

# SCIENCE AND SUBJECTIVITY

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This journal is dedicated to the memory of Mr. Harvey Krueger.

1929-2017



**It is** all too easy for a Professor to take charge, set the agenda, produce the syllabus, and then give the grades. Nothing wrong with that, except that the Professor must pay a high price: no reciprocal empathy with any students; no real chance to learn from them.

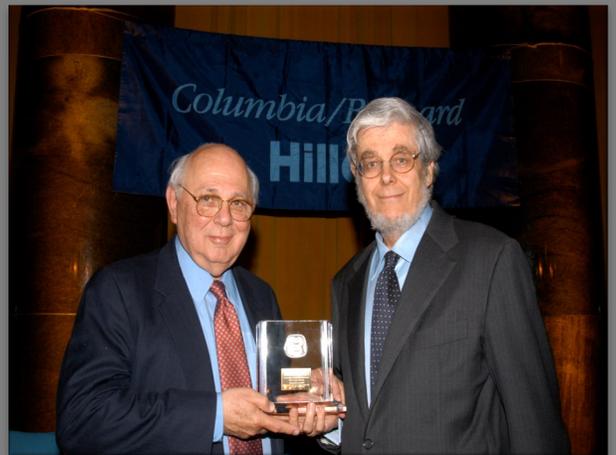
I began the experiment that has become the RCSS more than 15 years ago, when I decided to ask questions that could not be subjected to scientific disproof, and so were not in the realm of the sciences at all. We all know these sorts of questions: why must we die? How do I know the right path?

My work since then has been to construct programs that allow me to be the student of my students, as they ask these sorts of questions. The RCSS has been by far the most successful of these programs, as you will see when you read the material in this new Journal. The Journal, like all the projects described in it, was the creation of a student, in this case the graduating Columbia senior Netana Markovitz. I am happy to have been able to provide guidance and some financial support, but the creative work is all hers.

So too for the other projects described below. Before you read these, there's only one more thing to say. This work to be the student of my students, costs money. I have that money thanks to Harvey Krueger C'51, who passed away this past month. His gift, the Krueger Endowment, assures that the novelty and creativity of students interested in proposing their own projects with an elements of science, an element of service, and an element of subjectivity, shall not perish from this campus.

Thanks, Harvey.

Bob Pollack C'61  
Director, RCSS



Mr. Harvey Krueger with Dr. Robert Pollack at the Seixas Award Dinner , 2008

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# A Snapshot of Some of the Intern Projects:

## The Constellation Project

Joseph Belmonte, Andrea Jurado, Kristopher Mizhquiri

Since at least the time of the Ancient Babylonians, humans have looked up at the night sky, recognized patterns within it, and recorded their observations. These observations have endured in many forms, ranging from catalogs of stars, planets, and celestial objects, to the better known myths of the Ancient Greeks that described the patterns and symbols that they saw. For instance, the Leo constellation is described as having been put there by Hercules after successfully slaying the Nemean lion.

While today it can safely be stated that a majority of Greek people no longer believe the Leo constellation is a result of his being put there by Hercules', it remains important to understand how these beliefs have changed over time (or how they have not).

The goal of this project is to consider how all peoples, such as the Babylonians or Greeks above, have throughout time found subjective meaning in an objective setting. The questions we aim to answer are:

1. What were the rationalizations for discerning, or not discerning, differences in celestial bodies

(planets or stars)? Were they up to myth or functionality?

2. What will be the criteria for determining inclusion of found constellations in this research?

How can this project avoid results or confirmation bias?

3. How have the geographical positions of different ancient civilizations influenced their interpretation of constellations (e.g. northern and southern hemisphere)?

4. In which a trend does occur across civilizations in the northern and southern hemisphere, are there overlaps due to functionality? Are there overlaps due to relative intensity?

5. How have the astronomical interpretations of civilizations become utilized in ethnomathematics? Have they consolidated into a pluricultural interpretation, and what are the nuances for each civilization?



## The Sunday Night Dinner Series on Race and Health

### Ewoma Ogbaudu and Neci Whye

There is a strong intersection between race and health, particularly in the US, that carries great implications. People of color and underserved populations receive a lower quality of care in healthcare settings and have historically been taken advantage of. Due to this, there is a lack of trust between these populations and healthcare professionals. We set out to address these topics with the Sunday Dinner Series. Beginning in November and carrying through the second semester, we hosted dinners once a month, totaling six dinners. Discussion topics ranged from “Health Professionals of Color” to “Police Brutality and the Epidemic of Gun Violence” to “Health and Activism.” Through this, we were able to provide a structured forum for discussions on race and health, bring together people of different backgrounds and experiences for these discussions, and work towards solutions for the issues presented. The Sunday Dinners have been an overwhelmingly positive experience and we're looking to broaden them next year to include more guest speakers and more dynamic conversations. Additionally, we're currently working with the

RCSS to expand the dinner material into a seminar course on race and medicine under the Medicine, Literature, and Societies major. While we planned this series, we could not have planned the wonderful discussions our participants created and the incredible insight of our invited guests: Dr. Robert Pollack, Amy Pollack, and Dr. Brenda Aiken. Our participants also took a lot from these discussions. Below we have included some anecdotes from participants. We are incredibly grateful to the RCSS, Dr. Robert Pollack, and Harvey Krueger for giving us this opportunity.



