Kevin Selby
March 30th, 2007

Ghiso Fellowship Final Report

Summary

My project went through several changes, but my core mission remained the same: experience and learn about the use of music in palliative care. My initial research into Boston-area resources was quite successful, revealing a rich community of people using music in health care, but with little communication between them. I then went through a faze of many grand schemes and little action; I redefined my project goals with exciting new ideas, but stalled for over four months. Finally, in the beginning of 2007, I grounded myself and focused on two experiences: shadowing more palliative care doctors at the Dana Farber Cancer Institute, and playing the piano for patients at the Hebrew Rehabilitation Centre.

Beginnings

My idea of researching music and dying was inspired by a 2000 British Medical Journal article "Music to be born to, music to die to". It's an appealing idea: critical hospital events could be accompanied by music. Music while dying was particularly fascinating because it is an event so fraught with conflicting emotions that it would be impossible to verbalize the significance of what is going on. When I thought of specific music, I almost immediately thought of the music that I would choose to die to: *In Paradisum*, the final movement of Faure's Requiem. The music seems to reach inexorably skyward, soaring magnificently before returning to a simple, peaceful ending. If I have a choice in mind, I was intrigued to find out what music other people would want, and whether there could be a way to bring this music to sick or dying patients. My proposal therefore contained three parts: learning about how music is used currently in palliative care, researching what music patients want in the form of a needs assessment at Sherrill House, and finding an effective way to present my results.

My research into current uses of music in palliative care happening in Boston and reported in medical literature went very well. I began by shadowing Diane Tow, a registered music therapist at Sherrill House. I sat in on a variety of activities that she provides including her 'music and motion' and 'sundowning' groups. My most vivid memory was watching a severely demented elderly man, Eugene, during a sundowning group. Alzheimer's patients often have increased agitation and severe confusion in the late afternoon, so Diane plays music at these times to engage the patients. Eugene was unresponsive at the beginning of Diane's session, but quickly it became obvious that he still had an amazing sense of rhythm. He began clapping out more and more complex rhythms to her playing, and eventually got up to dance. It was incredible to watch a man who is being robbed of his sense of person and place by Alzheimer's come to life with music.

From here I met with a variety of other people. Through Suzanne Hanser, chair of the music therapy department at the Berklee School of Music, I gained a wider perspective on music therapy, access to her extensive library, and watched several student presentations. I then met Dr. Mark Jude Tramo, head of the Institute for Music and Brain Science, and sat in on several of his seminar classes at Harvard College. I have to admit I didn't understand a lot of what he talked about (I had not yet studied neuroscience…), but I learned a lot about what is and isn't understood about the processing of music in the brain. I also exchanged emails and spoke with Peter Stickel, executive director of the New England String Ensemble (NESE); but unfortunately, I was not able to meet with him. Mr. Stickel led a project called "Healing Strings" that brought members of the NESE into the houses of terminally ill patients to play music and help them in their reflections. He had a series of programs and feedback from participants that I would very much have liked to have seen. Finally, I met many times with Dr. Buxbaum and shadowed him. Through Dr. Buxbaum I was able to meet Yehudi Wyner, a prominent Boston composer, learn about the Forest Hills Trust, meet Dr. Dan Federman, and enjoy

several fine concerts. His many contacts provided fruitful leads and he helped me refine and focus my ideas.

One of the most rewarding contacts I made through Dr. Buxbaum was Dr. Alex Smith, a palliative care fellow at the Dana Farber. By chance, Alex was giving palliative care grand rounds at MGH about music and palliation this past spring. We met several times and talked extensively about the uses of music in palliative care, cases we had heard about, and contacts in the Boston area. I then shadowed Alex a couple of times, and he became the palliative care doctor that I identified with most closely. Unfortunately, I was already in Zimbabwe for the summer when he gave his talk June 21st, but I was lucky enough to get a sneak preview several days before and a final copy soon after. Alex did an excellent job of synthesizing current research and giving samples of various possibilities including music therapy and music thanatology.

My search of the primary literature revealed scattered, well-written qualitative reports of music being used to help medical care and weak empirical evidence. Most empirical reports to date have been small, totalling 100 patients or less, and have looked at patient satisfaction before and after an intervention by a music therapist. I talked to Dr. Tramo about this lack of reliable data, and he has plans for a larger randomized-controlled study, but said that it's difficult to get necessary funding.

All of this research left me much better informed but thirsting for my own contribution. My original plan of doing a needs assessment at Sherrill House was inappropriate for two reasons: I learned while organizing my summer project that getting permission to do research with patients can be very complex and time consuming, and more importantly, Diane Tow was already doing amazing work at Sherrill House, and they were undergoing the process of hiring a second music therapist, indicating that they already understood the importance and effectiveness of music. So, I began the process of rethinking my project.

More Ideas, Less Action

First, I narrowed what I wanted to two projects: a review article of the current uses of music in palliative care and a concert showcasing music that people associate with dying. I drew up some outlines of a possible review article, but soon realized the huge amount of time and expertise that is required for this type of work. Four months of research definitely did not make an expert in the field, even if there has been little written and awareness among most doctors is low. I replaced this idea with that of a website. I thought a website would be a good way to present what I had learned, while also providing a link with the different people and resources I had discovered in Boston. My real hope, however, was to develop a forum where people could suggest the music they would like to die to; I would then find this music online and provide a link so that people could listen to other people's choices and reflect on their own. These contributions would also serve as inspiration for the concert, which would showcase the music people had chosen and their reasons.

