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Neil Samuel Ghiso Fellowship Final Report

For the Neil Samuel Ghiso Fellowship, I had the opportunity to work across specialties with a palliative care specialist, Dr. Robert Buxbaum, and a radiation oncologist specializing in treating patients with CNS disease, Dr. Naren Ramakrishna. Through two focused months of work as well as preparatory and continuing projects, I focused on my goals of clinical work, patient narratives, and research.

During July and August I joined Dr. Buxbaum at the Boston Center for Rehabilitation and Dr. Ramakrishna at Brigham and Women's Hospital's Department of Radiation Oncology. I joined Dr. Buxbaum and his team while rounding on patients in the rehabilitation center, participated in interdisciplinary team meetings, engaged in family meetings, and learned more generally about the goals of palliative care. When patients with brain metastases arrived at the Boston Center for care, I conducted more prolonged interviews with them and occasionally with their families to better understand their goals of care and challenges with decision-making. For two patients with whom I had extended time, I am writing narratives about their journeys and some of my personal reflections.

This clinical work was the centerpiece of my experience as a Ghiso fellow. Although I was not writing orders, performing physical exams, or participating in some of the more typical clinical duties of a medical student, I was engaging with patients not about their physical illnesses and about the psychosocial and spiritual impacts of their disease. By spending time and sometimes just being with these patients during their illness, I think I was also able to provide comfort and companionship during a time of great suffering. Unfortunately, during the months of July and September, my dedicated months for this project, there were not many patients in the Boston Center with brain metastases. This fact limited the number of patients with whom I could spend extended time conducting interviews. Although I was able to connect with several patients during their rehabilitation, I would have appreciated the opportunity to get to know an even wider variety of patients.

An outcome of this clinical work that I had not expected was communication of goals of treatment between radiation oncologists and palliative care professionals. Unfortunately, the goals of "oncologic" care can often seem at odds with the goals of "palliative" care. As a future radiation oncologist, this fact surprised me. Throughout the Ghiso fellowship I was able to explore with physicians and other health professionals how they think about whole brain radiation – what are its benefits and risks, and what does "palliative care" even mean? As a Ghiso fellow, I found that I was occasionally able to communicate these goals between the two communities and broaden individuals' perspectives about the intersection of oncologic and palliative care. However, I also

found that the definitions of “palliation” and the perceived benefits of treatment or cost/benefit ratio of certain treatments remain contentious.

In addition to this clinical work, I also began a research project with Dr. Ramakrishna. After several meetings, we decided that my original concept for the project was unlikely to yield quantifiable outcomes. We carefully considered how to still study the treatment practices and impact of whole brain radiation in such a way that would be quantifiable and produce meaningful data for the radiation oncology community. With these goals in mind, we decided to devise a physician survey. Broadly, this survey aimed to:

- (1) Assess current practices for treatment of patients with brain metastases.
- (2) Assess opinions and attitudes about treatment side effects.
- (3) Collect demographic data about treating physicians.
- (4) Explore correlations between attitudes, beliefs, and demographic data with treatment practices.
- (5) From these data, generate further hypotheses about treatment patterns and influential factors to support additional investigations.

After several iterations, the survey was completed (please see attached: *confidential* pdf text of physician survey). We obtained online access to the database of physicians registered with the American Society of Therapeutic Radiology And Oncology (ASTRO) and, complying with their privacy policies, obtained email addresses for the majority of ASTRO-registered physicians. We also obtained Institutional Review Board (IRB) approval through Harvard Medical School (HMS) and emailed the survey to physicians, allowing one month during which to fill out the survey. I have collected the results (please see attached *confidential* pdf summary of results) and am currently consulting with Dr. Ramakrishna and a statistician for analysis of the data. Later this winter/spring, we aim to prepare these results for publication and consider a second iteration of the survey to a more diverse physician audience through the Society for Neuro-Oncology.

This survey stimulated significant dialogue, demonstrated by comments left by participants on the survey and multiple e-mail contacts from physicians. Although many of these were positive, including many physicians interested in seeing the results and others thanking Dr. Ramakrishna and me for undertaking such an important project, there were also many critical responses. A number of physicians felt that their treatment practices were not represented by the answer choices. Additionally, some of the questions required responses even if the physician’s experience was not represented (i.e. participants were initially required to assign some amount of time to “administrative duties,” which was irrelevant for some).