Participants at Le Monde

Photo: Ewoma Ogbaudu

### Reflections from Participants:

“[The dinner series] got the gears working in my mind about a number of topics I don't always have



the space to discuss. I also learned from other people things I could not have absorbed from a textbook.”

“I really appreciated meeting Dr. Aiken, I think it was really valuable to get historical context through her life story. The Police Brutality and Activism days were also really enriched by the people around the table, I remember students who were personally involved in both those fields sharing really valuable insights.”

“Aside from the vivid conversations and excellent food - I think a wonderful other feature of the dinners is the networking aspect. I think it's really valuable to connect this group of people that all have an interest in POC representation, health, and access.”

“I’ve had a lot of these conversations within my community so this allowed me to hear different perspectives and then bring those perspectives back to the conversations I have within my community. I

wouldn’t have been able to do this without these dinners.”



## Faculty “Fridays” with Nobel Laureate Eric Kandel

Leeza Hirt

On Monday evening, April 24th, hundreds of people filed in to a large auditorium in the International Affairs Building for the RCSS's largest event of the year: a lecture by Nobel Laureate and Columbia neuroscience professor, Dr. Eric Kandel. Dr. Kandel discussed his latest book, *Reductionism in Art and Brain Science: Bridging the Two Cultures*, in which he argues that both science and art employ reductionism to arrive at higher truths. Drawing on examples from his own research and 20th-century abstract expressionists painters, Dr. Kandel captivated the audience with his knowledge, charisma, and wit. He is able to talk about art history with the same confidence and candor as he can about his life's work, neuroscience. This reinforced in the audience a lesson that is central to the work of the RCSS: that science and the humanities are not mutually exclusive, but can complement and enhance one another.

When I emailed Dr. Kandel in January to ask him to speak on the Morningside Campus, I frankly did not expect him to respond. I have planned several events over my time here at Colum-

bia, and had gotten used to not hearing back from high profile speakers. To my absolute shock, Dr. Kandel replied to my email within minutes of my sending it. Although he is a recipient of the scientific



Photo by Noa Herman



community's highest honor, he still took the time to respond to this lowly undergraduate. And he didn't just respond—he wrote me a lovely note, and made me feel like it was his absolute pleasure to speak with us.

Dr. Kandel is a world-famous scientist, survivor, educator, writer, and Renaissance man. But he is also a genuinely kind human being who treats everyone with respect. Perhaps this is what makes him the most extraordinary of all.

# A Snapshot of Reflections from an RCSS Course: American Studies UN3930.6: Life at the End of Life, Palliative Medicine, and Service



# To Understand Another: A Lesson on Empathy

Sophie McAllister

**I was** not invited to great-grandma Lola's funeral. While the details from my 8-year-old memory are hazy, I remember my mom dressed in black one morning and leaving – Lola had died and my mom told us she was going to the funeral alone. But this did not faze me or my sisters in the slightest. Lola was almost a stranger to us, although we saw her often. 89 years old with grasps of only staggered English and a memory lost to Alzheimer's, she would sit in the garden of our grandma's house and simply observe all around her in silence. Our mom would drag us over to talk to her: "Lola, these are your great grandchildren!" But she would just look at us silently without a hint of emotion on her face – and this placid silence is how she remains in memory.

In hindsight, this type of attitude seems so cold and unfeeling – how cruel it was to devalue my own relative because of her mental capacity. I think this detached attitude stemmed from a failure on my part to understand Lola as another person because she could not interact with me the way I am accustomed. Yet I was not confronted with these

thoughts until I volunteered at the long-term care skilled nursing facility Terence Cardinal Cooke (TCC) and witnessed the flip side of the coin. The residents at TCC are often low-income, suffering from debilitating illness, and very lonely. One HIV/AIDS resident with dementia I often visited would ask me why his brothers and sisters never visited him; I brought it up to his social worker who scoffed and told me they were simply "out of the picture," perhaps also emotionally detached from their family member in the same way I was with Lola.

This family absence was also evident for the Huntington's patients, despite this unit having the highest rate of family involvement. I was tasked with creating a support group for Huntington's families and called all contacts in the nearby area. Among those who did not attend, some never replied, while others said they were too busy. Still others simply could no longer bear to visit the facility – one husband stood out in particular because he said he could not emotionally handle his wife's current state. I grew frustrated by this abandonment because it seemed so self-serving; the husband could ignore the



woman he once loved while I would witness the confused anguish of the wife and attempt to compensate. While I always viewed my role as an attempt to fill in the void of loneliness, there were some holes I did not think I could replace.

While this reaction from family is not necessarily excusable it is certainly understandable. There is no universal reason families choose to stop visiting residents at TCC, but there is an emotional trauma in seeing your loved ones suffer. Dr. Craig Blinderman brought up this very topic in our in-class discussion of suffering, proposing that when a physician treats a patient, they really must treat the suffering of the entire family, including the confusion and emotional sympathies that I witnessed in some of the Huntington's family. And like my experiences with Lola, an empathetic barrier can also develop – one family member in the Huntington's support group expressed that sometimes she struggled to know how much of the sister that she knew and loved “was still there.” Through disease, a loved one can appear to morph into someone unrecognizable, and emotional attachments can be lost in

this confusion.

