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Ghiso Fellow 2006
Final Report
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Neil Samuel Ghiso Fellowship Final Report

I want to open this final report by offering my immense gratitude to the Neil Samuel Ghiso Foundation for creating this important and innovative fellowship in compassionate care; the support it has offered to my own work in palliative care has allowed me to pursue several personal and professional goals that would not have otherwise been met during my years in medical school. It has provided me with protected time for developing skills in compassionate care, with the opportunity to work with a community of dedicated students and faculty who share common interests in end-of-life care, and, most importantly, with a sense that I was able to make a meaningful, if small, contribution to one of the hospitals that has most sustained me throughout my medical education, the Cambridge Hospital. For this and much more, I remain profoundly grateful.

My original motivations for applying for the Ghiso Fellowship were personal and professional alike. I had developed a strong interest in palliative care during medical school in great part due to family experience with my mother's terminal illness that occurred concurrently with my formative clinical training. Like Neil Ghiso, my mother was diagnosed with a brain tumor in the prime of her life—the two even shared a tumor type, the slow, but persistently growing oligodendrogliomas that would eventually take both of their lives. More significantly, both Neil Ghiso and my mother were moved by their own experiences with life-threatening illness to advocate for more compassionate, more humane, more human care for others who shared in their difficult illness experiences. It was being inculcated with this sense of advocacy during my mother's final years that motivated me to pursue a Ghiso Fellowship during my final year at Harvard Medical School.

In many ways, my project—looking at family meetings and communication at the end-of-life—was directly motivated by my mother's words. I remember with great clarity a warm August evening in 2002, just days before I would begin medical school orientation, when my mother pulled our family members together at the dining room table. We sat down as a group, and my mother began an explicit recitation of her wishes. She reminded us that while her recent surgery had been successful, there remained a great probability that the tumor would one day return. She planned to decline any further therapies offered by her medical

team, as she and my father—himself a physician—felt strongly that risk of cognitive decline that might accompany possible adjuvant radiation therapy would outweigh the potential longevity benefits that such a modality could offer. "Quality of life, for me, is much more important than quantity," she noted firmly that evening and would repeat on many occasions thereafter. She then showed us paperwork designating my father and me as her health care proxies and, in closing, handed over a sealed envelope that contained a self-written obituary that she hoped would one day memorialize her, perhaps sooner than I then realized. Though I could not recognize it at the time, our family had concluded an immeasurably important conversation that, though painful and frightening, would pave a smoother path during her illness, one guided by her own wishes and desires for the conclusion of her life. Though I could not have named it at the time, this was my first family meeting.

It was to be the first of many such meetings throughout by medical school years. Between pre-clinical experiences in Harvard's Living with a Life-Threatening Illness course, multiple longitudinal relationships developed in the Integrated Clerkship during my third-year, and a rotation in Palliative Care and Psychosocial Oncology completed as a fourth-year, I had many opportunities to attend, witness, and even occasionally lead challenging conversations with seriously ill patients and their families. Through these experiences, and with my mother's story always near my heart, I came to realize the importance of open and candid conversation in allowing patients to express their wishes, family members their concerns, and clinicians their plans and hopes. It was only later that I would find that this realization had also been validated in the literature, with research studies repeatedly showing patients and family members to value, above all, the communication skills of those providing them care. It was later, too, that I began to realize how challenging coordinating such family meetings could be, as they required time, sensitivity, and patience, each occasionally in short supply in our often harried clinical institutions. With all this in mind, I designed a project with my adviser, Dr. Loring Conant, examining the role that family meetings play at the Cambridge Hospital, the community and teaching hospital that was home to my clinical development in the Integrated Clerkship.

