in the U.S. rely primarily on Medicare, other public programs, and private insurance to pay for their care. In the U.K., hospice care operates largely outside the National Health Service, which provides about one-third of hospice budgets; most hospice care is supported by the charitable sector, requiring an emphasis on fundraising.

The U.S. emphasis on Medicare has promoted universal availability for hospice care among U.S. elders, but has also created unique challenges not necessarily related to patient need – as a political compromise, Medicare regulations require doctors to certify that hospice patients have an expected lifespan of six months or less. British patients have not been burdened by this requirement, allowing the provision of hospice services upon diagnosis with a life-threatening illness. While U.S. hospice care is primarily based in the community, with home care provided by committed family members, British programs have greater opportunities for residential care.

The breadth of social work services also vary considerably. In U.S. hospices, social workers and the psychosocial services they provide are routinely part of each patient's care. In the U.K., social work services are limited to those identified, often by nurses, as requiring psychosocial care, thereby restricting such care to patients presenting complex family or social situations. Unlike clinical social workers in the U.S., who have master's degrees and expertise in mental health counseling, British social workers have bachelor's degrees and may not have training or experience in mental health services.

To enhance my awareness of the needs of lesbian and gay elders regarding long-term care, end-of-life care, and health care decision-making, I met with U.K. academic researchers and a program officer from Age UK, one of the largest elder service organizations. Community leaders from both of our countries have similar challenges – obtaining recognition from government policymakers of community needs, and identifying supports and resources for serving LGBT elders. The service and research needs in both countries are enormous and at early stages of development.



Dr. Gary Stein conducting a class

The Fulbright Program offered a unique experience to collaborate with U.K. researchers and providers. I hope to further develop these relationships through ongoing partnerships through scholarship and professional training.