This topic is complicated when the mental capacity of the patient is compromised. Looking back at my encounters with Alzheimer's in my family, I think my mom went alone to Lola's funeral operating on a desire to protect us – to emotionally distance us from a woman who she did not think could love us back; we would be safe from something that she herself could not come to terms with. Indeed, there is an uncomfortableness in interacting with those we do not identify with or understand, as reflected by our human tendency to surround ourselves with people similar to ourselves, and mental illness is perhaps one of the most formidable tests for someone's ability to empathize with those unlike ourselves.

My own empathetic capacity was challenged when I was paired with my long-term companion Susan\*, an 89-year old resident with dementia whom staff thought could benefit from socialization. That first meeting was marked by perceived failure – as I attempted to speak to her, she would look at me for a second, vaguely aware that I was attempting to speak and then to babble over me on a somewhat



non-linear and repetitive chain of thought. My usual tactics of questioning about her life and current thoughts had no effect because her very awareness of my presence seemed to be compromised. I typically build relationships with residents and others in my every-day life through communication and understanding their point of view, but Susan responded to my actions and questions in a manner that I could not understand. As the hour went on I felt myself grow frustrated – is this what the rest of my semester would be like? Would I be no more than a body for Susan to speak at, or perhaps an observer to Susan speaking to herself?

In these first couple of days, I was certainly frustrated by my inability to connect or understand my LTC. But unlike a casual visitor who might stop visiting Susan after this failure to connect, I viewed my role as a responsibility, so when I left Susan's room, I was determined rewire my thinking. If I could not use my usual tactics of conversation-based connection, I would have to approach this relationship from a different angle, and I would need some advice. I first reached out to the recrea-

tion department, who revealed that Susan has poor hearing and noted that dementia patients react well to creative activities. So my next visit I came armed with a whiteboard for communication, some printed out coloring pages, and markers, a bit self-conscious in the childish and perhaps patronizing activity. But I placed it in front of Susan and she was completely absorbed. I was giddy with excitement and a bit of disbelief in the success. I felt myself becoming better able to provide Susan more than just a listening ear. Yet perhaps more importantly, this activity gave me a little bit more of Susan – something I could understand about her and the way she thinks.

This desire to understand Susan would persist in the remainder of the semester, as every week brought a new layer of her that continued to surprise me. For instance, one day I walked in and a nurse had left a note scribbled on a napkin that read, "You look like a movie star! You'll get your flu shot today so you don't get sick." Susan adored that note and kept it for months, periodically holding it up to me and reading the first line to me, "Me! I look like a movie star!" This love for such a simple gesture en-



deared Susan to me even further and spoke to how differently she viewed and valued the world around her. But it also brought a sort of sadness – I imagined leaving after our visits and Susan sitting alone in her room as she always does, re-reading this note and treasuring this form of validation from another person. Indeed, TCC can be a lonely place, with many residents leading lives in separate spheres despite the proximity to so many others. Yet Susan’s loneliness did not seem to stem from choice but circumstance – her severe dementia and deafness makes it difficult for her to form instant connections, and her poor memory likely exacerbates any chance for lasting relationships. In class, Dr. Pollack repeatedly refers to our volunteer work as accompanying others who cannot thank us, and this has been entirely true with Susan. She will likely never remember my name nor understand why I come to talk to her, and this aspect of the work is one that I have come to embrace as both a deterrent to frustrations and a means of widening of my appreciation of others.

With Susan, validation does not come from

direct acknowledgment but rather through signs of connection that I constantly attempt to strengthen in my attempts to better empathize with her. After hearing her speak about “God in the corner” on numerous occasions, which I had figured out meant a Catholic altar, I decided to take her to explore the chapel on the ground floor of the facility, which she had not seen in months because she could not sit through an entire mass and is prohibited from leaving her floor alone. When we got to the chapel on the, she gave me a funny look and told me, “you are very religious to come here.” While this response was amusing it was also a bit disappointing because I thought she would enjoy this excursion. However, this room was filled with chairs from mass which she found absolutely amazing. She would sit in one chair and then insist I help her up so she could sit in a different chair across the room. When I brought her back to the room, I wondered if this trip was worth making again, but for the remaining weeks, whenever I would visit her, she would light up when telling me about the time she “went to Heaven” where there “were so many chairs” and then she would pause and



remember, “you were there!!”

The first time she recognized me in this way, I was taken aback and honored – this act of remembering was more than I had imagined would happen in our relationship. This act also quelled one of my earlier fears about my role and the futility of accompanying someone who would not remember that our time together ever happened. Yet the question still lingers in my head – what if Susan had never remembered me at all? How would I view my position in that case? While I am still troubled by these thoughts, in my observations of Susan’s dementia and in reading about communities for other dementia patients in reflection session readings, I have come to see that the role of the provider is to create an environment of comfort. So while Susan does not always remember the specifics of our interactions or even that I was ever there at all, she still has a general sense of memory and emotion from our interactions.