Cambridge Hospital is a flagship hospital within the Cambridge Health Alliance, one of two Boston area "safety net" hospital groups with an explicit mission to provide care for members of the low-income and often underserved communities in their neighborhoods. Patients at the hospital are frequently un- and under-insured, with a significant number relying on

MassHealth Medicaid support or Free Care funds to obtain health care. The population is quite diverse and includes large numbers of recent immigrants from Central America, Brazil, and Haiti—one is just as apt to hear Spanish, Portuguese, or Creole in the hospital wards as English. This diverse and vibrant population, however, offers additional challenges to those already aforementioned barriers to providing family meetings. Health care providers at the hospital need to receive additional training in working with interpreters and in understanding a wide variety of cultural and religious beliefs around death and dying to adequately care for their patients at the end-of-life and the family members caring for them. As a third-year student, I saw first hand the impressive efforts of health care providers, interpreters, and care coordinators to offer outstanding palliative care, but also recognized many other obstacles facing them (language barriers, widely varying cultural beliefs about death and dying, difficulties in financing hospice and long-term care settings, often inadequate chaplaincy resources, etc).

To better understand how family meetings functioned in this complex environment, we designed a process of intensive observation to allow a witnessing of meetings conducted in the Intensive Care Unit (ICU) and on the medical floors as well as to assess the ways in which training house officers were being exposed to the skills necessary for conducting future family meetings. After developing an observational template, I attended eleven family meetings conducted by a variety of clinical practitioners, including medical and surgical attendings, resident house officers, and ICU nurses. Additionally, I had the opportunity to interview two medical attendings and six house officers to better understand how skills needed to sensitively conduct family meetings were taught, and learned, respectively.

What follows (in the Appendices) is a detailed description of the methodology and findings from our project, as well as two informal tools that emerged from our work: The "Family Meeting Timeline Tool" and "Musing before a Meeting: Themes to Consider" which offer suggestions for clinical teams preparing for an upcoming family meeting. This information was presented in detail in a poster format for Medical Education Day at HMS last fall and will again be shared with the Cambridge Hospital community itself at a research day this upcoming spring. We learned that while there can be no hard and fast rules for conducting family meetings, especially among richly diverse populations, much common preparatory work—examining the reasons for a given family meeting, developing sensitive and clear

communication skills, and assisting trainees assuming newfound leadership roles—can pave the way to smoother and more productive, compassionately-conducted conversations.

For me, this project was an educational gift in two important ways. As a young clinician still very much in the throes of developing my own style, the privilege of witnessing a variety of experienced clinicians engaging in often challenging family meetings was an invaluable aid in learning how to communicate better about a variety of difficult subjects. I know that these skills will be of paramount importance as I begin my internal medicine residency this summer at the San Francisco General Hospital, where palliative care and attention to diversity and cultural awareness are among the institution's top priorities. As a future educator, too, I will remember the conversations held with house officers striving to further their own skills in conducting family meetings and their suggestions for the ways in which these skills might be more effectively taught. But perhaps most importantly, this project proved to be a personal gift, for it allowed me to witness compassion again and again being displayed towards families most in need of a gentle word and a guiding hand. It provided me with the reassurance that compassionate communication would make the most difficult experiences of many other families, like mine, a small bit easier.

Appendix A: Family Meeting Observation Template

Background Information: Current Date: _____ Date of Admission: _____ Diagnosis: _____ Patient Language: _____ Meeting Language: _____ Interpreter? _____Who? _____	**Discussion Diagram:** (spatial details, sitting…)
Gathering: Who called the meeting? _____ Where held? _____ Who is here? _____ _____ _____ _____ Patient present? _____ Patient aware of meeting? _____ Start on time? _____ How late? _____ Beepers? _____ Beeped out? _____ For what? _____ Tissue or Water Present? _____	**Agenda Setting:** Introductions made? _____ By whom? _____ Who sets? _____ What is it? _____ _____
Content: Does family offer initial perspective? What is it? _____ _____ _____ _____ How is family concern addressed? _____ _____ _____ _____ Note language used, terminology, etc: _____ _____ _____ _____ *Remember to attend to eye contact, silent participation, etc.	**Closure:** Family invited to add perspective/Ask further questions? _____ _____ _____ _____ Summary Offered? _____ _____ _____ Was the patient/family question addressed? _____ _____ Post-Meeting Review/Feedback? _____ _____ _____

Appendix B: Poster Sections

Abstract

Recently, there has been increasing emphasis placed on improving the quality of end-of-life care in our medical institutions. With multiple studies demonstrating that patients and their families tend to receive unsatisfactory care near the end-of-life, many clinicians have attempted to better meet the needs of patients and families in these challenging times. It has been reported that families rank the communication skills of physicians as equally or more important than their clinical skills. Despite this, medical students, house officers, and even attending physicians note inadequate educational exposure to communication skills necessary for providing care at the end-of-life.

