

Ghiso Fellowship Reflections

After consulting with Dr. Buxbaum, I have decided to submit the following pieces of writing as a compilation of my month as the Ghiso Fellow: 1) A copy of the most polished narrative medicine / reflection piece that I wrote entitled “Mr. James” 2) A copy of the quantitative paper that I wrote on the impact of gender and marital status on end of life outcomes, which will be submitted for publication (we’ll see if it gets accepted by a journal!) within the next month 3) A copy of the Powerpoint presentation that I created for use by the Massachusetts Compassionate Care Coalition & 4) The following reflections.

I feel so grateful to have been awarded the Ghiso Fellowship. Working under the mentorship of Dr. Buxbaum, the fellowship month was the most rewarding month of my medical education. I basically split my time between three different projects, which I designed in order to approach compassionate care at the end of life from three different perspectives. As I will elaborate on in more detail within this paper, I spent time 1) meeting with individuals approaching the end of their lives during my time with Hospice, 2) working with the Massachusetts Compassionate Care Coalition, and 3) writing a research paper (based on publicly available data from the National Mortality Followback Survey) on the impact of gender and marital status on end of life outcomes. I will write about each of these three parts of my Ghiso Fellowship individually, though there are also intertwining themes that run through all of the work.

As stated above, I worked with two organizations during my Ghiso Fellowship, VNA Care Network Hospice and the Massachusetts Compassionate Care Coalition (MCCC). While they both focus on end-of-life care, the ways that they do so are quite distinct from one another. MCCC is a statewide coalition that Dr. Buxbaum is the president of, and its mission is “to promote informed choice, dignity, comfort and compassionate care at the end of life through community-based initiatives”. As MCCC’s

mission statement says, their work focuses on community-based initiatives, and they are not involved in the direct care of people at the end of their lives. Two of the initiatives that MCCC is working on are “Compassionate Sabbath” and “Conversations Before the Crisis”. The former is an effort to work with interfaith counsels around Massachusetts to educate clergy about end-of-life issues and help religious communities organize programming for congregants about end-of-life planning and decision making. The latter is an effort to encourage people to talk with their loved ones about their end-of-life wishes before they face a medical crisis. In contrast, VNA Care Network Hospice is an organization that provides direct care to patients with diagnoses that, when they run their usual course, are terminal within six months. Hospice is built around a genuine team approach to caring for patients. As compared to my experience as a medical student on inpatient services, where the “team” referred to the attending physician, the resident, the intern, and the medical student, Hospice teams are much more diverse. The Hospice teams consist of nurses, physicians, social workers, trained volunteers, home care aides, and pastoral and bereavement counselors.

I worked with MCCC on several projects. I worked on the Compassionate Sabbath project, designing a Powerpoint presentation to be used to educate clergy about end-of-life care and decision making. In addition, I researched possible sources of grant funding and attended both a grant proposal meeting and the MCCC annual meeting. During my time as a medical student at Tufts University School of Medicine, I have also completed a Masters in Public Health (MPH) degree. I have taken classes in which we discuss the role of coalition building and community empowerment in improving health, and working with MCCC was a wonderful opportunity to see such work in action. The keynote address at the MCCC annual meeting was on how medical residents can be better teachers around end-of-life care, which could not have been more timely for me, since I will be starting a residency in internal medicine this coming June. The address was given

by Dr. Daniel Federman, who is on faculty at Brigham & Women's Hospital, where I will be doing my residency. In addition to attending his talk, I was able to meet with him several days later to establish our common interest in this topic and talk at greater length. I think that what I took away from my time working with MCCC was a greater appreciation of and knowledge about the breadth of community resources that can be drawn upon in order to create community initiatives to improve end-of-life care.

My goal with the Hospice component of my project was to learn more about the organization and their approach to patient care, and to spend time talking with patients who were reaching the ends of their lives. Initially, I created a list of open-ended questions to use when meeting with Hospice patients. However, I quickly learned that the stories and reflections that unfolded when I simply introduced myself, asked the patient how they came to Hospice, and then took on the role of an engaged listener were the richest stories I heard throughout my medical education. After month upon month of medical school rotations where the primary goal of patient history-taking is to determine the medical diagnosis, a process in which the doctor (or medical student) leads and the patient follows, last month was entirely different. Last month, I learned what people want to talk about when you give them the time and the space to do so - when they create the agenda. They want to tell their life stories and how their illness is affecting the things and people that are most important to them. I have noticed a universal interest in sharing stories about important relationships in their lives – stories of how they met their spouse, of raising their children, and, with the exception of a meeting with a 30 year-old gentleman, during every meeting, I got to bear witness to proud grandparents sharing stories (and often pictures) of grandchildren. Another theme is that often patients expressed an interest in knowing something about their health care providers – not just what we, as doctors, know about the pathophysiology of their condition, but also what we

know, as doctors and fellow human beings, of the experience of illness. And this, we rarely share with them, hiding behind the excuse of professionalism. Rita Charon, a physician and professor at Columbia University who is known for her pioneering work in the field of narrative medicine, challenges this approach. She has led courses in which she asks medical students to write about their personal experiences with illness not as providers, but rather as patients and family members, a writing exercise that I did prior to my first meeting with a Hospice patient. I think that it is important that we, as providers, have thought through our experiences around illness and death, and, perhaps, as Charon recommends, written about them. I think it helps universalize the reality of illness and suffering, and decreases the emotional distance between doctors and patients.

