

## **Neil Samuel Ghiso Fellowship: Report for 2005-2006**

I have been honored by the support of the Neil Samuel Ghiso Fellowship during the past year. Shadowing talented and compassionate professionals formed the cornerstone of my experience during the summer. Several themes emerged during the time I spent with physicians and hospice workers. In turn, these themes provided a foundation from which to expand my knowledge, and from which I view it as my duty to advocate and educate others. The fellowship additionally allowed me to continue work on two research projects. This report details: 1) my shadowing experiences; 2) my educational and continuing advocacy efforts; and 3) research I have worked on during the past year. Finally, I wish to thank and acknowledge Dr. Robert Buxbaum for his knowledgeable, kind, and openhearted mentoring during the year. Dr. Buxbaum encouraged my independent work most importantly by serving as a sounding board for my many questions and thoughts.

### **I. SHADOWING**

#### *A. Breadth of experience*

During the summer I had the opportunity to shadow physicians and other professionals working in rehabilitation facilities, home hospice, inpatient, and outpatient palliative care services. I observed visits with patients, impromptu family meetings, and teaching and patient care rounds. Most of the physicians and professionals I shadowed integrated my presence into their work. Some allowed me to ask questions of patients

during their visits, others discussed medical and social aspects with me after patient interactions. Dr. Buxbaum additionally arranged several opportunities to speak with seriously ill patients alone, during which I tried some of the communication techniques learned from others.

These experiences provided an extensive breadth of exposure, and afforded quite different perspectives on the field. While my previous contact with palliative care was largely through scholarly research, the real life interactions of patients and physicians added a much richer dimension to my growing knowledge. Instead of reading about topics such as advanced directives, concerns about opioid addiction, and cultural competence, I observed and participated in discussions with patients surrounding these issues. For each of these formerly theoretical scenarios, I now have images and stories in mind of patients who illustrated these for me. I was privileged to observe these intense and private situations in part because end-of-life (EOL) can heighten experiences, but in part it was due to the work of talented physicians adept at teasing out what lies beneath the surface. By probing deeper, looking beyond the physical, and expressing an openness and willingness to travel with the patient, physicians elicited the emotions and preferences most important to care. These situations were far more subtle and nuanced than I had previously imagined, confirming the importance of a unique approach to each patient and family, and demonstrating the inadequacy of a cookie-cutter perspective on patient care.

The summer proved my first intense exposure to clinical medicine. In college I learned about the American health care system – how it worked, how it was financed, its strengths, weaknesses, and possibilities – through the lens of palliative care. This

summer I was introduced to some of the fundamentals of clinical medicine – rounds, team meetings, diagnosis, pharmacology, patient-doctor communication – through the perspective of palliative care. My scholarly research and experiences indicate that palliative care is in many ways a radical approach to medicine, especially in its holism, focus on quality of life, and attention to patients’ and physicians’ emotional reactions. As I learn medicine more broadly in the coming years, I know I will need to hold on to what I have learned from palliative care. I hope these experiences serve as a protective inoculation against the many aspects of physician socialization that I find troubling.

*B. Themes*

Over the course of the summer, a number of themes emerged; these were ideas or concepts I saw repeatedly, although with variation during shadowing. These coalesced in the journal I kept, which I used to reflect upon my experiences during the fellowship. Here I will describe some of these themes, and illustrate them using examples.

My understanding of patients’ fears of addiction and resistance to taking certain medications was enriched significantly through the conversations I observed. Sometimes patients could explain their reluctance or fears, other times they simply wanted to avoid medication for as long as possible; resistance often ran deep. Most often patients feared opiate medication. The physicians I observed handled these fears with skill and flexibility. They explored patients’ concerns, corrected misconceptions, normalized the need for and fear of medication, and advocated for pain and other medication until they realized patients were making informed decisions, whatever they were. I accompanied Dr. Joanne Nowak, medical director of HealthCare Dimensions Hospice on a home visit to a woman with significant shortness of breath due to a large pleural effusion. The older

woman had been the rock for her large family, and was struggling with feelings of being a burden. She was also reluctant to take morphine, although it would have eased her breathing significantly. Dr. Nowak squatted down at the feet of this tiny woman in a wheelchair and addressed her fears by explaining that morphine would not make her get up and start robbing stores to support a habit. Dr. Nowak said that just like the disease had been treated with medicine before, the pain and shortness of breath were now the problems of the body that could be helped to heal. On another occasion, Dr. Janet Abraham helped ease a patient's fears by saying that addicts use drugs to get out of life, while the patient was using pain medications to get back *into* life.