This project attempted to examine the uses of, and education about, one particular type of end-of-life communication, the family meeting, at a community hospital. As a part of a broader palliative care needs assessment at the Cambridge Hospital, we designed a program of intensive observation to better understand the demographics, content, and teaching of family meetings in the both the ICU and the general medical wards. Arrangements were made for the medical student to be notified about the occurrence of family meetings at the hospital, and a template was developed to facilitate a detailed observation of each meeting. The student joined the ICU team for morning rounds to better contextualize the family meetings and conducted informal interviews with house officers and attending physicians involved with the meetings.

Over a three month period, the student attended a total of 11 family meetings addressing topics ranging from changing code status to withdrawal of life support. Meetings were attended by attending physicians (81.5%) and house officers (54.5%), and they were primarily facilitated by attendings (81.8%) rather than house officers (18.1%), who largely conducted the meetings when an attending could not be present. In two cases, attendings and house officers actively collaborated about a strategy for an upcoming meeting, with time for education about family meeting goals and styles. Subsequent interviews with house officers revealed widely varying levels of desire and comfort regarding facilitation of family meetings, though all agreed that the skill was important for good clinical practice. Most requested further educational emphasis on family meeting communication skills during residency, with the majority favoring pragmatic “on the spot” discussions with attending physicians before and after family meetings rather than formalized seminar discussions or lectures.

Family meetings occur regularly in this community hospital setting. Both attending physicians and residents place great importance on developing communication skills to competently and sensitively conduct these challenging meetings. Further commitment, including increased time to plan and reflect on family meetings with attendings, might increase resident skill and comfort in facilitating family meetings.

Introduction:

In recent years, improving clinical care at the end of life has emerged as an important objective throughout the health care system. With increasing literature documenting patient and family dissatisfaction with care at this challenging time, numerous novel programs and interventions have been developed in hopes of augmenting delivery of excellent palliative

care. One area receiving increasing attention is the family meeting or conference, an important venue for making decisions, offering emotional support, and sharing information in many clinical settings including the intensive care unit. In the critical care arena, families rate the communication skills of clinicians as having equal or more importance than their clinical skills;2 nevertheless, studies show more than 50% of families receiving inadequate communication in this setting, such that they could not understand a loved one's diagnosis, prognosis, or treatment after attending a family meeting.3

An emerging literature is examining the detail of family meetings in the critical care setting to better understand how the timing of and content within these gatherings might improve overall palliative care. One group found that scheduling regular multidisciplinary family meetings shortened ICU stays and decreased conflict among families of critically ill, dying patients.4 Another group has documented that families report greater satisfaction when more time is allotted for them to speak at family meetings;5 moreover, family satisfaction is increased when clinicians offer support for their decision-making process, offer assurance of patient comfort,6 and express non-abandonment of their loved one.7 Nevertheless, clinicians often miss opportunities to insert these sentiments into the dialogue of a family meeting.8

Despite this need for thoughtful communication during family meetings, medical students, residents, and attending physicians alike all report inadequate educational training in end-of-life communication skills.9 This is particularly true for skills needed to conduct family meetings; it has been reported that although residents routinely attend family meetings during their ICU rotations, they rarely serve as the primary discussant.10 Such active participation in family meetings, however, has been documented as an important source of resident confidence to lead these meetings in their future practice.11

Given this centrality of communication during family meetings to patient and family satisfaction in the ICU, the present project was designed to examine the structure and function of such family meetings, primarily in the critical care setting, as a part of a heightened sensitivity to palliative care issues at the Cambridge Hospital and in the Cambridge Health Alliance. Moreover, it aimed to begin assessing the ways in which house officers are exposed to the skills and training necessary to facilitate strong family meetings.

