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Neil Samuel Ghiso Fellowship: Report for 2009

Since being awarded the Ghiso fellowship back in March my personal struggles in coming to terms with the tumultuous health of my very elderly father and what that means for my family has been undeniably entwined with the drama of finishing third year medical school, anxieties of studying for medical board exams, and residency applications, not to mention the soul-agonizing process of finding the specialty that I will dedicate my career to. However, in having the fortune of being awarded a Ghiso fellowship, I had the privilege of taking a couple of months off to become more involved in a palliative care research project that I care very much about.

August: The Initial Project-- Advanced Care Planning in terminal cancer patients

My initial research project during my Ghiso fellowship year involved using a 5-minute video decision aid, for advanced care planning for cancer patients, to see how it affected patients' care preferences. The video depicted three levels of end of life care, including life-prolonging care, basic care and comfort care. The project is a randomized trial to see how the video influences the decision making of terminal cancer patients deemed to have 6 month life expectancy. My personal responsibilities included interviewing patients, data collection, as well as general integration into the palliative care team caring for these patients. My previous experience interviewing cancer patients enhanced my ability handle these responsibilities.

This project is ongoing, having begun in April 2009 and will continue through 2010. My realistic goals for myself during the project were to learn how to talk to very sick patients about their goals of care, which I thought would be a powerful experience for me as an aspiring oncologist. I knew going into this project that there was no easy way to assess my personal success with the project, but I did chronicle my journey through journal writing and reflection pieces (some of which I will excerpt throughout this final report).

I joined the project in August. My training consisted of first shadowing and doing observed interviews with a professional nurse, and then transitioning to conducting the interviews by myself. As part of the unwritten curriculum of lessons learned during the project, I became more aware of the demographics of oncology in Boston. In June I attended a talk by Dr. Karen Winkfield, MD, PhD, where she shared the results of her research on oncologic disparities of care, specifically in Boston. Dr. Winkfield had mentioned that while Boston is 25% African American, in the Partners healthcare system, all services only see about 5-6% African American patients. This number is particularly disheartening, when one considers that "all services" includes services without longitudinal follow up, such as pediatric urgent care and obstetric care, which were a

large percentage of the visits by African American patients. Even during my own research at Dana Farber Cancer Institute, in interviewing almost 100 survivors of gynecologic malignancies, less than 5% of my patients were African American or Latina.

The accrual of patients for the advanced care planning study was based at MGH and Boston Medical Center. It was my first time working clinically at BMC. It was also the first time I saw such a large percentage of patients of color receiving oncologic care. As a Caribbean- American medical student, it was a particularly rewarding experience to work with this patient population, but also educational in terms of learning how culture can influence patient's views of end of life care. Many times, even though I asked the survey questions to the patient, adult children were present, and were active participants in the discussion. More than once, I heard patients invoke faith and religion as reasons why they did not wish to be full code at the end of life.

“If it's God's will that I go, that is the way,” one 54-year-old Brazilian woman with recurrent ampullary carcinoma told me. She was adamant that her code status be DNR/DNI

My experiences interviewing patients at BMC have made me more interested in racial/ethnic disparities in oncologic care, and also how culture impacts end of life care preferences. I plan to remain active with Dr. Volandes' research, and during my residency I am particularly drawn to programs that offer the opportunity to work at a comprehensive cancer center with multidisciplinary patient resources and strong public health schools. Moreover, I have become involved with Dr. Winkfield's project of building community networks to improve the health status of the underserved population in the Charlestown Boston Housing Authority (BHA_ housing development, the largest public housing project in New England. More than 60% of the patients in this area are racial African American or Latina, and many receive their primary care at the MGH community health center. My role will be to interview key informants who either live or work in the BHA and have a good understanding of the dynamics between racial ethnic groups in the community. We will conduct focus groups that will assess perceptions among minorities of the health care system, and its impact on them receiving health care services, including cancer screening and treatment.

Another lesson I learned during my first month with the advanced care planning study was the importance of timing. In general, summer months were pretty slow in the oncology clinic where I was working. Often, there would only be 1 patient per clinic day. The first day of a new chemo regimen or the day a patient learned that they had disease progression was never a good time to administer the study (at least per the treating oncologists, who would frequently pre-screen their patients as not 'ready' to take part in the survey). I frequently heard the concept of not wanting to “rob our patients of hope.” Obviously, in these situations I deferred to the judgment of the treating oncologist. However, I realized that especially in an already emotionally charged situation where prognosis is uncertain, a lot of times our resistance as clinicians to have end of life discussions with our patients stems from our own discomfort with the reality that our interventions may not be working. The irony is, that in these moments when a patient's

condition is deteriorating, it is perhaps MORE important to have an honest discussion about advanced care preferences.