I also found that this experience of going to “Heaven” grew my emotional connection to her. In the elevator and in the lobby, she would huddle be-

hind me and look to me whenever she was confused, telling me “you lead, I trust you!” I could also feel this responsibility and pride when a newspaper reporter came to TCC; when she met with Susan, I felt myself peek back at the reporter, hoping she was seeing what I saw in Susan – her sharp humor and good nature – rather than merely a senile dementia patient. In these moments, I felt like what I imagine a parent feels for their child – protective and responsible for another in a way I have not really been responsible before. That was one of the beauties of having Susan as my LTC, she brought me into a new role that I would not have experienced if I had been paired with anyone else.

Nevertheless, in considering my persistent desire to better know Susan, I often stop to question the validity in some of my motivations. One of my most persistent thoughts was triggered by comments made by Dr. Blinderman, who told us that the beauty in our work was that we were coming and meeting a patient as they are because we did not have prior knowledge of their background or medical history. Yet I always find myself wanting to know more about



Susan's past and relish the moments I can add another piece to my understanding of the woman Susan used to be.

For instance, I found a stack of photographs from fifteen years ago in Susan's drawer and went through them with her. Through this activity, I found out the Susan loved children and used to throw parties for the kids in her apartment complex. I also discovered that she once lived in Rhode Island and loved hiking in the Red Wood Forrest near San Francisco. In some ways, these small details of Susan's past make her more of a person I can identify with and understand. On one hand, these explorations of Susan's past may be a source of good for Susan, as it may strengthen the bit of memory that still lingers and create a more enjoyable existence for her if she can still bring back those happy emotions. On the other hand, I also use these memories of her past as a tool to strengthen my own connection to her as well, while ideally I should care and accompany another regardless of how much their thoughts or actions mirror my own. This struggle speaks to the fact that this type of care

is not always instinctual, and these crutches are part of my own growth as a caregiver. Indeed, I have had to work against and rewrite many past assumptions since I was first introduced to TCC, and this rewriting will perhaps always be an ongoing process.

Of course, the development of my relationship with Susan was not the only struggle with empathy that I encountered, as other residents tested this capacity as well. In particular, some residents that were regarded as "problem patients" or a nuisance by staff and other residents presented a struggle. Perhaps the most glaring memory of this challenge occurred during my first day at TCC. I was on a tour around the facility that eventually led to 8 Cohen – a floor in which nearly all patients have mental illness and need constant supervision, either because they pose an elopement risk or have violent tendencies. The attitude of the staff on this floor could range from frustration to fear, which could be evident in their treatment of residents and concerns expressed during staff meetings. On my first day, residents followed me around, invading the normal boundaries of personal space, which instilled a sense



## The Path Less Traveled: Willpower in the Face of Access

Zoey Chopra

**I have been** fortunate in helping begin a journal club at TCC, for specifically designated, AIDS-afflicted residents. Weekly, I (alongside another classmate occasionally) head to floor six, and begin my rounds, starting diagonally leftwards to ask the two reliable residents, who have yet to deny my request to share stories, and then requesting that they both help me in gathering any other residents who may be interested in conversational engagement. After a nice five minute chat down the halls, usually with resident C— regarding cable access across the street, we all convene in the plant-laden lounge and begin our beautifully meandering discussions. Starting with the *New York Times*, we progress through political opinions to the “War on Drugs” to residents’ experiences in New York to the delicatessens closing down this year to education, and generally finish with an Op-Ed, at the end of one-and-a-half to two hours. And yet, though wonderfully organic, our weekly routine is nonetheless premeditated.

Walking through the halls at TCC, it is straining not to feel a sense of overwhelming sad-

ness, alongside a certain weight. As a volunteer, the onus is to spread and maintain feelings of hope via company—to try and raise collective happiness, per say. And yet, many moments at TCC border feelings of despair: hearing the elevator lock when a restricted resident attempts to flee their floor, or watching nurses calmly follow as a resident breaks for escape, oftentimes TCC appears more like an enclosure, with the ever-elusive freedom just beyond the security desk (a sentiment we’ve discussed in seminar discussions quite often this semester). In that way, it is amazing to volunteer effectively, and dispel these sentiments from the residents, even for mere moments—not just incredible, but obligatory. That’s where the weight originates from—volunteering for the sake of volunteering quickly becomes something that cannot just be done, but rather must be done, to alleviate the mood-defining pall surrounding many residents. Taken one step further, I have found that not only must I volunteer, but must do so *effectively*. While this burden does not mitigate the wonderful times shared at TCC and in fact is oftentimes motivational, another dimension is added to the TCC expe-



rience that cannot, and should not be ignored.

Upon reflection and retrospection, I have found that though I hope to keep journal club as unbounded as possible, inevitably a routine has been created, almost to force that volunteer *effectiveness* that is so hard to avoid (and perhaps should not be avoided). I have realized that I make that first turn down the leftwards corridor because I know both residents I will find, C— and M—, are almost always excited to leave their rooms and roll down the halls with me. We sit in the heavily windowed, plant-laden lounge so that in case there is any break in conversation, or unprecedented silence, conversation may easily be switched to the fate of certain cacti, or changes in the immediate outside scenery. I choose the articles we read based upon previous weeks' conversations and fields of interest, and constantly gauge my audience's interest in the reading material. While of course I am reading excessively into my own actions retrospectively, I am still surprised by how easily I can rationally justify the way I approach journal club so similarly every week—in a way, I seem to have

molded an easily adaptable formula to journal club, so as to garner the greatest *efficacy* possible when volunteering.