One theme emerged from a more medical angle: the persistence of consciousness despite appearances. I observed the care of many patients with altered consciousness – exhausted patients, patients who could not communicate, patients with an unknown connection to the outside world. At the time I was surprised to witness practitioners attempting – sometimes gently pushing – to communicate and engage with such patients. I reacted first with skepticism. Could these patients hear? Understand? Respond? Yet it was with equal surprise that I often saw proof of patients' continuing connection with their world, sometimes despite closed eyes and the impression that they were somewhere far away. I saw vivid evidence of this theme while shadowing HealthCare Dimensions Hospice Chaplain Steve Gross as he visited a dying man with chronic heart failure. Mr. J. was completely alone in a dingy room in a nursing facility. His hair was matted, his eyes remained closed throughout our visit, and he coughed often. As Mr. Gross introduced himself and said a few words, there was no response from Mr. J. But as Mr. Gross began to read from a prayer book, Mr. J's coughing subsided some, and he

appeared physically calmed. Throughout the prayer, Mr. J. uttered “mm-hmm” and “that’s right” at appropriate moments. This man seemed to understand he was being prayed for.

Although I intellectually understood many of the barriers to enrolling eligible patients in hospice care, I was shocked with the extent of resistance at all levels. One of the most constant threads throughout my experience in palliative care was the need to sell, advertise, and push for hospice. Getting patients into hospice occupied a very large percentage of rounds discussions in the hospital and rehab settings. The amount of energy required to reap the benefits of one of the most compassionate and helpful services is truly a tragedy. Hospice is not a perfect service, and there are limitations; but the fact remains that it is underused.

Barriers to hospice use have been well-documented. I repeatedly witnessed the following: lack of knowledge; the perception that hospice means “giving up”; the perception that hospice is only for those imminently dying; and the belief that it is somehow an added burden to families. I was surprised by this latter barrier, which was illustrated by a family meeting facilitated by palliative care fellow Dr. Jillian Gustin as she discussed an elderly patient’s impending hospital discharge. The patient’s daughter was actively involved in her mother’s care, understood that her mother was dying, and wished to bring her mother home to be cared for until the end. These factors seemed aligned to create a good environment for hospice care. In response to Dr. Gustin’s initial mention of hospice, the daughter said that she wanted to bring her mother home first, and consider hospice at a later date. The daughter felt that hospice would be an additional stressor to her already intense caretaking responsibilities. Dr. Gustin then focused her

discussion of hospice on factors that would be most helpful in the family's specific circumstance. Most importantly, the daughter wanted her mother to spend her final days at home, and needed to know what to expect as her mother died. Dr. Gustin responded, "Hospice can help you keep your mother at home and educate you as to what to expect – they are experts at that".

Repeatedly, I saw physicians use this strategy of advertising hospice and palliative care by tailoring the message to problems patients and families were struggling with most urgently. During rounds at Massachusetts General Hospital, one physician said, "If you believe the family or patient will benefit, lobby the family for hospice." Although it was difficult to witness resistance to a service designed to improve and ease the transition to EOL, it was useful to learn an approach to educating patients and families about the program. Similarly, patients and families were often confused and occasionally fearful as to the role of palliative care. Palliative practitioners likewise explained their role as focused on whatever problem was most pressing, whether that was symptom management, EOL decision-making, or helping families deal with difficult issues.

## **II. ADVOCACY AND EDUCATION**

### *A. Compassion Sabbath*

Compassion Sabbath is a branch of the Massachusetts Compassionate Care Coalition; its mission is to engage religious leaders in addressing EOL issues for their congregants, recognizing the reality that many clergy are ill-prepared to for this task. During the summer I worked with Arlene Lowney and Betsy Goodwin to edit educational

materials originally prepared for Florida clergy about the breadth of EOL issues. As part of this process, we adapted these materials to Massachusetts, especially those sections pertaining to EOL decision-making and state law. I additionally reviewed and edited the section of these materials designed to teach clergy about some of the medical signs and symptoms seen in dying patients. In researching this information I learned an extensive amount about common EOL symptoms and treatment, much of which I have been able to share with my classmates.