An example of this came from a patient I interviewed in the infusion room, a 64-year-old gentleman with advanced lung cancer who was accompanied by his wife. Mr. J was on a trial of a new chemo agent, as his disease had rapidly progressed over the past couple of months. His oncologist informed him (while I was present) that he was running out of therapeutic options. Mr. J insisted that, even though his oncologist had explained that it was time to get his affairs in order, that because he did not have any existing heart disease and his health was “excellent, except for the cancer,” he wished to remain full code. “I’m probably healthier than most 65-year-olds...well, except for the cancer” he quipped.

In sum, my first month on the study was incredibly valuable. Many things went well: I was able to learn how to administer the survey, got to work with a more diverse patient population at a hospital I had not previously worked in clinically; and had the privilege of many meaningful discussions with the patients I interviewed. Still, there were some things that did not work as well—for example, the fact that the clinics were slower in much of the summer months, with fewer patients. Also, since I was working in a system where I had less experience with the oncologists (ie BMC), I think they were sometimes more protective of their patients and would not let me interview them if they felt the situation was “bad timing.” I was not as keen enough to perceive these biases in physician screening of patients for the study until I worked at MGH, where the oncologists were more open to having an HMS student survey their patients about this sensitive subject matter.

This issue of timing (ie when is it good to have end of life discussions with patients given their tenuous health status and often precarious prognosis) changes from clinic day to clinic day—this was often a challenge of the project in general. Nevertheless, while I met my immediate goals, I think I was able to set new ones, and the lessons I learned colored the lens I would subsequently bring to my additional clinical rotations.

September—applying a new lens I: Neurology consults for an oncology service

Mr. R is a 66-year-old right-handed gentleman with a history of stage IV renal cell carcinoma (RCC), and known metastases to his thoracic spine. He presented to the emergency department with one week of progressive right arm weakness and intractable 10/10 pain. He said the pain started with excruciating arm pain and he began to have increasing hand clumsiness. He found it difficult to adjust his zipper, and do fine motor movements such as holding a pen or cutting his food. The latter symptoms caused him much embarrassment and frustration, in spite of the obvious support of his wife, children, and grandchildren.

“I’m a grown man,” he told me with frustration. “And I have to have my wife cut my food for me, like a child!”

Neurology was consulted due to his intractable pain and right arm weakness. In talking with Mr. R, I noticed that he was particularly sad. His renal cancer had been discovered incidentally on a routine chest CT (surveillance for an existing chronic medical condition). His oncologic course had been filled with disease progression through various experimental protocols, blood clots and back pain. He explained to me that he needed his arm strength for an important reason—his wife had multiple health issues of her own, including debilitating pain, requiring a scooter to ambulate. Further, his youngest son was disabled in an automobile accident, and now required a wheelchair, as he could no longer walk. For Mr. R, a former airport employee who had worked refueling planes, heavy lifting was not just part of his prior profession; it was essential to his home life and his family depended on it.

In the work up of his pain, a CT showed impingement of a nerve root. Before I could present Mr. R's case to my neurology attending, a spine surgeon had already met with Mr. R, explained that surgery may be able to eradicate his pain, and planned to take him to the OR by the end of the week.

This is when the situation became complicated. Because of the bleeding nature of renal cell carcinoma, he would have to have an interventional radiologist embolize some of the blood vessels to the lesions his spine, otherwise the spine surgery would be life-threatening due to bleeding. The primary medicine team caring for Mr. R were concerned about moving forward on this front, given Mr. R only had one kidney left and had very insufficient renal function, and it was questionable whether he could tolerate the dye load for the procedure without subsequently needing dialysis.

For Team Neurology, it then became an issue of whether or not the spinal surgery was even the best option for controlling Mr. R's pain and saving his right arm function. Sure, the CT showed impingement of an obvious nerve that controlled arm function...but from our neurological exam, it appeared that the deficits Mr. R was experiencing could be due to a subset of nerve involvement, a nuance that would be better visualized by an MRI.