This is where my project stood at the start of June 2007, when I wrote my last exam of first year and flew to Harare, Zimbabwe for two months. I used Office of Enrichment Programs money to research male attitudes towards antenatal care in a high-density suburb of Harare. The summer was an amazing experience that re-centred my desire to pursue international medicine and taught me the process of health research, from getting initial approval, organizing actual interviewing, sifting through piles of data to doing actual statistical analysis and preparing results for publication. I learned an enormous amount, but this work spilled over into September and October and derailed my focus on my Ghiso project. My second year of medical school has also proven to be busier and more overwhelming than my first, and I lost the momentum that I had in the spring. Dr. Buxbaum tried to push-start me several times, but I floundered. Plans for October became plans for November and hopes for December.

Finding Closure and Reflecting

Over Christmas, I realized that my second year of medical school was only going to get busier and that I needed a realistic way to continue my Ghiso project. My former ideas were good, but, for me, they were overwhelming in the context of medical school. I decided that I would spend more time learning about palliative care and shadowing at the Dana Farber and begin playing the piano on a weekly basis at the Hebrew Rehabilitation Centre, a long-term care unit for seniors. Playing the piano for patients would allow me to return to the contact that I wanted most when I originally applied for this fellowship, without needing to design questionnaires or get approvals.

In terms of shadowing, I worked through Dr. Susan Block, chief of psychosocial oncology and palliative care at the Dana Farber, to get in contact with Drs. Harriet Delima Thomas, Douglas Brandoff and Jessica Masterton. I went with them as they did afternoon referral rounds visiting inpatients in the Brigham. I was most surprised by the variety of patients they see, solving problems ranging from chronic hiccups, to pain management, to difficult family situations. I learned about sitting at the bedside and making time and allowing space for patients to explore their problems. However, I also learned that palliative care probably isn't for me. I want to be in a field where I can treat the whole patient, but inpatient palliative care has more discussion and reflection than I think I can handle. From palliative care doctors I've learned about compassion and discussing feelings rather than avoiding them, but I left my afternoons with palliative care teams feeling that something was lacking. I don't want to see only the sickest patients at their most difficult moments in a hospital large enough to have a palliative care service. I want to have a range of patients, some who I can help return to good health and some whom I diagnose for the first time. After almost two years of medicine I see myself heading towards being a primary care physician with ties to academic medicine.

Playing the piano at the Hebrew Rehab Centre has been both refreshing and challenging. The most challenging moments, for me, are interacting with patients with advanced

dementia. Once while I was playing one of my favourite Brahms Waltzes, a demented woman started yelling "I need help! Get me out of here! Help!" and there were no nurses in the room. From the lack of reaction by the other seniors, I could tell that this woman yelled like this often, but I still didn't know what to do. At first I kept playing, but I felt horribly awkward and eventually went to get a nurse who wheeled the woman out of the room. As budding doctors, we're exposed typically only to patients who appreciate us and are cooperative, but real medicine is obviously not always so straightforward. Nonetheless, most of my Saturday mornings at the Hebrew Rehab have been very gratifying and the residents have been both receptive and appreciative. As a medical student trying so hard to learn everything at once, you forget that something easy can make a huge difference. I enjoy playing the piano and I choose repertoire that comes easily to me, but the responses I get are almost overwhelming. One woman told me I was "Kevin from heaven" as she sang along to the better-known melodies, while another time a woman began crying and explained to me how her daughter also plays the piano but now lives out West.

These experiences have reaffirmed for me that music has an obvious and important role to play in palliative care. The key will be to find effective ways to integrate music into everyday patient care. Music therapy can offer personalized, interactive music for patients, but requires a skilled professional to be on-hand, which will be cost-limiting for most hospitals. However, with the incredible increases in digital music, I think that patients will soon be able to choose and customize music for their own rooms. It wouldn't be that difficult for a hospital to have a giant central reservoir of digital music that patients could then use to download music onto their own hospital-provided iPods to then hook up to a sound system attached to their bed. With a system like this, patients could basically listen to whatever music they want when they want. The key would be finding a company willing to donate the equipment to run a pilot project in a hospital.

With a little more business acumen, I could be the one for the job, but such ideas will have to wait with the rest of medical school looming.

Similarly, I see a huge gap in physician awareness of either music therapy or other uses of music in medicine. I was lucky to see the example of Diane Tow at Sherrill House, where she has been able to make doctors aware of her work and thus be integrated into care teams. Most nursing facilities don't have a full-time, staff music therapist and music therapy remains peripheral if it is offered at all. A well-written review article could start by educating palliative care doctors about how they could use music for their patients. Beyond that, more empirical research is needed if doctors are going to be convinced of the effectiveness of music in patient care.

In terms of recommendations for future Ghiso fellows, I would be wary of taking on a project without a set block of time to devote to the fellowship. I thought that I could fit a project into my 'spare' time, but soon discovered that spare time is fleeting in medical school, even with the more freely structured New Pathway program. You seem to have a lot of free afternoons some weeks, but then exams or more demanding courses come along and you find yourself scrambling to find any time at all. I think that my project could have been more cohesive and produced more results had I had a specific month set aside, or had I not tried to do a completely separate international project over the summer. While I learned a lot, I don't feel like I've yet lived up to the full potential of this fellowship. I would encourage future applicants to think very realistically about what their priorities are going to be during the time frame of the fellowship and whether they can give their best time and effort. This being said, my project taught me an enormous amount about music in palliative care and instilled an interest that I will carry forward. I will continue to play at the Hebrew Rehab Centre on weekends and will seek out opportunities to remain involved in palliative care in the future. And even if I don't specialize in palliative care, I will be aware of what it has to offer and be able to refer my own patients and educate other doctors.