At a surface level, this subconscious imposition of formulaity fails to affect my relationships with residents. Three weeks ago, for example, after finishing my sub-acute shift at journal club, a resident asked if I could walk him back to his room, and looking down, expressed just how thankful he was for us volunteers, and began speaking to how the journal club felt to him like one of the few safe spaces in which he could express his thoughts freely, where someone seemed to be listening—really a touching moment. It's amazing to think how in under a collective 48 hours—in less than two days—such feelings can be shared openly.

At a deeper level, however, this weight can create personal distance. About a month ago, one of the journal club-affiliated residents, A—, asked to speak with me aside from the others, and began discussing a case of patient maltreatment, where he felt neglected by his assigned doctor at TCC, and was refused an appointment for over two months; once the



doctor finally appeared for his rounds, A—'s sister had visited at the same time, resulting in a missed appointment and another month of waiting. As the tears began to well at the corner of A—'s eyes, two conflicting emotions arose within me in parallel: first, the desire to effect change in TCC's system to prevent these occurrences, to discover how this instance could even have occurred in such a well-orchestrated, legally-concerned (if nothing else) system, to comfort A— and empathize; but second, the feeling of doubt as to the *efficacy* of my volunteering. I have since been reflecting on how I reacted in this situation, and can more clearly relate to Dr. Craig Blinderman's discussion of caretaker fatigue—the desire to *effectively* effect change can become almost oppressive, and sort of as a self-fulfilling prophecy, can become debilitating in caretaking as well. What appalled me most, however, was how unfair my journal club routine was to the residents, fundamentally, even if nothing changed on the surface—the routine was more for myself than for them. Because my weekly routine provided me with personal satisfaction, seeing the residents

engaged and interested and appearing happier, I never bothered to wonder whether they would prefer change regardless, or if I could change anything to make them even happier and so make our mutual experiences more fulfilling, as I do with my LTC. Fundamentally, I approached journal club as if the residents had preferences on the micro level (i.e. article content, favorite seats, proper shoe attire for walking along the cold floors, etc.), but did not consider to a full enough extent their desires on a broader level—how journal club operates. In this way, I realized I unintentionally denied the residents their full decision-making capacities in shaping journal club without their permission and desires in mind—only a sole e-mail from Wenlan.

This past semester, I have been caught by the question of capacity and the privileges that capacity affords. Having explored caregivers' obligations towards empathy and emotional intelligence from many perspectives, including that of chaplain, doctor, and administrator, our class has discussed how our own obligations may or may not change in regards to caretaking.



Most of the time, I take decision-making capacity for granted, and unfortunately, feel far from alone. Able-bodied, financially stable, and studying at the reputable Columbia University in the City of New York, my amazing fortune is readily apparent, and privilege effectually infinite, at a micro and macro level. On the micro level, I can walk wherever, whenever, and have variety surrounding me, from classes to meals to even coffees. At a broader level, I can enter one of our libraries and immediately be surrounded by a wealth of knowledge and resources—and so can learn to the  $n^{\text{th}}$  extent in any subject desired. This semester, for example, I took classes ranging from Physical Chemistry to the Economics of Japan—a richly intellectually liberating experience. It's wonderfully freeing to have choices, and the freedom and resources to use that variety, whether it's a question of which vending machine snack to purchase, or which library to frequent.

At TCC, there's a stark contrast—especially with the AIDS-afflicted residents I am most often in contact. Many residents have lost memory faculties,

attention spans, mobility, eyesight, hearing, and daily engage with a number of limiting difficulties that affect their day-to-day lives, namely fiscal issues.

Frequenting even the nearby Central Park is no walk in the park, but a grueling endeavor, a battle betwixt resident's mind and body, as well as between patient and administration. A blind resident I am often with, T—, constantly must ask nurses for socks because he cannot happen upon a pair himself, and because I am prohibited from helping with personal, physical needs (as I was told by a nurse). My LTC ever complains about pain in her left arm, which has limited functionality post-stroke. Resident L— never learned how to type, and so spends endless moments at the computer lab aimlessly, hoping to understand the intricacies of the QWERTY system, but forgetting the next day. Due to physical and mental conditions, some limits do exist for residents, especially when compared to a day-to-day life within a coddled, private university setting.