The reasoning for this was well-intentioned: Mr. R's renal function was already compromised—why subject him to a morbid surgery (and radiology embolization procedure) he may not need? Or worse, a procedure that he may receive but would not improve his arm function/pain. As our neurology team brought up these points, it was clear from my perspective as the student on the team, that this came from a lack of understanding on our part as to how the case would be managed differently if the MRI had shown more extensive or less extensive involvement of the nerves of the arm. In other words, the academic question of the precise diagnosis that additional imaging provided, would not necessarily alter the management decision: surgery or not, based on what the patient chose. I think our team's reaction was also rooted in responding to the surgeons in a territorial way, rather than probing to understand why Mr. R preferred surgery. This was all additionally complicated by the fact that Mr. R had a cardiac device which would have delayed our ability to schedule the requested MRI. All of this was perceived by Mr. R as neurology interfering and stalling a potential intervention on his arm pain, ultimately causing suffering and making his hospital stay much longer.

I visited Mr. R that evening. As the medical student on the neurology consult service, it was hard enough for me to comprehend the contradictory messages specialists were saying about tests to be done, surgery or not, and what would, at the end of the day, help Mr. R's pain. When I asked Mr. R if he understood what was happening, he burst into tears. He told me how frustrated he was by the care he was getting. He actually was developing animosity towards neurology because they seemed to be holding up this surgery that he now believed would save his arm function. Didn't we [the neurologists] understand that he needed his arms to help his wife and son for as long as he had left?

The whole experience underscored for me the HUGE problems with communication that can come from being on a consult service. Communicating the plan to and understanding the goals of the primary team has to be a priority. It is also of primary importance that the patient understands why we offer tests and want to do the interventions that we suggest. At the end of the day, especially when dealing with a patient with a terminal diagnosis, these should be in line with the overall care goals of the patient. I think that, sometimes, physicians may assume reverence to palliative care means not pursuing an intervention—here, for example, neurology felt that by detracting from the operation they were respecting Mr. R's palliative care wishes and potentially saving him from a morbid procedure. Unfortunately, he saw them as devastating his quality of life—to him, surgery, however aggressive, was more in keeping with his care preferences.

My experience on the neurology consult service, especially since we focused on patients with terminal cancer, exposed me to the nuances and politics that can be involved in what tests are done, what interventions are offered and how all of this is explained to the patient. For me, these lessons learned came in the context of a poorly executed inpatient consult, but they emphasized the importance of communicating goals of therapy to a patient and respecting their autonomy. Never assume what a patient would want given their prognosis- one must always understand their perspective.

In the end Mr. R had his surgery. Miraculously, his arm pain improved and required minimal medication to be pain free. He still carries his wife to and from her scooter, and looks forward to resuming another experimental protocol for his RCC, once his renal function stabilizes. My interactions with Mr. R gave me new goals in terms of how I would examine end of life care in patients with terminal cancer. I now wanted to further examine how inpatient consults were functioning and examine systematically how we may improve team communication. But first, I would experience the other side of this team interaction, during my medicine sub-internship the following month.

October-- A new lens II: the medicine sub-internship, or “almost the doctor, but not quite”

JS is a 74-year-old woman with a history of mild high blood pressure, who was presenting for work up and second opinion for a one month history of a wasting illness and abdominal distension since a colonoscopy about 1.5 months ago. Abdominal CT and

MRI showed hepatic cysts that appeared benign. Since her colonoscopy she reported low-grade fevers, especially at night. When her condition continued to deteriorate, her children decided she should leave her home in upstate New York and come to the MGH.

I admitted JS to the private service, and greeted her adult children who had accompanied her. She was my final admission, on my final call day as a sub-intern. My senior resident and I poured over JS's outside medical records (which came in 3 large binders). Surprisingly, her entire odyssey began so abruptly. Her medical history had been remarkably benign for a 74 year old woman. She played tennis daily, and spent her afternoons watching soap operas.

"I was playing tennis daily up until the night after the colonoscopy!" she vented, frustrated at the lack of explanation for her symptoms.

As JS's case unfolded, I realized that I was in the midst of a case which would inform my method of patient care for the rest of my career. Not only was her situation a diagnostic dilemma—no one knew what was causing her distension—but the steps in her management also underscored key values I internalized about how inpatient, especially oncologic care should be delivered.

We analyzed some of the fluid from her abdomen. The results from our lab were concerning for an exudative process- something usually associated with "badness," like disease of the liver or kidneys. Or cancer.

Almost as a knee-jerk, we proceeded to involve multiple specialists in our decision making about JS. Gastroenterology to evaluate the ascites fluid. Hematology to evaluate unexplained anemia. Infectious disease and rheumatology for her fevers.

As we proceeded through the battery of blood work and imaging tests to find a diagnosis, we did—though without a cause. The radiologist called me to relay that JS's abdominal CT showed diffuse caking of her abdominal organs and their lining, likely caused by metastatic cancer of a now unknown primary.