*B. Educating classmates*

As mentioned earlier, there is a fundamental lack of understanding as to the role hospice and palliative care can play in the care of seriously ill patients. Perhaps more tragic than the public's lack of knowledge about these services is the medical community's own ignorance. Students receive no formal education about hospice care, despite the fact that certified services have been funded by Medicare since 1982. Throughout this fall I have found opportunities to discuss hospice and palliative care with my classmates. During "tutorial", Harvard medical students learn by focusing on an instructional "case" in small groups. As the prognoses of our "patients" worsen, there has been a window in which discussion of EOL issues is appropriate. I taught classmates about such topics as pain management, terminal sedation, and advance directives. More importantly, I provided an overview of hospice care in several tutorials. Most students had almost no prior knowledge of hospice, and were eager to learn more. As a result, I lobbied course directors – so far in pathology and pulmonary medicine – to include mention of hospice in future tutorial cases. I believe that students need to see and hear

the word hospice early on in their education, in order to peak their curiosity and familiarize themselves with a service about which they may have little exposure.

*C. Palliative care interest group*

Throughout my first two years of school I have been a leader with the student interest group devoted to palliative care. As a result of my summer – and in response to the enthusiasm of classmates – I arranged for Dr. Joanne Nowak to speak to students about the basics of hospice care. Students mentioned how misinformed they had been prior to this talk, and how much they appreciated the information. Additionally, I arranged for a panel of fourth year students to speak about caring for dying patients on the wards. Students may be unprepared to face patients and families dealing with EOL issues, and teaching staff may not be sensitive to the emotions these encounters can raise. The goal of the panel was to have first and second year students begin to consider these issues, as well as hear about ways that students have dealt with these challenging experiences.

### **III. RESEARCH**

*A. Blame in medicine - editorial/qualitative research*

During the summer I continued research looking at the culture, function, and risks of blame in medicine, under the guidance of Dr. Nicholas Christakis. Using interviews of physicians involved in the care of dying patients, I analyzed those in which there was discussion of blame surrounding perceived errors. Although blame is shunned by policy organizations because it conceals the systemic factors largely responsible for errors, we found that blame is pervasive throughout medicine and has some positive functions.

Blame can be useful in teaching valuable clinical lessons, allowing physicians to forgive one another for errors that are inevitable, and permitting the expression of emotions, especially sadness. We believe these findings are important and new, and decided to present them in the form of an editorial; we are in the final stages of editing and expect to submit to journals in the near future.

*B. Crying among medical trainees*

During the past year I have worked with Dr. Susan Block and a third year medical student, Anthony Sung, looking at crying among medical students and interns. We developed a survey and administered it to all medical students and interns in two medical schools and hospitals in the Northeast. We asked questions about the frequency and circumstances in which trainees cried, attitudes toward crying, perceptions of institutional attitudes and behaviors surrounding crying, and the prevalence and adequacy of institutional support and training regarding crying. We found that crying was common among both students and interns, with women crying more often than men. Participants reported crying as the result of both stress and sadness. Additionally, trainees wished for greater discussion of crying with their superiors, although superiors missed important opportunities to discuss their own crying with trainees, by walking out of the room or returning to work without discussion. We believe that more frequent discussion of crying in medical training may redress the stigma associated with crying, and encourage the healthy emotional development of physicians. I will be presenting this data at the Society of General Internal Medicine meeting on April 26<sup>th</sup>. We are currently in the process of submitting the paper.

## **FINAL THOUGHTS**

One of my goals for this summer was to consider further whether I could specialize in palliative medicine as a career. I worried about the emotions involved and about the effects of encountering sadness and suffering on a daily basis. These were real challenges I experienced during this past summer, but I found they were not more than I could bear. Although I remain open to other career choices, I feel more secure now continuing research and envisioning myself as practicing in this field. If my path diverges from the expected and I enter a different field, I know that the lessons I have learned are central to the practice of all medicine.