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The Neil Samuel Ghiso Foundation

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Neil S. Ghiso Fellowship: Report for 2003-2004

Over the past academic year, I have felt incredibly fortunate to be a part of the Neil Samuel Ghiso Foundation (NSGF) for Compassionate Medical Care as a Fellowship grant recipient. In its mission statement, the NSGF states that it “is dedicated to fostering compassionate care for chronically and terminally ill patients and their families through medical education, research, and training.” I have tried my best to keep that mission at the forefront of the various experiences related to palliative care that I have weaved into my third year at Harvard Medical School (HMS). My time spent as a Ghiso Fellow can best be described under three broad activity categories: (1) learning more about the field of palliative care and how it is taught in medical school; (2) publishing what I have learned about caring for dying patients and teaching compassionate care; and (3) becoming an advocate for greater public awareness of issues surrounding palliative care.

I. EDUCATION

A. Palliative Care Didactic Sessions with Dr. Robert Buxbaum

Richard Lin (my Ghiso co-Fellow) and I had the great pleasure of meeting with Dr. Robert Buxbaum periodically throughout the year for didactic sessions on various topics important in the field of palliative medicine. Richard and I selected the subjects ourselves and met at HMS with Dr. Buxbaum (the Harvard faculty mentor for the Ghiso Fellowship) and Jeannie Hess (Director of the Community Service Program at the HMS Office of Enrichment

Programs) to discuss what we had learned. As part of the sessions, Richard prepared a PowerPoint presentation entitled “Principles of Pain Management” that both Dr. Buxbaum and I found to be a concise and systematic review of basic concepts behind how pain is best treated clinically. I also prepared a presentation entitled “Terminal Sedation” that defines the practice of sedation, explains how it is clinically achieved, and explores the controversial ethical and legal issues that sedation raises.

In March, I attended a workshop given by Dr. Buxbaum entitled “Common Geriatrics Problems” at a Harvard conference primarily centered on the office practice of primary care medicine.

B. HMS Palliative Care Clerkship Elective

In February, I spent a month working full-time at Brigham and Women’s Hospital (BWH) and the Dana-Farber Cancer Institute (DFCI) as a medical student in Dr. Susan Block’s Psychosocial Oncology and Palliative Care department. The clerkship (PS516M.J, Psychosocial Oncology and Palliative Medicine) consisted of two weeks on the DFCI Psychosocial Oncology service and two weeks on the DFCI Pain and Palliative Care service.

While on Psychosocial Oncology, I worked closely with DFCI psychiatrists Dr. John Peteet and Dr. Jacob Roth, consulting on cancer patients at the BWH who were struggling with various mental health issues and difficult social circumstances. I also accompanied Dr. Peteet on several of his psychiatric outpatient sessions, learning how to help comfort and support those suffering from extended disease courses. As the medical student on the Pain and Palliative Care service, I worked with specialists Dr. Janet Abraham, Dr. Mary Buss, and Dr. Gary Hsin as well as the BWH anesthesiologists to develop individual pharmacologic and non-pharmacologic treatment plans for patients suffering from oncology-related pain.

At the end of my rotation, I gave a presentation entitled “Overview of Delirium in Patients with Advanced Cancer” to all the members of Dr. Block’s department.

C. Improving End-of-Life Care Education for BWH Internal Medicine Residents

At the suggestion of Dr. Buxbaum, Richard and I arranged a meeting during Fall 2003 with Dr. Daniel Federman, former Dean of Medical Education at HMS, to chat about how we as Ghiso Fellows might be able to help develop the evolving curriculum regarding end-of-life care for BWH Internal Medicine residents. Dr. Federman gave us access to academic papers and materials related to palliative care that he has collected over the years and also put us in touch with Dr. Joel Katz, Director of the BWH Internal Medicine Residency Program.

At a meeting with Dr. Katz, Dr. Abrahm, Dr. Becky Cunningham, and Dr. Jane Sillman, Richard and I introduced ourselves and explained the mission of the Ghiso Foundation. The physicians present at the meeting used the time to jumpstart various new ideas for presentations that could be given to residents regarding palliative care and rotations that could be offered those house officers interested in treating the terminally ill. We also decided that it would be helpful to make self-directed PowerPoint presentations on various palliative care topics developed by The Education on Palliative and End-of-Life Care Project (EPEC) available for all medicine residents to access on their own. After the meeting, Richard composed a letter to the BWH Medicine house staff explaining what the EPEC learning modules were, and I created a CD-ROM that included the PowerPoint files as well as Richard’s and my own presentations on pain management and terminal sedation. The CD-ROM is now on file and available at the BWH Medical Residency Office.