As I hung up with the somber radiologist, I paged the attending. Unfortunately, he was out of the hospital for the rest of the week. I felt bad—not only was JS from out of state and had just 2 days to briefly form a relationship with our team, but now she was on the brink of rapidly changing clinical problem and had several new faces on an increasingly larger team of care providers. I knew JS's children were visiting the next day from NY—hopefully we could have more answers by then so that she could have her familial support present for what looked like an upcoming "bad news conversation." I called the pathologist, to try to expedite the results of some studies which would confirm if cancer cells were in the fluid filling her abdomen. I then sat down to call the covering attending to relay the developing clinical picture.

The covering attending felt strongly that JS should know that we were more strongly considering cancer as her diagnosis, sooner rather than later. I explained to him that I

agreed had attempted to expedite the pathology reports and that JS's family would be present the next day.

Later that afternoon, I poked my head into JS's room. It was late afternoon, after the normal run of soap-operas, and the time I'd usually pay her a visit. Tears streaked her face. Her uneaten lunch on a tray by her bed. It turned out that the covering attending had paged an oncologist friend, and asked them to stop by as an informal consult. JS had learned that she likely had cancer from a visiting oncologist who did not know her, her original attending, or her story.

"I was so confused," she told me, her voice breaking. "He said we think you have cancer based on your scans, but we'll know for sure in the morning. Then left after 10 minutes! I'd never met this person before, hadn't seen him involved in my care...and he stops by in the afternoon to tell me my life is over."

So many things were wrong with how this case unfolded and I was left with so many unanswered questions about how this case could have been handled. Should an oncologist be the one to break "the bad news" to a patient that they have cancer? Should a cancer diagnosis be given based on imaging, without pathology confirmation? Did we help JS by telling her she likely had cancer before we had all the pieces of the puzzle? Was she better served by hearing about cancer from a "specialist" who did not know her, rather than someone from her primary team? Should specialists deliver this information, without the consent or knowledge of the primary team? And did we improve the clinical situation, our patient's morale or the likely outcomes of her care by insisting on telling her she had cancer, at the end of the business day, before we "punched out", when we knew her family and support system were going to be there bright and early the next day?

My gut response to all of those questions was NO. I felt devastated for JS. I sat with her for a couple hours, and with the help of my resident, we were able to find emotional support resources for her, in what would have been a very dangerous night to leave her alone. We made sure to touch base with her children when they arrived and let them know all the pieces we had, and what was missing. I also apologized to them and JS for the manner in which her potential diagnosis was revealed. When I left the rotation/service that Friday, 4 days later—the pathology still had not confirmed malignancy and JS was discharged to home, with plans to have further diagnostic work up in upstate NY. I still do not know if she actually has cancer or not.

November: More Advanced Care Planning, and Reforming Inpatient Consults

Tracy Balboni, MD, MPH, is a radiation oncologist at the Dana Farber Cancer Institute, currently working to improve the existing palliative care service at DFCI, including a new initiative to specifically meet the needs of radiation oncology patients. A major component of this project focuses on streamlining and improving the way inpatient consults are conducted. My experience with Mr. R and JS had taught me that unfortunately, oncologists are sometimes called in as consultants and their presence ends up "breaking the news" to a patient that they have cancer. To me this is a huge system

failure, and in seeking out mentors who agreed with this sentiment, I found that Dr. Balboni had actually been working to systematically fix this problem. Naturally, given my interest in this topic, and motivated by the Ghiso Fellowship—I joined her research project. It proved to be a unique opportunity as a medical student to work with a physician who is essentially trying to design an inpatient model to fix many of the problems I noted during my rotations in September and October. My role in Dr. Balboni's work is primarily as a consultant. As both a student and an outsider to the department, I was able to provide ideas and feedback to her existing framework, with the hopes that in the next year, the DFCI Radiation Palliative Care service will be up and running. Or, as a more humble goal—fewer, if any new oncology patients at Brigham and Women's will find out that they may have cancer when a radiation oncology resident that they have never met, walks into their inpatient room as a blind consult.

Our ideas involved going through anonymous surveys of some of the residents, who gave their feedback on how inpatient consults were currently being conducted. Sometimes, residents felt that they were called into clinical situations where the patient was not aware they had cancer, and this led to strained team dynamics, not to mention patient distress. From these surveys, we designed general themes or AIMS that Dr. Balboni framed as goals for the inpatient service. Some of my contributions to these aims included.