I am pleased that we were able to complete the survey, and I found it particularly rewarding to see a research project from concept through data collection and finally into a manuscript later this spring. Moving through this extensive process, including IRB approval and data analysis was challenging, but has also made me confident that I could replicate this process in the future with less difficulty. Although the data are limited, I also believe that the results of this survey will fascinate the radiation oncology community and provide a fertile foundation for generating new hypotheses about the value of different treatment modalities. It will also be fascinating to see, if and when they

are uncovered, what types of patient-, physician-, and systems-centered factors contribute to treatment practices. If such correlations can be appreciated, or at least suspected, from this survey, those data will be interesting to explore through further studies.

However, I was frustrated that the survey did not go as smoothly as Dr. Ramakrishna and I would have liked. We had hoped for a higher number of responses, and it was frustrating to field emails and comments that criticized the survey. I am disappointed that some of these comments rightly indicated weaknesses of the study, which might limit the impact of our findings. Ultimately, these responses will help us to formulate a better second-round of the survey, and they have given me ideas about how to field-test and better prepare a similar project in the future.

Looking back at my initial application for the Ghiso Fellowship, I recognize that many of my goals and objectives changed over the course of the project. My main idea remained the same: aiming to better understand the role of whole brain radiation therapy and the general treatment and experience of patients with brain metastases. The second step of these personal goals was to produce research that could meaningfully inform and possibly change medical practice. That goal remained, although the research project that I undertook changed significantly. I am optimistic that the manuscript will be completed this spring, and I eagerly anticipate its potential impact future research and clinical practice.

More specifically, my first goal from my application was “[t]o uncover a more thorough understanding of themes that guide patients’ and physicians’ understanding of the goals and effects of palliative whole brain radiation.” I was only able to conduct a handful of formal, one-on-one interviews throughout my several months working with patients and in clinical teams. Despite the limited volume of prolonged interviews, I was able to accomplish my first goal through asking many questions and informally discussing the benefits, risks, and challenges inherent to whole brain radiation therapy with patients, physicians, and other health professionals.

My second and third goals were: “[t]o elucidate points of dissonance between physicians’ and patients’ understanding of the goals and effects of this radiation;” and “[t]o understand root causes of this dissonance and make recommendations to minimize this dissonance.” These goals proved significantly more elusive. By observing patient encounters and discussing treatment goals with patients and physicians, I believe that I was able to accomplish a portion of this goal. However, my initial research proposal proved unlikely to yield meaningful results. In the process of re-working the research project, its focus shifted, and I was not able to study dissonance through quantifiable terms. However, the survey does provide the opportunity to see how physicians’ opinions align with patients’ desires through some of the patient-centered factors about which we elicited physician opinion.

My final goal was: “[t]o tell patients’ stories.” I am still working on revising narratives about a couple of patient experiences, and although I have not yet submitted them for publication, I still hope to do so in the coming months.

Being honored with the Ghiso Fellowship has been exceptionally formative for me. Not only did I have the opportunity to explore the interface of oncology and palliation – which will be central to my clinical and professional work in the future as a

radiation oncologist – but also I was able to undertake a challenging research project.

The clinical work during the Ghiso Fellowship further reinforced my passion for becoming a radiation oncologist. It also highlighted many of the challenges of the silos of medicine and the importance of honest, open communication with patients and among specialties. I aim in my future career to keep these lessons close and to break down some of the barriers in communication and information that can separate physicians from each other and from their patients.

I aim in the future to become an academic physician, and seeing my first research project from concept to fruition, including all of the obstacles, delays, frustrations, and failures, was an extremely valuable experience. The Ghiso Fellowship enabled me to approach new mentors with a concrete concept and funding to demonstrate my commitment before even the first research meeting. With this platform, I had an unparalleled opportunity to act as a Principle Investigator on a challenging project exploring palliative and compassionate care within radiation oncology.

Thank you for the opportunity to be a 2008 Ghiso Fellow; I look forward to carrying these experiences with me throughout my career.