Methods:

We utilized a method of intensive observation to better understanding how family meetings were initiated, structured, and discussed in the ICU setting. Initially, the medical student scheduled informal conversations with the medical director of the ICU, the ICU nurse manager, and a social worker experienced in critical care to better understand how and when family meetings occurred at Cambridge Hospital. Between April and June 2006, the student met with the house staff covering the ICU during each of three rotation cycles to describe the observation project and to request notification when any pre-planned family meeting was being coordinated. She additionally attended morning work rounds with the ICU team at least twice weekly to both gain medical context for the meetings and to better anticipate when future family meetings might occur. She functioned only as an observer during these rounds and did not contribute to the clinical care of any ICU patients. To achieve breadth of experience, the student also coordinated with house staff on the general medical floor to attend family meetings in this setting as well.

A template was designed to allow for detailed tracking of family meeting demographics and content elements. Shown above, this was reviewed by an internist skilled in family communication for usability and completeness. Prior to each meeting, the student met with the clinicians caring for a given patient to acquire information about the circumstances surrounding the upcoming meeting, and she requested permission from the patient and/or family members to attend and make notes at each meeting. At meetings, she was introduced as a medical student studying family communication; she did not participate in meeting conversations.

After completion of the three month period of active observation, data analysis involved basic quantification of various meeting elements (demographics, agenda items, etc.) as well as a review of dialogue outlines using modified qualitative techniques to identify themes and questions that repeatedly arose during family meetings. These themes, as well as existing templates in the clinical literature, were used to construct a family meeting "timeline" and "musing guide" for potential use in preparing for family meetings.

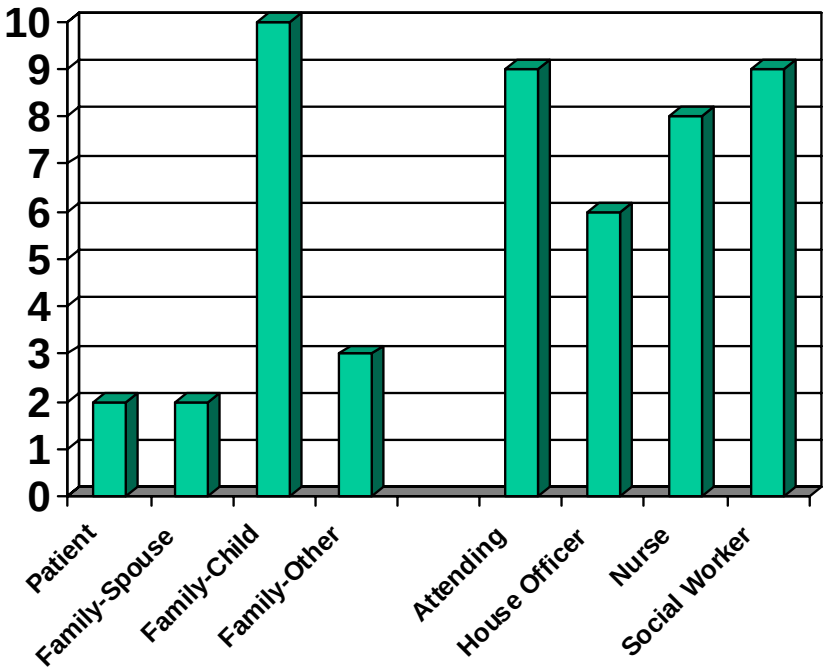
Finally, to better understand the role of house staff participation in family meetings, and the ways in which residents are taught communication skills needed to conduct these meetings, the student conducted informal interviews with several interns and residents (n=6) who had rotated through the ICU during the project period, as well as with two attending physicians who had been observed conducting family meetings.

Results:

Meeting Demographics:

Age	80.7 (72-87)
Sex	M=50% F=50%
Primary Admission Diagnosis	
Respiratory Failure	4 (50%)
Dementia	1 (12.5%)
Cancer	2 (25%)
Hypertensive Urgency	1 (12.5%)

Family Meeting Attendees:



About the Meetings:

Meeting Characteristics (n=11)	
Hospital Day*	5.9 days (range 3-11 days)
Meeting Language	
English	11 (100%)
Family Language (n=8)	
English	8 (100%)¶
Haitian-Creole	1 (12.5%)
Location	
Family Meeting Room	10 (90.9%)
Patient Room	1 (9.1%)
Level of Care	
ICU	7 (63.6%)
Step-Down Unit	1 (9.1%)
Medical Ward	3 (27.2%)
Requested By:	
Medical Team	10 (90.9%)
Family Members	1 (9.1%)
Meeting Started on Time?	
Yes	0 (0%)
No	11 (100%)
Duration of Delay	16 min (5-30 min)
Total Meeting Duration	30.5 min (10-70 min)
Beepers sounded?	4 (36.4%)
Average Beeps per Meeting	5 beeps (range 1-12 beeps)