→ Physician education: promotion of awareness of the Radiation Oncology Urgent/Palliative care service through colleague education, such as personalized emails to departments based on their services and how this overlaps clinically with rad onc in terms of patient care. For example, my experience with Mr. R taught me that surgeons may see therapeutic options for a patient with limb weakness due to metastases to the spine differently than neurology. Also, many people have the tendency to delete mass emails. However, if we tailor our message and explanations to departments based on how relevant it is to their practice, we may educate our colleagues and subsequently avoid delayed or inappropriate consultations.

→ Requisition forms for consults: a short survey that can be completed on an electronic interface as the requesting physician pages the on-call radiation oncology resident. Our hope is that this interface can include basic information such as whether the patient already carries a confirmed diagnosis of cancer, and/or whether or not this patient has an existing oncologist. Other useful information includes the status of the patient's oncology management (ie, new diagnosis versus already on treatment) and the current goals of care (which should be verified by the primary team and patient). Much of these questions are to avoid the situation with JS, which is all too common- that is, the oncologist as a consultant not known to the patient (and also not realizing that the patient is unaware of their diagnosis), being brought in as inadvertent, initial "bad news breakers."

The rest of my November was spent in thoracic oncology clinic, again interviewing patients and asking them about their advanced care preferences. In that capacity, I had the privilege of working with Dr. Jennifer Temel, a medical oncologist at MGH. One of my most memorable patients was LF, a 40-year-old former dancer, mother of young children, and patient with stage IV lung cancer, who presented in clinic for evaluation of

progressive shortness of breath. She had never smoked a day in her life. She was currently enrolled in a clinical trial of a biologic agent to see if it would shrink some of the widely metastatic lung cancer that had taken over her body. She was as elegant as ever. Even before hearing of her substantial dance background, her presence and poise struck you when she glided into the exam room, accompanied by her supportive husband. She did not look like someone dying of stage IV lung cancer.

She crumpled when we told her she had a pulmonary embolism, or blood clot in the vessels to her lungs—which meant that she had to come off of the chemotherapy trial. As I watched Dr. Temel explain her options, and how she did not recommend that LF, given her disease status, remain full code...it was one of the most heart-wrenching, yet dignified and compassionate patient interactions I'd ever seen. I did not give the advanced care planning survey for my study to LF. Instead, I learned from her courage and by sharing in that difficult conversation with her and her oncologist. In many ways, as I grew with my Ghiso research project, it became less and less about the accrual of subjects, and more and more about those patient interactions. I had the privilege to work with several clinician artisans, who bridged the science of oncology to the art of supporting dying human beings through their transition to the end of life.

Dr. Temel taught me a few key things. First, oncology should be an outpatient specialty. When patients are hospitalized, it is usually due to a failure of that system. And when a patient is terrified, their health decompensating rapidly in a hospital room, away from family and familiar surrounds--this is not the best time to initiate an end of life conversation, especially with a new team of consultants. In short, JS's bad news conversation could have waited until the next morning.

The second major lesson is one that this entire fellowship experience made salient: that end of life discussions can be done in a non-scary way. They will never quite be happy conversations—but they can be hopeful, and respectful. Demonstrating reverence for one's life, by valuing their life's end.

Final Thoughts

The semester I dedicated to my Ghiso fellowship activities has much personal and professional meaning. My primary mentor, Dr. Volandes, has remained an active advisor and mentor to me during the project and even in selecting residency programs. I also had the privilege of meeting and working with other fantastic clinicians, such as Dr. Balboni and Dr. Temel. This project has exposed me to a whole community of physicians within Boston who care about end of life issues, and I feel without the doors opened to me by the Ghiso fellowship, I would have not had access to the opportunity to learn from these resources.

Where am I in my career? I've decided to pursue radiation oncology as my specialty, with a focus on racial/cultural disparities in cancer care particularly as they pertain to end of life. On the interview trail, often I am asked how a radiation oncologist can focus on palliative care and end of life issues. Many times, I was able to explain the Ghiso

fellowship, and how through its noble mission and funding, I was able to gain substantial exposure to end of life care and palliative medicine in an academically rigorous way. The experience has made me more mindful and certainly more critical about how I, personally, can improve health care delivery at the end of life, and how I can facilitate prospective analyses of palliative care interventions, while building on the clinical skills that will enable me to be an advocate for my terminally ill patients. Now I feel that I will always be an advocate for these issues, as they are a natural extension of the type of physician and oncologist I would like to be.

I reached my goals with this project. And now I've set new ones. I sincerely thank the Ghiso family, the fellowship, my mentors and patients for making this journey possible.