Yet, overall there is decision-making capacity. My LTC checks to make sure she has all her medications every dosage period, and corrects the nurse



when pills are missing or mistaken. As I spend my weekly two hours with her, she asks for different animal print-outs to color, and illuminates whenever I bring new song lyrics for us to sing together, or new Spotify songs for her to critique. At journal club, residents speak to me of IUPAC naming and the Latin studies they did in high school, or their thoughts on the Red Cross relief efforts in Haiti, or which Manhattan deli was recently exposed as non-kosher—the desire for variety, be it in conversation or lyric, is omnipresent. Coherent, current, and capacity possessing, the residents have free roam in the halls, outside of physical difficulties. Though T— must ask for socks given his physical impairment, he musters the courage time and time again to ask nurses to fulfill his small request, though oftentimes embarrassed to do so. Furthermore, whenever I am talking to him, we always start our conversation the same way: he asks what the outside is like, seeking a sensory change of pace, although blind, and brightens at the thought of a day different from the previous, even if his days remain more uniform than not. The fundamental differ-

ence, then, lies not in the capacity residents have, but in the access to resources—the choices—afforded them at TCC.

What surprised me most at TCC initially, specifically for the resident population I interact with, was the amount residents can do—and therefore, the amount residents cannot do. With a fundamental lack of resources, such as the lack of a library, or computer training programs for residents, or journal clubs, or interest circles, all that residents have capacity for becomes irrelevant to a large extent because that capacity cannot be exerted or used to capacity at TCC. For example, a resident could decide to walk to Central Park one day, but unless the proper clearance is obtained—a laborious process—that decision will be for naught, to the point where resident decisions seem to become more and more TCC-focused, rather than broad. Instead of complaining about geopolitical affairs, journal club complaints are most often directed towards a nurse's negligence or TCC administrative issues; instead of talking about whether or not to meet new people on the floor, socially inclined residents discuss which TCC



meeting to attend, in order to bring to everyone's attention the shoddy cable connection in his room.

The lack of access to choice, be it variety in food or in T.V. channels, and to resources, becomes a drain on decision-making capacity, to nobody's benefit. My first week at TCC, as aforementioned, my LTC checked over her medications (as she had been doing for the past few months apparently—a habit given she used to be a nurse before contracting HIV) and noticed a missing painkiller in her afternoon dosages, and said as such to the presiding floor nurse, who promptly and respectfully asked for a description of the pill, and after poring over my LTC's diagnosis and searching through her drawers, found the missing pill within the next 15 minutes. The next week, a similar situation occurred, with similar conclusion except that the nurse was much more annoyed, time-pressed and stressed herself. A few weeks later, as my LTC received her medications, instead of looking through the pills, she downed the medications immediately, without even a second glance. Upon asking her why her attitude towards her medication had changed, she shrugged with one arm, and quietly noted that it wouldn't matter anyways. A journal club resident, B—, once felt

disrespected by a few of the nurses, who he thought failed to evaluate his pain seriously. For three weeks, he passionately discussed his issues at journal club with me and a few other residents, seeking support from the masses, it seemed, which was readily given. At one point, he decided he would bring the matter of his ineffectual care giving to Cardinal Dolan (who technically presides over TCC as a catholic institution). The next week however, he became entirely silent on the matter. When the issue was jokingly brought up in conversation, he noted that without access to a phonebook, let alone a phone, neither of which were provided upon incessant request both to nurses and to family members, he resigned himself to defeat. Unfortunately, not just capacity—the desire to effect change about one's own situation—is required. Rather, the lack of access, to materials or even to an ever-engaged ear, not only suppresses the desires derived from that capacity, but also stifles the very ability of that capacity.

Understanding the subtler, hidden layers behind residents' decisions, and desires for variety changes the onus of volunteering. Rather than evoking empathy and disseminating hope, companionship-based volunteering seems to avoid many of the critical issues that residents



## How have you been inspired or impacted by the time you have spent at TCC?

Jenny Davis

face—and from the residents’ perspectives, maybe even purposefully.

Listening to residents is one thing, and is bound to effect mutual positivity. When I visit my LTC, for example, we embark to the sixth floor to sing together, and even sometimes dance a little jig to her all-time favorites, like Soldier Boy’s *Crank That*—and it helps both of us mutually. Seeing the first hints of a smile crack the right side of my LTC’s face is beautiful—I can’t help smiling just thinking about it. The laughs shared as she frowns at TCC’s “version of a meatball,” as she calls it, are infectious, and can only brighten one’s day. Being able to play checkers with my LTC and tell her after the second game that improvement is really necessary for us to play a second round—to crack such personal jokes and feel close afterwards, after a mere 40 or so hours spent together—inspires only delight. And yet, in retrospect, those hours alone only seem to suffocate the very capacity my LTC still extends day in and day out. I provide a change of pace, listen to stories of her past and woes of her present, and effect small differences in her immedi-

ate environment by playing different board games, imitating different accents when singing, and sharing my own thoughts mutually. Yet, at the end of the day, when I leave TCC, though I think of the residents I talked to at journal club and my LTC, I do not take the next step, be it calling C—’s cable company, or approaching Dr. Tony Lechich with smaller, specific resident complaints (outside of after class once); instead, I merely listen.