Reflecting on the meetings that I had with people reaching the end of their lives, I was struck by the discordance between what they prioritize and what we as medical professionals prioritize. What I feel like I learned from the admittedly small number of meetings I had with patients is that at the end of life, for the most part, people do not want aggressive medical intervention. Granted there is a major selection bias in the cohort of people I talked with, given that the majority of them were enrolled in Hospice, presumably because they did not want aggressive medical intervention. However, I also met with a young man with metastatic cancer who was not enrolled in Hospice, whose priorities were similarly focused on comfort and a desire to be remembered by his children. I think that taking the time to have open-ended conversations with patients about what their priorities are, particularly when they are seriously ill, is crucially important in order to ensure that you are providing compassionate care in line with the patient's priorities. The conversations that I am envisioning go beyond discussions about

DNR/DNI status. I think that, at least in some cases, invasive interventions are undertaken simply because patients get swept into the inpatient system, unaware of other options such as Hospice.

Anecdotally, I found patient satisfaction with Hospice to be very high, though it is hard to know what bias people may have been expressing when they spoke with me. In addition, the providers that I interacted with - nurses, physicians, social workers, and chaplains - seemed very fulfilled by their work. Something that struck me was that compared to the nurses I have interacted with in inpatient medical settings who often seem overwhelmed, Hospice nurses seemed to have much higher job satisfaction. Hospice nurses also struck me as more compassionate than the average hospital-based nurse. In part, this may be explained by selection bias – Hospice as an organization may work incredibly hard to ensure that they hire exceptionally compassionate nurses. But I do not think that this is the whole story. While I think that there is probably a range in terms of how inherently compassionate different nurses – or doctors or other health care professionals – are, I think that compassion is also something that can be nurtured in some work environments and squelched in others. Hospice is an organization that values compassion, and therefore, affords Hospice nurses the time to really get to know their patients in a way that enables them to provide the most compassionate care possible. In contrast, nurses working in inpatient settings often have much higher patient:nurse ratios. Therefore, while they might love the opportunity to sit down and discuss a patient's reflections on his illness, his hopes, and his fears, it is incredibly difficult to fit that into their shift. This issue of the impact of work environment on ability to provide compassionate care is a topic that I have reflected upon a lot since completing my Ghiso

Fellowship. I think that my greatest fear about starting residency is the fear that I will not be able to provide care that is as compassionate as I would like it to be. The stresses and time pressures of residency are intense. I was in a privileged role during my month as the Ghiso Fellow because I had no clinical responsibilities. I could just sit and listen to people talk without having to check their vital signs, adjust their medications, or review their lab tests. Yet, as a resident, I will have all these responsibilities and more. So the question as I write these reflections, one month removed from my month as the Ghiso Fellow and also just over a month away from starting my medical internship, is, how do I bring all of the skills that I learned during my month as the Ghiso Fellow to the patients who I care for as a resident? While I have some ideas on the matter, I do not think that I have all the answers, and I promise myself that I will reevaluate after I have actually been in the inpatient environment for a while. I think that, while I may not have hours on end to sit down and talk with patients, there are some important things that I can do, even in a time-pressured environment to ensure that I am providing compassionate care. First, it is important that in deciding how to treat a patient and formulating the so-called “plan”, you ask the patient himself what he wants – is he focused on symptom-relief or is he hoping for a cure? This is always important to know, but is absolutely essential in the case of patients facing imminently life-limiting diagnoses. At Brigham & Women’s where I will be doing my residency, Hospice is an underutilized resource. Having done the Ghiso Fellowship, I feel much more prepared to identify potentially Hospice-eligible patients and to talk to patients and families about Hospice.

Another idea that I like is the idea of “social rounds”. This is a concept I first heard talked about by a current resident at the Brigham. The idea is that perhaps once a

week, on a day that is not as busy (I am told there actually can be days like this!), after all of your “official” work is completed, you go and just chat with your patients, perhaps in a way similar to the way I talked with patients during my Ghiso Fellowship – without an agenda.

I have also learned through experience that it only takes an extra minute to ask patients, as part of morning rounds, whether there is something that could be done at this moment to make them more comfortable. Often, the simplest things can help a patient and show them that you care about their overall well-being. For example, retrieving a patient’s eyeglasses from their bag across the room can convert a morning of boredom into a morning filled with hours of pleasure reading.

Switching gears, I want to touch briefly on the research paper that I wrote. My motivation for writing the paper stemmed from the belief that one important component to improving end of life care is to document disparities through research. I have a particular interest in women’s health and there has been a paucity of research comparing gender differences in end of life care outcomes. Therefore, to study the impact of gender and marital status on end of life outcomes (note: a draft of the paper is attached).

Again, I want to thank all of you at the Ghiso Foundation for the amazing opportunity to pursue the month-long fellowship and your generous support that accompanied it.

. Touch on research paper and how it connects

Wrap-up and thanks again...