II. PUBLICATIONS

A. End-of-Life Care in the Medical School Curriculum

During the summer of 2002, I worked in Dr. Block's DFCI office as a research assistant to Dr. Amy Sullivan, one of Dr. Block's research associates. I helped Dr. Sullivan's research team on a project aiming to describe the attitudes and practices of end-of-life care teaching in the American undergraduate medical curriculum as reported by administrative leadership and to identify opportunities for improvement. For data collection, we conducted a telephone survey with Associate Deans for Medical Education or Curricular Affairs affiliated with a random sample of 62 accredited medical schools.

Our project results (with an 82% response rate), which were accepted for publication this year, show that the majority of Medical Education Deans support integration of end-of-life care into existing courses throughout the undergraduate medical curriculum. Based on our data, we concluded that successful integration depends most on proper faculty development, which includes both the development of faculty leaders to drive change efforts as well as education of all faculty who teach students and exert influence as role models and mentors. The leaders we interviewed showed strong support for end-of-life care education; given the fact that previous national studies conducted by Dr. Block's office showed a high level of interest in palliative care among medical students, the potential exists for meaningful change in end-of-life care education to happen.

The manuscript for our study, "End-of-Life Care in the Curriculum: A National Study of Medical Education Deans," will appear in the journal *Academic Medicine* later this year. In October 2003, I helped Dr. Sullivan and Anne Warren, another HMS student, present a poster

summarizing our project at HMS Medical Education Day at the Tosteson Medical Education Center.

B. Personal Reflections on Breaking Bad News

During my first year of medical school, I spent a few afternoons following Dr. Vicki Jackson, who was then a Pain and Palliative Care Fellow at the DFCI, on her consultations with inpatient oncology patients. One session during which I witnessed Dr. Jackson counsel a 30-year-old woman about her lack of treatment options for end-stage cervical cancer made such an impression on me that I wrote a short reflection paper about the experience. In the paper, I discuss how watching the patient's and her family's reactions to the news really emphasized in my mind and heart the importance of compassion among the many attributes that good doctors strive to possess.

This past year, my paper was published in the journal *Current Surgery*. It appears in the September/October 2003 issue under the title, "An Emotional War on the Wards."

III. ADVOCACY

During March 2004, I took a month off from my clerkships in the hospitals and worked as an intern for the Massachusetts Compassionate Care Coalition (MCCC). The MCCC, of which Dr. Buxbaum serves as President, is a tax-exempt charitable organization that exists to enhance care for people with life-threatening illnesses and their loved ones in the Commonwealth. The Coalition is formed by a grassroots, voluntary collaborative of agencies, institutions, and individuals in Massachusetts; it includes both providers *and* consumers of health care services, and it aims to promote informed choice, comfort, and compassionate care at the

end-of-life. During my month with the organization, I became involved with a number of different initiatives, all of which were focused on achieving the Coalition's mission.

A. Putting Together a Grassroots Initiative

During my month with the MCCC, I worked closely with Dr. Buxbaum and Arlene Lowney, the Coalition's Executive Director, to help out with the administrative side of running a non-profit organization focused on improving palliative care. On March 2, I attended an MCCC Board of Directors Meeting, during which I met the leaders of the Coalition and learned about the various projects that agencies associated with the Coalition were putting together. I also helped Arlene organize the MCCC Fourth Annual Meeting on March 9 at the Massachusetts Medical Society; the meeting facilitated networking among people from all over the state with an interest in end-of-life care and featured a presentation by Dr. Kathleen Rusnak on "Meeting the Spiritual Needs of the Dying."

Over the course of March, I did research on various sources of funding for non-profit organizations, presenting Dr. Buxbaum and Arlene with multiple options that the Coalition had for pursuing financial support. In particular, we focused our efforts on applying for a Rallying Points Community Coalition Award of Excellence, a grant specifically designed for coalitions that have improvements in end-of-life care as their goals. I helped Dr. Buxbaum and Arlene brainstorm ideas for our grant application.

To explain the goals and initiatives of the MCCC at meetings with other end-of-life care organizations and potential financial supporters, I also developed a PowerPoint presentation that summarizes the Coalition's mission, past projects, and current activities. The MCCC now has a copy of the PowerPoint to use whenever appropriate opportunities present themselves in the future.

B. Compassion Sabbath

The MCCC has focused most of its collective efforts over the past year on Compassion Sabbath, a statewide multi-faith initiative to engage clergy, lay ministers, and religious educators in proactively meeting the spiritual needs of members facing the end-of-life. This project was inspired by the Midwest Bioethics Center (MBC), an agency in Kansas City (Missouri) that organized a weekend a few years ago during which ministers in Kansas City from different faith traditions highlighted compassion for the dying as a theme in their respective worship services. The goal for the Massachusetts version of the project was to take the previous work of the MBC and expand it into a statewide event, during which clergy from all different types of religious traditions would use the month of May 2004 to increase awareness of issues surrounding death and dying in their congregations.