Meeting Themes and Content:

Meeting Content (n=11)	
Purpose of Meeting/Initial Agenda*	
Decision Making about Management	5 (45.5%)
Establish or Change "Goals of Care" (code status, shift to palliative care, etc.)	3 (27.2%)
Provide Answers to Family Questions	3 (27.2%)
Discharge Planning	11 (18.1%)
Sharing a New Diagnosis	1 (9.1%)
Address Tension between Team and Family	1 (9.1%)
Who sets the agenda?	
Patient or Family Member	1 (9.1%)
Member of Clinical Team	10 (90.1%)
Introductions of meeting participants were made?	8 (72.2%)
Who offers the initial perspective on the patient?	
Patient or Family Member	6 (54.5%)
Member of Clinical Team	5 (45.5%)
Family members are asked if they have questions prior to the close of the meeting?	5 (45.5%)
A verbal summary of the discussion is provided?	9 (81.8%)

House Staff Thoughts on Family Meetings:

Selections from informal interviews conducted with six house officers (3 interns, 3 residents) who rotated through the ICU during the project period.

- **Attendance at Family Meetings:**
  -Quite variable, ranging from 5-10 meetings attended yearly to meetings attended each week

- **Leadership Opportunities:**
  -House officers report leading anywhere from 25% of meetings attended to nearly all family meetings attended
  -"If I feel knowledgeable, I ask to lead the meeting"
  -"I'm not that active, I'm not the attending…"
  -Family meetings should not be "practiced"
  -"I seek them out, it's an important skills for house officers"

- **Learning Communication Skills:**
  -"Through watching what others have modeled to me, winging it"
  -"By doing it…you just have to do it"
  -Through observing a thorough and efficient attending
  -From medical school seminars and a humanism in medicine course
  -"By watching myself and others"

- **Comfort with Conducting Family Meetings:**
  -More comfort when the disease is understood and the family is known
  -"Not ready to take charge and give options to families"
  -"More comfortable when providers are on the same page"
  -"I don't feel alone when another member of the health care team is there."

- **A Role for Further Training:**
  -Some desired role-playing exercises, others specifically declined them
  -"We don't need further lectures or noon conferences"
  -More chances to witness others "to collect more observational data"
  -Desire more than just observing; need "take home points"
  -"More applied learning, more time with attendings to discuss meetings"

Discussion:

This project was initiated in the setting of a heightened awareness of palliative care issues at Cambridge Hospital, to better understand how family meetings figured into the broader health care delivered by this particular institution. We learned that family meetings are a regular occurrence, particularly in the ICU setting but also on the general medical floor, with at least one pre-planned meeting happening during most weeks. Meetings were most often called to address issues of management decision making (especially regarding the aggressiveness of management strategies) and to discuss "goals of care" including code status, end-of-life treatment preferences, etc. Meetings were usually instigated by the medical team rather than the patient and his/her family, and the medical team usually set the agenda for the meeting. Most meetings did not occur at the bedside but instead in a family conference room with plenty of seating; patients only rarely (2 of 11) were able to attend meetings, generally due to

inability to communicate/make independent medical decisions. Attending physicians were present somewhat more often than house officers at meetings; on two occasions, attendings and house officers actively collaborated about a strategy for an upcoming meeting, allowing time for shared education about family meeting goal-setting and communication styles. These findings are meant to be interpreted with some caution, however, as the number of meetings observed was small; additionally, our observations were limited to pre-scheduled family meetings—spontaneous family gatherings and around-the-clock bedside communication were not witnessed in this project.