Perhaps the greatest takeaway this semester from class and from my experiences at TCC is understanding the extent to which volunteers can maintain not only a hopeful atmosphere at TCC, but also the very independence residents desire within TCC’s confines. In class, we discussed much about the relevance of listening to residents’ respective stories, so that they may be heard and remembered, even when no one else seems to care. What I’ve found is that while this aspect of volunteering is crucial, and oftentimes may be all that is required, in other circumstances this attitude stifles subtler indications of residents’ decision-making capacity. Residents do not necessarily need audiences, but rather advocates—



## “Not a Colon Cancer Patient but a person”

Tess Cersonsky

*“Sometimes you have to accept that you’re a colon cancer patient. Don’t sugar coat a diagnosis, don’t sugar coat death.”*

These are words, paraphrased, that I heard in one of the sessions of American Studies (AMST) UN3930.6: Life at the End of Life. This class is unlike any I have ever sat in; I don’t often cry in class unless I’m overwhelmed by the amount of orgo work I have to do, or if I haven’t slept enough and it’s cold outside and I end up crying anyway. I am not volunteering, and therefore I cannot imagine the emotional experiences of others in the class. I can’t know what it feels like to sit with residents at TCC for four hours per week, if it is overwhelming or fun or upsetting. I do know what I experience in class; I sometimes find myself in intense conversations but more likely think so much about whether or not everyone is engaged in the conversation. There are times that certain lines stick out to me, though. And the line above, does so incredibly.

Our minds have a tendency to gravitate towards what we know. I am a musician, so when

someone starts discussing music I listen more. Our brains are sensitive to those things we already know, making neural connections between what we know and what we are learning. Spontaneous release of neurotransmitters from presynaptic neurons strengthens neural connections to increase neural plasticity. So it is inevitable that, when a speaker in our class brings up “religion” or “chronic disease” or “colon cancer” or any other variety of topics with which I have experience, I follow these words and phrases closely.

This leads me back to the original quote.

When I was 11 years old, my father was diagnosed with colon cancer. He died when I was 14, and those neural connections linking topics such as colon cancer, death, family, etc. are still strong even 8 years later. So, I perked up and took note of a mention of this specific term. Since I don’t have TCC residents with whom I can empathize, I turn instead to a patient I knew: my father. In this paper I will attempt to uncover the connections between my understanding of my father’s illness with the person he was, as, contrary to the quote above, he was defined by both



his diagnosis and his personhood, but neither descriptor fit him alone. Through an analysis of both my experiences in class and some papers of my dad's from 1968, I will attempt to understand the individuality of this person I knew so closely in order to bring that awareness and empathy to those for whom I will provide emotional and medical care as a future doctor.

My cousin sent me a folder of papers from my grandparent's storage bins, full of report cards and kid's art and tons and tons of homework assignments. Most of these point to a smart but mildly disorganized 15-year old young man in senior year of high school (he skipped two grades). I found something that spoke to me more than anything else - twelve pages of reflective essays written in 1968 "In Partial Fulfillment of the Requirements in English 4X." I did not anticipate what would come next:

One of my main concerns is the prospect of death. Pain is not my worry. My concern is where my brain stops what will there be. I cannot see that nothing follows. This prospect, although possible, is

not anything to look forward to, and I do not consider myself a fatalist. So I much imagine an afterworld. But what kind of afterworld?

I couldn't believe it; my father, at 15, talking about death candidly and openly, with such reflection that I hadn't even gotten close to until I was almost 21. No one talks about how scary death is, and yet, here it was, the words of my dead father talking about death. My dad was diagnosed with Crohn's disease (a disease I now also share with him) when he was much younger than this, and he had already had a surgery to ameliorate the symptoms. So here I attempt to understand: what would it have felt like to be 15 and young for your grade and always sick, always dealing with some disease you can't understand because even now, 49 years later, we barely understand it. I know how frustrating it is for me, but how frustrating could that have been to be so young and so sick? It is inevitable that one fears death when faced with serious illness at such an early age. But I couldn't imagine facing that fear so openly at 15, just about the same age I was when my dad died. Talking about death, about that taboo, was scarier than death



itself.

I would have thought that writing about this would have also scared me beyond what I could imagine. However, my time at TCC made that less difficult. At TCC, you can't avoid chronic illness. I tried to avoid it because I found it hard to face, and that made me even more anxious. When I finally allowed it to let me face my own mortality and life, I was happier. It's easy for me to say that I avoided chronic illness because I wasn't the one experiencing it. But when we think about those experiencing it, we have to realize that they can't ever avoid it.

My dad seemed to sum that up quite well:

My concern of death is not only for myself. I worry for others. I have never lost a close relative, but I worry where they will go when they die? Will life exist for them, or will it be like that second of anesthesia during my operation - only not for a second but for a much longer time - indefinitely. I am thoroughly concerned about death, but I will live my life to the fullest and let it come when it may.

We can't know what death is like, just like I can't imagine what anyone reading this is thinking

while they read. But my main concern here is that my dad did not define himself by the notion that he may die someday. Like me, he probably feared that it would come sooner rather than later because of our chronic illnesses (he died at 58). But he said "let it come when it may" and continued to live. When he had cancer, he did not let that define himself either. He grew a beard despite chemo, and having cancer was another part of his identity, but not his entire identity.

He wrote about many other things, from love to prayer to God to capital punishment to happiness. Death and illness were only a portion of my dad's journal. He spoke mostly of finding happiness amidst all of those things:

I must here state my purpose of life. Before, I have said that I will live it to the fullest. But this vague statement does not express my complete emotions. I strive for what the Peanuts characters are always exhibiting - happiness. How to achieve happiness is another point entirely, though.