In October 2003, faith leaders interested in Compassion Sabbath met at Trinity Church in Northborough, MA, to find out more from the MCCC about the goals of the project. Over 120 people from all over the state attended the conference, entitled “A Matter of Life and Death: Pursuing Excellence in End-of-Life Ministry.” Those clergy who became interested in organizing worship services and workshops on death and dying within their respective congregations attended a second statewide MCCC conference in January 2004, which focused more on leadership training in preparation for events in May. In addition to equipping religious leaders with tools helpful in promoting end-of-life care, the MCCC has also organized several public events featuring speakers on end-of-life care in Worcester, Franklin, Wellesley, Lexington, and Framingham in April and May to build momentum for Compassion Sabbath in May.

During March, I focused most of my efforts primarily on putting together a Compassion Sabbath “Resource Guide” to help clergy with worship services and discussion groups in their congregations in May. The Guide, based on a similar handbook that the MBC created for its Compassion Sabbath project in Kansas City, contains sample sermons, prayers, scripture passages, and reflections relevant to end-of-life concerns from many of the major faith traditions, including Christianity, Judaism, Islam, Hinduism, and Native American spirituality. It also contains ideas for workshops to aid religious leaders in leading small group discussions on death and dying. Building on the MBC’s previous work, I helped the MCCC with several new modules of the Guide, including a section of thought-provoking quotations by Morrie Schwartz, a man afflicted with Lou Gehrig’s disease who appeared on *Nightline* 1995 before he died and inspired viewers with the insight that the dying process had given him into life itself. I also helped organize information about local and national end-of-life resources to place at the end of the guide to make clergy aware of what is available to them—including the Last Act Partnership, a national non-profit organization that maintains a website containing end-of-life care publications, educational materials, and advance directives. Once the entire Resource Guide has been completed, it will be made available on the MCCC website (www.massccc.org) for ministers and clergy to download and use.

Although the majority of the Compassion Sabbath publicity campaign took place in April and May, I was able to help out with some initial efforts in March. On March 24, I accompanied Dr. Buxbaum as the guest speakers at a networking meeting at Winchester Nursing Center for people local to Winchester whose work and interests concerned care for elders and the dying. Dr. Buxbaum used the MCCC PowerPoint that I had developed to introduce the audience to the Coalition, and I spoke about the goals and vision for the Compassion Sabbath initiative. In

addition, I contacted local radio stations (e.g., WBUR, WGBH, and WFCR) to help Arlene and Dr. Buxbaum explore other publicity options.

C. Making Information on Palliative Care Readily Accessible to All

The MCCC is planning on making a couple of other documents available on its website soon that address particular areas in end-of-life care of importance. One area is explaining to the public all of the various legal documents and financial considerations that one must be aware of if one is terminally ill or has a loved one who is dying. Mr. John A. Fedorochko, an engineer from Lexington, MA, recently suffered the death of his wife from terminal disease; after his wife passed away, he decided to write a layperson's practical guide to preparing for the end-of-life. I worked with Mr. Fedorochko during the month of March to help edit his article, entitled "The End-of-Life Scenario: Ready or Not." Mr. Fedorochko has agreed to let the MCCC make his document available on its website for all those who will benefit from its clear explanations of advance directives, hospice options, and financial considerations.

In addition, I also helped Dr. Buxbaum revise an article of his entitled "Palliative Care in Extended Care Facilities: the Ideal Unit." Recently, Dr. Buxbaum has been involved in efforts to incorporate palliative care teams into local nursing homes, a concept which up until now has not been explored in depth. To express his vision for the project, Dr. Buxbaum has been working on this article, which discusses the context for the initiative as well as specific areas such as team communication, care continuity, and family support that are crucial to make the integration a success. The MCCC is also planning on making this manuscript available on its website soon.

As a Ghiso Fellow this past academic year, I have tried to put together a collection of experiences from which I would learn about caring well for the dying from a variety of different

angles. Medicine is a field in which learning never ends, especially in the field of palliative care where experience and the art of communicating compassion supercedes knowledge; as a medical student, I have been blessed to spend time working with Dr. Buxbaum and to be involved with end-of-life care at the DFCI and BWH. I also feel very fortunate to have been able to publish some of what I have learned from my limited experiences with palliative care in medical school so far. Finally, the chance to be involved with end-of-life care advocacy work in the midst of my clinical clerkships was unique and invaluable, an opportunity for which I am clearly indebted to the Ghiso Foundation for its vision and support.