Examining the observation templates and conversation outlines completed during each of the meetings revealed several recurring themes and questions arising during family meetings. Though limited in their generalizability and word-for-word precision (as they represent the inherently biased recordings of a single observer), issues of confusion between providers and families, family conflict about decision making, and family need for reassurance by the medical team—among many others—emerged repeatedly. Although an interesting literature is starting to develop in hopes of offering clinicians guidance about approaching these family communication challenges, it becomes increasingly clear that no single answer will inform the structure of all family meetings. Rather, we used the literature and our own observations to construct two tools for potential use in preparing for an upcoming meeting: the "Musing before a Meeting" question set that teams might consider when discussing family meetings in general, as well as "Family Meeting Timeline Tool" that offers ideas for consideration when planning for a specific meeting. A published guideline by Ambuel and Weissman12 was particularly helpful in constructing the timeline tool.

Finally, informal discussions with six residents and two faculty members involved in house staff education were notable for widespread interest in further training in family communication skills, preferably employing "on-the-spot" pragmatic teaching instead of formalized lectures or conference sessions. Many residents requested more opportunities to observe experienced attendings and to receive further feedback on their communication skills from these attendings as well. Attention to formal and "hidden" curricula covering communication and palliative care skills will be important for residents rotating through critical care settings; indeed, a French study has found that resident/junior physician involvement in family meetings and communication is associated with greater family satisfaction.13 As physicians-in-training develop competencies and transition towards leadership roles themselves, improved communication skills for conducting family meetings might help to augment the delivery of compassionate care at the end-of-life.

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Appendix C: Tools for Planning Family Meetings

1. Family Meeting Timeline Tool

Preparing for the Meeting	Meeting with the Family			After the meeting ends
	Opening	**Middle**	**Closure**	
□ Agenda planning □ Clarifying goals □ Identifying who should attend □ Location of a quiet venue □ House staff/medical student teaching opportunity	□ Introductions □ Review goals □ Soliciting the perspective of patient/family members—"tell me your understanding…"	□ Clarifying clinical situation □ Answering questions and providing education □ Offering empathy □ Assistance with decision-making □ Conflict resolution	□ Inquiry about any remaining questions or confusion □ Providing resources for decision-making and support □ Summarization of meeting developments □ Closing words	□ Reflection with care-giving team—how did the session go? □ Opportunity for further teaching □ Later—possible follow-up with patient/family—how was meeting received?

Example Cases:

a) The patient is an 87 year-old gentleman who has been experiencing recurrent episodes of aspiration pneumonia severe enough to require intubation and ventilator support. He was recently extubated following one of these episodes; now, a few weeks later, he has again aspirated while eating dinner at a nearby rehabilitation unit. He was readmitted to the ICU three days ago with respiratory distress and delirium necessitating repeat intubation. The medical team is now considering whether to recommend future tracheostomy and feeding tube placement for this man; a family meeting is called to discuss goals of care.

b) The patient is a 72 year-old male who recently underwent CABG at another hospital and subsequently had several admissions to Cambridge Hospital for frustrating lower back pain and difficulty ambulating, complicated by worsening confusion. During this admission, a PSA level was checked and found to be dramatically elevated; subsequent bone scan revealed several "hot spots" suspicious for metastatic disease. A social worker has scheduled a meeting for this afternoon so that the medical team might share this new diagnosis with the patient and his family.

2. Musing before a Meeting? Themes to Consider:

- **What are the triggers for calling a family meeting? Who requests the meeting?**
- **What are the agenda topics for the meeting?**
- **Who might be invited to attend a family meeting? Will an interpreter be needed?**
- **Could time be found for a pre-meeting planning session among participating clinicians?**
- **Is there a quiet location available for meetings?**
- **Might we have water, tissues, etc. available for family members?**
- **Will we be able to start on time? What arrangements would facilitate punctuality?**
- **What to do about pagers/beepers? Should they be switched off? Is this feasible?**
- **Who will offer the initial perspective during the meeting?**
- **Do all participants know one other? Might we offer introductions?**
- **How could the seating be arranged to better facilitate comfort and communication?**
- **When will patients and families be invited to ask questions?**
- **How will we assess whether the patient/family concerns have been addressed?**
- **What are some strategies for defusing conflict that may arise during the meeting?**
- **How could we create closure at the end of a meeting?**
- **What have we learned from this meeting that just ended?**
- **How might this meeting experience inform planning for a next family meeting?**