We search for achieving happiness because illness does not define everything. That is incredibly



easy for me to say, though, because, even though my own illness runs much of my life, I do not live in a place where I am sick and have few other choices. This is, from what I understand, what it is like at TCC most of the time. I haven't been there in quite a while, but, like a hospital, the medical feeling permeates. So it must be difficult to separate one's life from their illness if they are constantly faced with a medical environment.

What am I learning from these essays? This feels like I am reading a deep historical memoir, but for the first time ever, it no longer feels cold and old. It feels intimate and meaningful. I see myself in this, and it feels like I'm talking to a friend. One of the hardest things is that it only makes me want to get to know him more. I think we would have been able to talk about mortality and life on a level that is not often achieved by others.

I feel like I'm reading the diary of Anne Frank because it is written so well, and so meaningfully. But unlike Anne Frank, I knew this person, but I didn't really know him. Reading these essays makes me realize how little I knew of the person I

called Dad, and how much I now want to know. I can't regret not knowing more because, after all, what emotional intelligence or maturity can one expect from a 14-year old? There is no regret, only sadness that I can't be friends with this person whom I am just discovering is more than a collection of stories or half-formed young memories.

I am amazed at how much of his thoughts are so close to my own. I know I am genetically half-my Dad, but this feels like I am connected by more than genetics. I am brought closer to him through a shared consciousness, a shared being, a sense of people who are close but individual and influencing one another regardless of current plane of existence.

I have to reconnect the world from 15-year old Jeff Cersonsky to 14-year old Tess Cersonsky. I have never before critically reflected on what it was like to take care of my father in the last days of his life, but I think that this helps make the connection between the personhood that still existed and defined him in conjunction with his illness.

When I was about 13, I started taking care of my dad. I stayed home from school one day because



he had a pinched nerve. It felt oddly protective. I had never seen him so vulnerable, and I can't think about what that must have felt like for him. He was a 58-year old pediatrician under the care of a 13-year old middle school student. I had no clue what I was doing, but it seemed to be pretty okay. It felt like I was helping him in whatever small way I could, which not only provided me with the confidence that I could indeed help people and do something good in this world, but also helped me connect with my dad on more of a peer level. Sure, I couldn't possibly say I was as medically astute as him (I'm still not as medically astute as he ever was; a lack of medical school training tends to do that) but he treated me like a peer because maybe that's the only way that he could reconcile his youngest daughter treating him.

Is that why we make connections between ourselves and residents? If they share their lives and we share ours, then we can be more like peers. That seems absurd; how could I be a peer of a 90-year old? Or a 50-year old patient with diabetes? Is it ap-

propriate to see oneself in that way?

Maybe the answer lies in what we learned about as "emotional intelligence." Emotional intelligence is a broadly defined term, but one of the most concise definitions given is "a set of abilities (verbal and non-verbal) that enable a person to generate, recognize, express, understand, and evaluate their own and others' emotions in order to guide thinking and action and successfully cope with environmental demands and pressures." The idea is not necessarily that I am a peer of a 90-year old akin to my status as peer to my classmates of the same age or generation or grade level, but I am a peer of emotions. My emotional or psychological state matches with another at a given time and place, providing a link through which we can establish a shared empathetic consciousness. With that empathetic consciousness comes a sense of understanding that makes it easier to bear someone taking care of you. I can think about how, although my doctor has much more training and knowledge than I do, if he relates to me on the level at which I am, as a



college student with a chronic illness, then I feel more at ease with his advice and treatment.

My dad went through a lot of treatment between 2005 and 2009, much of which I did not know all that much about. I knew he had a portion of his colon removed and had an ileostomy bag; I knew he had chemo and radiation and many other things. Maybe it is a testament to my age and lack of understanding and maybe it points to his persistence in all things that defined him besides his cancer (being a doctor, parent, friend) but he did not seem to me to only be a colon cancer patient. I saw mostly everything but. It is probably the blindness of youth that led me to that, but nonetheless it defies the notion that in order to accept one's diagnosis, you must see yourself defined by it.

In late February 2009, my dad came home on Hospice care. I had never heard of this before and yet it was now in my study where the piano once was. I remember lots of family around, the principal of my middle school coming to my door (that's a fun

story), and lots of pizza. I also remember wanting to help, but my uncle's wife stepped in because she was actually an MD. I didn't really know what was going on, and I still don't. But I think some of the confusion of this time was important. If I was 14 and completely comprehended the situation, it would have overwhelmed me beyond anything else. I was no longer in a state where I could operate as a peer or have any empathy. My dad was comatose by now, and the shift turned to me from caregiver to one who needs care. I stepped into the role of someone who needed to be treated, which I can only understand now, even though those who were around me could tell right at the moment.

As I've said, I'm not volunteering, so I can't imagine what it is like to be in the minds of anyone volunteering. Regardless of whether or not I'm volunteering I can't even do that anyway, because I can't be in the mind of anyone else. I can, however, try to empathize. If this class has taught me anything, it is the importance of empathy.